Fred Hutch
Cancer Center

Allogeneic Transplant Manual

Contents

Important phone numbers

Fred Hutch Cancer Center

Transplant clinic front desk (Building 1, 6th floor) Mon to Fri, 8 am to 10 pm Sat and Sun, 8 am to 6 pm Holidays, 8 am to 5 pm	(206) 606-7600
After hours (Fred Hutch Cancer Center Hospital and UW Medical Center-Montlake)	(206) 598-8902
1st floor reception desk	(206) 606-1000
In the unlikely event of a Fred Hutch phone outage	(206) 467-8762
Health Information Management/Release of Information	(206) 606-1114
Institutional Review Board for Fred Hutch	(206) 667-6567
Interpreter Services	(206) 606-6419
Long Term Follow-Up	(206) 667-4415
Medical Nutrition Therapy Services	(206) 606-1148
Patient and Family Resource Center	(206) 606-2081
Patient Financial Services	(206) 606-1113
Patient Relations	(206) 606-1056
Pharmacy	(206) 606-6500
Physical Therapy	(206) 606-6373
Radiation	(206) 606-7318
Social Work	(206) 606-1076
Transition Services	(206) 606-2125
Security (lost and found)	(206) 606-1111
Spiritual Health	(206) 606-1099
Volunteer Services	(206) 606-1075

Fred Hutch Hospital and UW Medical Center-Montlake

Patient Floor 8 NE (Fred Hutch Hospital)	(206) 598-8902
Patient Floor 7 NE (UW Medical Center)	(206) 598-7770
UW Medical Center Human Subjects	(206) 543-0098
UW Medical Center Office of Regulatory Guidance	(206) 616-8222
UW Medical Center-Montlake Pharmacy	(206) 598-4363

Welcome

Welcome to the Fred Hutch Cancer Center Blood and Marrow Transplant Program. We are devoted to giving you the best possible care and support throughout your time here.

As part of that commitment, we created this transplant manual. The purpose of the manual is to help you understand your transplant 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/allo-manual or by scanning the QR code. We hope this manual 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, where we honor diversity, equity and inclusion.

Fred Hutch complies with applicable federal civil rights laws and does not discriminate on the basis of race, color, national origin, age, disability or sex.

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 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.

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 work 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 against any patient or patient's family member on the basis of race, color, religion, creed, national origin, sex, age, disability, marital or veteran status, sexual orientation or gender identity. 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, creed, religion, sex, sexual orientation, gender identity, national origin, disability, age, status as a disabled veteran or having an advance directive.
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, creed, religion, sex, sexual orientation, gender identity or expression, ethnicity, national origin, disability, age, veteran or military status, or other aspect of difference — 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):

Attn: KEPRO
5700 Lombardo Center Dr., Suite 100
Seven Hills, OH 44131
Phone: (888) 305-6759
TTY: 711
Fax: (844) 878-7921
Web: keproqio.com/bene

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.

Participating in research

Clinical missions

In choosing to come to Fred Hutch, you directly benefit from the knowledge gained by previous patients who participated in various research studies. You, in turn, may be asked to participate in similar research studies. The results may benefit you as well as future patients. By working together, results can be improved. We believe that the goals of patient care, teaching, and research work together for the benefit of patients.

How research studies are developed

Research studies are first developed by a staff member working in a specialized field of study. A proposal is written and shared among staff members working together, and then among the members of a scientific staff review committee. After review, the research proposal is turned in to the Institutional Review Board. Their task is to ensure that being in the study is reasonable in terms of benefits and risks. They also review the written consent form to be sure that it clearly describes what will be done and the possible risks.

Informed consent

You will be asked to sign a written consent form for each research study in which you participate. Your signature indicates that the study has been explained to you, that you understand the risks, that you have had a chance to ask questions, and that you freely agree to participate. Consent forms also state that you remain free to withdraw your consent.

Benefits and risks of research

It is often a possibility that you will personally benefit by participating in research studies. There is also the possibility that you will not benefit or that a harmful reaction may occur.

Some studies involve assigning patients to a treatment by a process called “randomization.” This means that treatment will be decided by random computer selection. This is often done when it is not known whether one treatment is better than another.

Comparisons are often made between a “new” treatment and a “standard” treatment. Randomization is a way to avoid any bias that might influence results of the comparison. It increases the confidence that any differences seen between groups reflect the effect of the treatment rather than other factors.

Benefits and risks of research, continued

You may feel uncomfortable about having aspects of your treatment decided by random computer selection. You might believe that the “new” treatment is likely to be better than the “standard” treatment, or you might be concerned that the “new” treatment may increase the chance of side effects. For either of these reasons, you may prefer to choose one treatment or the other. These feelings are understandable; however, we hope you will understand that there is no factual basis for any preference between treatments in this situation. If there were, we would not need to do a research study to find out which treatment is actually better.

Long-term participation in research

Being involved in research will likely extend beyond your stay, especially if you have problems that need ongoing treatment. We are able to carry on this research by working with your physician. You may be asked to return for a periodic check-up.

Research results

Information gained from research studies is reported at scientific meetings and published in medical journals. In this way, we are able to share results with other professionals.

Confidentiality

Patient confidentiality is always protected. Names and initials are not disclosed in any report. Records are kept locked, and access is limited to authorized staff.

Questions about research

Care is taken to ensure that your treatment is not endangered by participation in research. If you have concerns about being in any research study, we hope that you will feel free to ask questions. Your continued participation remains essential, and we are grateful for your willingness to work with us. If you would like to know more about clinical research, please ask your nurse or physician.

Financial interest in medical research

Medical researchers occasionally have financial relationships with private industry, such as:

- Owning shares of stock
- Serving on advisory boards or consulting for companies
- Receiving consulting fees and payments

A medical researcher who has such an interest or relationship is required to disclose it.

Institutions carefully review these disclosures. Decisions are made as to whether the study can be carried out by the medical researchers and whether the personal financial interests and relationships can continue. We do this to safeguard patients and the integrity of the medical research.

Connection with private industry

For many years, medical researchers and private industry have worked together to study ideas that might become useful to science and patients. Drug companies and biotechnology firms sometimes pay for medical research studies. This financial support can lead to new ways to prevent, diagnose, and treat illness.

Our commitment to you

Fred Hutch is committed to protecting the rights and well-being of participants who volunteer for medical research studies. Fred Hutch has policies and procedures for the disclosure, review, and management of the financial interests and relationships between medical researchers and private industry.

If you wish to learn more about policies and procedures

If you wish to learn more about these policies and procedures, you may contact the resources listed here.

Fred Hutch:

- Fred Hutch Patient Relations office: (206) 606-1056
- Institutional Review Board office: (206) 667-6567
- The principal investigator of your study

UW Medicine:

- The principal investigator of your study
- Human Subjects Division: (206) 543-0098
- Office of Regulatory Guidance (Office of Research and Graduate Education) at UW Medicine: (206) 616-8222

Introduction to our clinic

This section introduces you to how the Transplant clinic works. It includes topics like how your appointments are scheduled, how to find patient education handouts and videos, and who is on your care team.

The basics

Your local phone number

We must have your cell or local phone number so we can reach you when needed. Your patient care coordinator keeps a current list of your phone numbers so we can reach you. Please keep the patient care coordinator informed of your current phone number and local address.

The mailbox system

The Transplant clinic uses a “mailbox system” to stay in contact with you. Your “mailbox” is managed by the front desk. It’s not an actual mailbox; it’s a file behind the front desk that is sorted and managed by Transplant front desk staff. Please ask Transplant front desk staff to check your mailbox for appointments and messages every day you receive care in the clinic. Do not use MyChart to communicate with your Transplant team.

Schedule and appointments

Your schedule will be coordinated by your patient care coordinator. Your patient care coordinator will meet with you to go over the details of the schedule and keep you informed of all changes to your schedule. Please check in with 6th floor front desk staff each time you arrive for an appointment. You or a family member must check your mailbox every time you are in the clinic so you do not miss any appointments. You can view your schedule in MyChart but do not schedule or cancel any appointments through MyChart. Contact your patient care coordinator to do this.

Pharmacy

The Fred Hutch pharmacy is open from 8 a.m. to 8 p.m., Monday through Friday, and 8:30 a.m. to 5 p.m. on Saturday and Sunday. New medication orders can be picked up anytime the pharmacy is open. All refills must be called in at least 48 hours (2 days) before you need the medications.

Release of medical information

To get your medical records, contact Fred Hutch Health Information Management or UW Medical Center Patient Data Services. You will be asked to sign an authorization form to release your personal health information. There is no charge for records released to you or your provider.

Sick family members, friends, or caregivers

Family members, friends, or caregivers should not come to the clinic if they have any of the following:

- Runny or stuffy nose
- Post-nasal drip (mucus dripping down the back of your throat)
- Shortness of breath
- Cough
- Wheezing or chest tightness
- Sore throat
- Sneezing
- Watery eyes
- Ear pain
- Fever
- Chills
- Diarrhea
- Nausea or vomiting
- New rash

Please tell your care team if anyone you are in regular contact with has any of these symptoms. Even if it the symptoms are only related to allergies, please contact your team.

All respiratory virus infections begin like allergy symptoms. It is possible to have allergies and a respiratory virus infection at the same time. Your care team will tell you how to manage the situation. Please remember that a respiratory virus infection with mild symptoms can become more serious in a person with a weakened immune system.

Secure email

The transplant team prefers to communicate with you in person or over the phone. If we send emails, we send them securely using an email encryption called TLS encryption to protect your privacy and comply with the Health Insurance Portability and Accountability Act of 1996 (HIPAA). If email cannot be sent using encryption, we will send you an email saying that you have a secure message waiting, with a link to a secure encrypted email portal. Clicking on the link will take you to a secure email portal where you will either need to register a new account or, if you already have an account, sign into it.

Patient and caregiver education

Our patient and caregiver education program has three major parts:

- **Individual teaching** on topics, such as central line care, medications, and blood glucose monitoring.
- **Online or in person classes** that teach you the skills you need for the treatment and recovery process. See class descriptions below for details.
- **Videos** about topics related to your care, such as how to flush your central line and what it means to be immunocompromised.

To find education handouts, videos (including recordings of online classes), and e-learning modules on a variety of topics scan the QR code or visit FredHutch.org/patient-education.

Class descriptions

Class schedules for you and your caregiver will be placed in your mailbox. The 3 classes you will attend online or in person are:

- **Managing care at home,** which covers the transplant process and what to expect during different steps of transplant, such as:
  - o Your role and your caregiver's role
  - o How to prevent infection
  - o How to manage common symptoms
  - o How to adjust to recovery at home

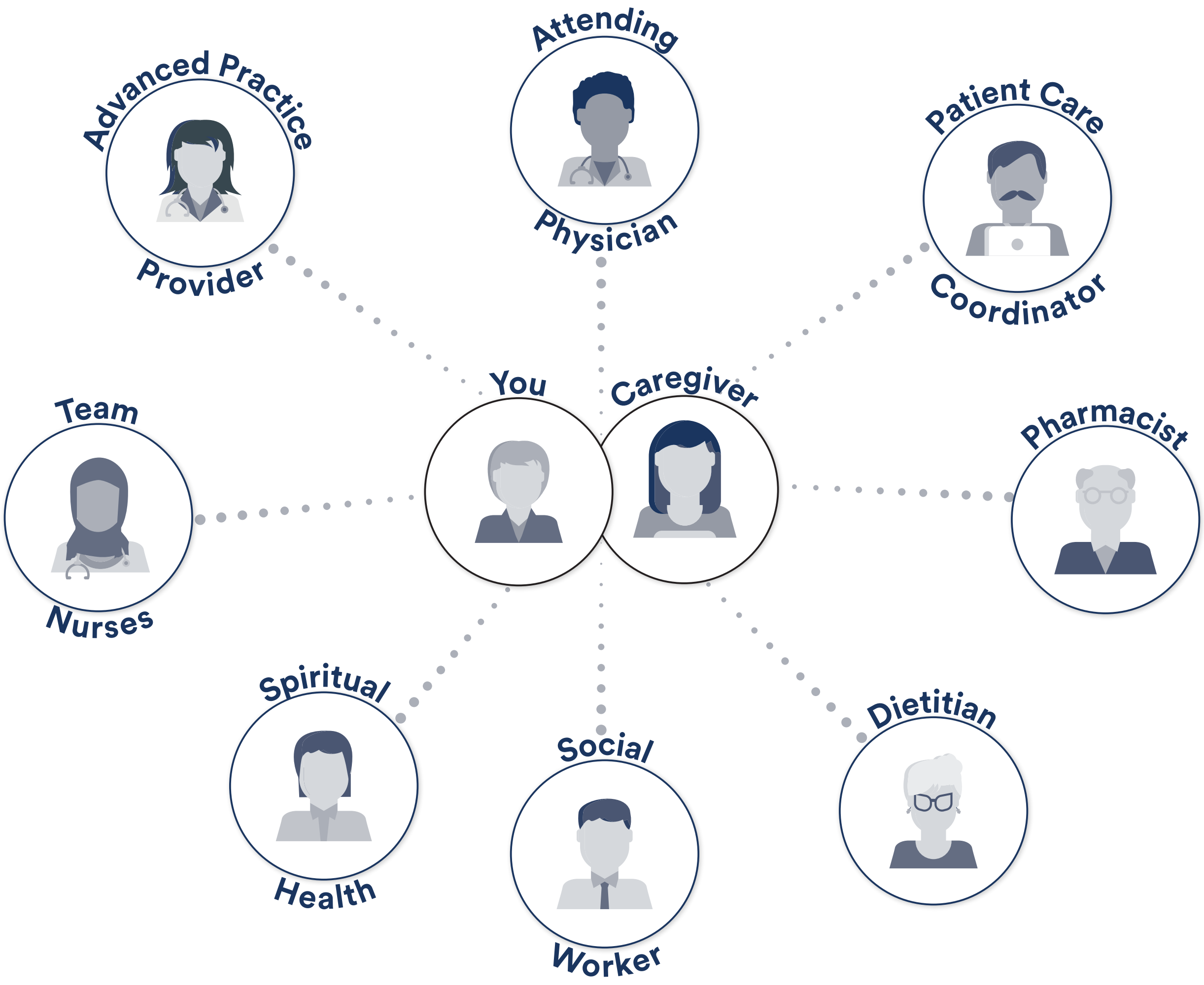
  Managing Care at Home is held each Tuesday. Classes will be offered in person or online.
- **Food safety,** which covers topics like:
  - o What foods to avoid
  - o How to choose safe foods
  - o How to safely handle, cook, prepare, and store food during and after transplant.

- **Long term follow-up,** which covers topics after transplant, such as
  - Immune system recovery
  - How to monitor symptoms
  - Guidelines for daily living
  - Coping with common mental and psychological reactions

Your care team

You, your family, and caregivers are the most important part of your care team. Your team is also made up of:

- Attending physician
- Advanced practice provider
- Team nurses
    - o Nurse coordinator
    - o Infusion nurse
    - o Transition nurse
- Pharmacist
- Patient care coordinator
- Dietitian
- Social worker
- Spiritual health



Each person on this team specializes in working with transplant patients and will be well-versed in your care.

Your care team, continued

You may meet more than one attending physician or advanced practice provider while you're in our care. This is because our attending physicians and advanced practice providers spend time in the clinic and in the hospital. Our physicians are also scientists who research ways to cure cancer. When a new attending physician or advanced practice provider joins your team, they have been briefed on your care and know your treatment plan. Your team nurse will meet with you on the day you arrive to the clinic and is your "go to" person throughout your treatment.

Descriptions of the roles of your team members are listed below.

- **Attending physicians or "attendings"** rotate at Fred Hutch and at UW Medical Center monthly, which means that you will see more than one attending while you are here. The attending leads your care team and will select appropriate treatment plans, conduct patient and family conferences, and get informed consent for procedures or clinical trials.
- **Advanced practice providers (APP) or "providers"** work closely with the attending physician. Some APPs rotate, so you may see more than one APP while you are at Fred Hutch. An APP meets with you often to manage your physical care, perform health history and physical examinations, and make decisions about medical care together with you and your attending physician. APPs prescribe medication and perform certain procedures, such as lumbar punctures and bone marrow biopsies. You may also hear them called nurse practitioners (NP) or physician assistants (PA, PAC).
- Your **team nurse** is the person you see the most throughout your visits and is the main contact for non-scheduling items related to your care. They are also your link to other members of your care team. Besides being the primary face of your care team, your team nurse monitors your symptoms and response to treatment and medications and provides education and support during your treatment. Your team nurse is often the first person you contact when you have questions for your care team. You will see other nurses during your time here, such as Infusion nurses and Transition nurses, but your team nurse will stay the same. Transition nurses help manage your care between the hospital, the clinic, and home. They will teach you about self-care after hospital discharge, help arrange home infusions and medications, and much more.
- Your **social worker** helps you access the non-medical parts of your care at Fred Hutch, including services such as housing, transportation, home health care, and finance. Your social worker can also connect you to supportive care services such as physical therapy, psychology, smoking cessation, and spiritual health.

- **Spiritual health** provides emotional, ethical, and spiritual care for patients and families through a variety of services. Your spiritual health clinician provides respectful, spiritual and emotional care for all faiths and spiritualities, including if you are nonreligious or nonspiritual. They will talk with you in a supportive and inquiring manner, rather than impose a perspective on you, and provide a safe place to talk about what is important to you.
- Your **dietitian** will help you understand the benefits of good nutrition to stay stronger and feel better during and after cancer treatment. Dietitians will work with you to minimize side effects from treatment while helping choose foods you enjoy eating. They also provide education on food safety while your immune system is compromised.
- Your **pharmacist** works with your care team to customize an effective medication plan for your cancer treatments. This includes monitoring for side effects and drug interactions and providing an additional safety check on your cancer treatments. Your pharmacist also provides education and information about your medication.
- Your **patient care coordinator** (scheduler) schedules your appointments and is your main contact for any scheduling questions.

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 enclosed brochure or visit FredHutch.org/supportive-care-services for more information on the following Supportive Care Services:

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

The transplant process

This section answers common questions about the transplant process.

What is a transplant?

A blood or marrow transplant (BMT) is a treatment option for people with a blood cancer, such as leukemia or lymphoma, or a blood disorder, like sickle cell disease. During a transplant, unhealthy stem cells are replaced with healthy ones.

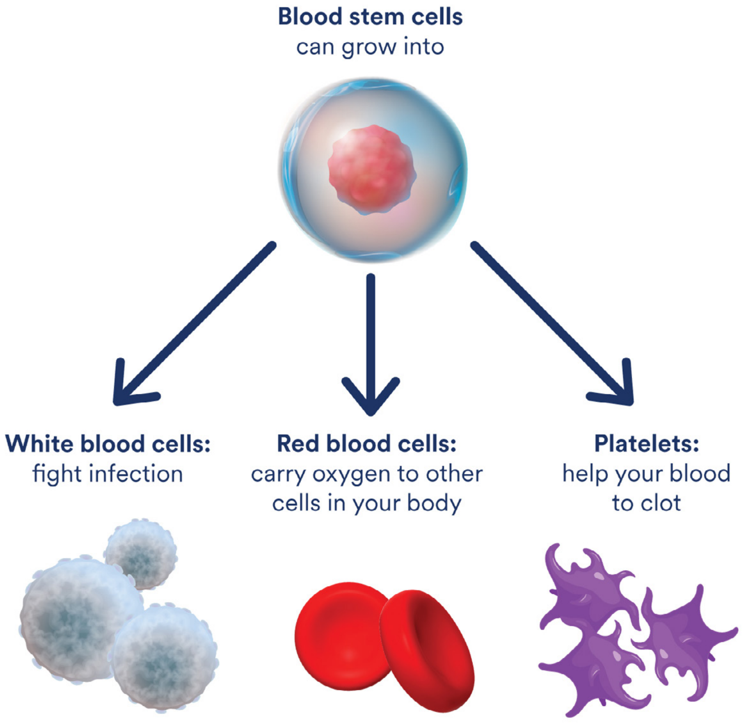
Why is a transplant done?

The purpose of a transplant is to cure or treat certain types of blood cancers or disorders using high doses of chemotherapy, radiation, or both. The intense treatment decreases the number of stem cells that make blood cells. After treatment, new stem cells are put into your body through an intravenous (IV) catheter to replace the ones that were destroyed. Over time, the new stem cells settle in the bone marrow and grow to make new blood cells.

What is a stem cell?

Stem cells are very young cells that can grow into mature red blood cells, white blood cells, or platelets. Stem cells are an essential part of your immune system. They are made in your bone marrow. There are 3 places to get stem cells for a transplant:

- bone marrow
- blood stream
- umbilical cord of a baby right after birth



How long does it take for stem cells to grow?

It takes several weeks, to months, or longer, for the stem cells to grow (engraft) in your bone marrow and produce red cells, white cells, and platelets. During this time, you are at risk for complications and need to be monitored closely.

The 7 steps of transplant

In general, there are 7 steps to getting a transplant. Each step has its own purpose and challenges. Keep in mind that your experience is unique and will differ from others based on your treatment plan and response to treatment.

1. Planning ahead
2. Preparation
3. Conditioning
4. Transplant
5. Waiting for engraftment
6. Recovery after engraftment
7. Long term follow-up

Step 1: Planning ahead

Before you can start treatment, there are several things that need to be planned, such as:

- Where you will stay during treatment if you don't live within a 30-minute drive to the clinic
- Who will care for you during and after treatment (a caregiver is required)
- How your treatment will be paid for

For more information on planning ahead, please read Preparing for Transplant at FredHutch.org/preparing-for-transplant.

Step 2: Preparation

Classes

You and your caregiver will take classes and get individual teaching sessions on topics such as how to manage your care at home and follow food safety guidelines. Classes are offered on a weekly basis to patients, caregivers, friends, and family members. Class recordings are available at FredHutch.org/patient-education-videos.

Medical evaluation

Physical exam and tests

Before treatment starts, you will have a medical evaluation that includes a physical exam, labs, and diagnostic tests. You may also get tissue typing, a bone marrow aspiration, pulmonary function studies, chest X-rays, and an electrocardiogram (EKG). The attending physician will review your medical records and current condition, then meet with you and your caregiver to outline the proposed treatment plan and start date and answer your questions. The length of time needed to complete the evaluation depends on your medical condition.

Meetings with other members of your care team

During the evaluation, you and your caregiver will also meet with other members of your care team, such as an advance practice provider or fellow, nurse, social worker, pharmacist, and dietitian. You may also be referred to Fred Hutch physical therapy to check your pre-transplant function, strength, and range of motion. This gives us baseline data to compare with your post-transplant progress.

Feelings of uncertainty

As you prepare for your transplant, you may experience a sense of urgency to get started with treatment and feel a sense of uncertainty while you're waiting for test results. However, this period of evaluation and orientation is essential to the success of your treatment.

Data review and consent for treatment conference

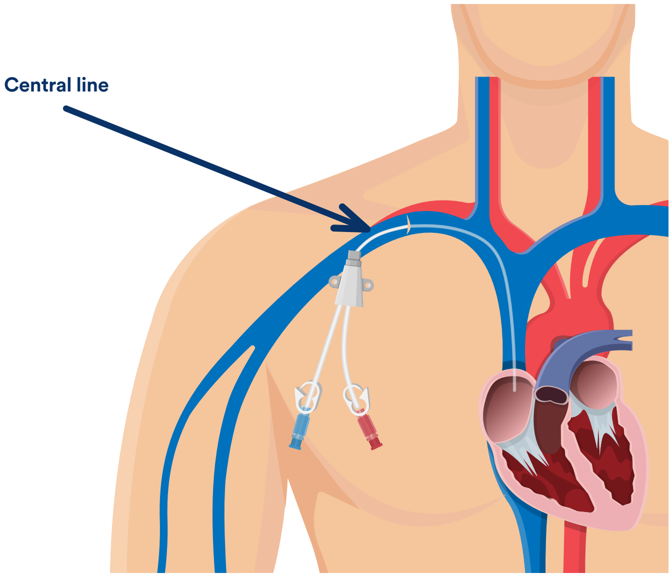
You will have a data review and consent conference with the attending physician and a nurse before treatment begins. During the conference, they will describe each part of your treatment plan, along with the risks, complications, and length of time you are expected to be in our care.

Data review and consent for treatment conference, continued

At the conference, you will sign consent forms that summarize the potential risks and benefits of each part of the proposed treatment. It is important that you understand this information and that all of your questions are answered before you sign these forms. You must give your written consent for the treatment plan before your therapy can begin.

You may be asked to participate in additional research studies during this time; please know that these are optional and do not impact your ability to get a transplant with us. We encourage you to read and ask questions about all studies before signing consent forms.

Central intravenous (IV) line placement



Before treatment starts, you will have a central line placed. A central line is a small flexible tube inserted into a large vein in your chest. It is used to give you fluid, nutrients, medicine, and blood products. It may also be used to get blood samples.

Inserting the central line is a minor surgical procedure. It is done in a procedure suite or an operating room and takes about 1 hour. Your doctor will use local anesthesia (medication) to numb your neck and chest. You may also be sedated (given medication that makes you sleepy).

Chemotherapy

You may get an extra cycle of chemotherapy to reduce the number of tumor cells even more before transplant.

Step 3: Conditioning

During the next step in your transplant process, you will receive a therapy called conditioning.

Conditioning therapy includes chemotherapy with or without total body irradiation (TBI). The goal of conditioning is to:

- Help make room for the new stem cells to grow
- Prevent your body from rejecting the donor transplanted cells
- Kill any cancer cells that are in your body

Conditioning can be either high dose or moderate dose. The type of conditioning you receive is determined by your physician and based on your personal health condition. Both are described below.

High dose conditioning chemotherapy with or without TBI

High dose conditioning chemotherapy with or without TBI is also called myeloablative (high intensity) treatment. The doses of chemotherapy and TBI are much higher than you received during traditional treatment. High dose conditioning therapy kills rapidly dividing cells, such as cancer cells and bone marrow cells. It also damages healthy cells that are found in your hair follicles, mouth, stomach, intestines, skin, and nails.

Cells in the bone marrow are an important part of your immune system. Your immune system helps fight infections and recognize cells that are not identical to yours. The high dose therapy will lower your immune system and allow the new stem cells to grow.

Side effects of high dose conditioning

You may experience side effects such as nausea, vomiting, fever, mouth dryness, and a mouth condition called mucositis when receiving high dose chemotherapy and TBI. We will give you medicine and tips to reduce discomfort and help manage your symptoms. It is important to follow the instructions we give you to help promote healing and relieve symptoms. Chemotherapy and TBI cause hair loss, starting about 5 to 10 days after treatment begins. Hair usually starts to grow back in a few months.

Please ask questions and tell us about changes in your symptoms. Sharing these important details can make a big difference in how we help you.

Lower dose conditioning chemotherapy with or without TBI

Lower dose conditioning chemotherapy with or without TBI can be used to prepare you for an allogeneic transplant. This is also called non-myeloablative (reduced intensity) treatment. The doses of chemotherapy and TBI are low and work to suppress the cells of your immune system so the new cells can grow in or engraft.

In an allogeneic transplant, we rely on the new immune system of the donor to destroy any remaining cancer cells. This is called the “graft versus tumor” effect. In this type of transplant, there is a time when there is a mixture of your immune system and the donor’s immune system in your body. This is called mixed chimerism (kai-mer-ism).

Side effects of lower dose conditioning

You may experience side effects such as nausea, vomiting, and fatigue when receiving lower dose conditioning chemotherapy with or without TBI. Generally, these side effects are mild. If you have conditioning chemotherapy without TBI, you may experience hair thinning, but not complete hair loss.

Safe management of chemotherapy (chemo) at home

Because chemo is made up of hazardous substances that can harm you, it is important to take steps to stay safe, especially at home.

Handling chemo

Only you or your caregiver should touch chemo. Any item that comes in contact with chemo is considered contaminated. You must take special steps to prevent chemo from touching household belongings, people, and pets. People who are pregnant or nursing, children, and pets should not touch chemo and waste with chemo on it. Always wear gloves when handling oral chemotherapy (chemo that you take by mouth).

Storing and taking your chemo

- Store your chemo and equipment in a safe place and out of reach of children and pets.
- Check your medicine labels for special instructions — some medications need to be refrigerated or kept away from light; follow other instructions from your care team.
- Take your medication at around the same time(s) every day, on a regular schedule. Oral chemotherapy doses are set up so that you will have constant levels of the medication(s) in your body to kill the cancer cells.
- Swallow your medication whole. Do not chew, crush, break, split, or open your pills or capsules. If you are unable to swallow your medication, contact your care team.
- If you miss a dose, contact your care team. Do not take two doses at the same time.
- If you have unused medication, do not throw it in the trash and do not flush it down the toilet or sink. Ask your care team for instructions on how to get rid of unused medication.
- Keep your chemo pills in their original container; do not transfer them to a pill box.
- Do not store chemotherapy in your bathroom because humidity may damage the medications.
- If you are not taking your medication as prescribed, contact your care team.

Other instructions

Body fluids and wastes

Urine (pee) and stool (poop) are bodily wastes. Vomit, sweat, vaginal fluid, and semen are bodily fluids. Your urine and stool contain chemotherapy while you're receiving treatment and for up to 2 days after you've finished treatment. Traces of chemotherapy may also be present in vomit, sweat, vaginal fluid, and semen.

- You may use the toilet (septic tank or sewer) as usual. After using the toilet and before you flush, put the lid down. Then, flush it twice to make sure all the waste is gone. Be sure to wash your hands with soap and water each time you use the bathroom.
- It is safe for your family to use the same toilet as you. Make sure any chemo waste is cleaned from the toilet using gloves, soap, and water. If your caregivers have contact with your body wastes, they should wear gloves.
- If you don't have control over your bladder or bowels, use a disposable, plastic-backed pad or adult diaper or sheet to absorb urine or stool. When it gets soiled, put on gloves, remove the soiled piece, remove the gloves, and then wash your skin with soap and water.
- If you have an ostomy, you or your caregiver should wear gloves when emptying or changing the bags. Empty any urine or stool into the toilet and close the lid and flush the toilet twice. Get rid of disposable ostomy supplies by putting them in a leakproof plastic bag. Put that bag into another leak-proof plastic bag so the supplies are "double-bagged."
- If you use a bedpan, urinal, or commode, it's important for your caregiver to wear gloves when they empty and clean the containers. Your caregiver should rinse the container with water after each use and wash it with soap and water at least once a day.
- If you vomit, it's important for your caregiver to wear gloves when they empty and clean the container. Your caregiver should rinse the container with water after each use and wash it with soap and water at least once a day.

Laundry

Wash your clothing and bedding normally unless chemo, bodily fluid, or waste gets on them. If that happens, put on disposable gloves and handle the laundry carefully to avoid getting chemo on your skin. Wash these items separately from other clothes. If you don't have a washing machine, place the dirty items in a sealed, leak-proof plastic bag until they can be washed.

Skin care

Chemotherapy can irritate your skin. If chemo touches your skin, thoroughly wash the area with soap and water, and dry it. If your skin gets irritated and it lasts more than 1 hour or if you get a rash, call your care team. Wear gloves when working with chemo, equipment with chemo on it, or waste to prevent it from touching your skin.

Eye care

If chemotherapy gets into your eyes, flush them with water for 10-15 minutes, and contact your care team immediately.

Spending time with others

Living, eating, and doing activities with others is safe. Hugging and closed mouth kissing is safe, too.

Pregnancy, sexual activity, and contraception

You should not become pregnant or get a partner pregnant while taking chemo. If it's possible for you to get pregnant, use effective birth control (also called contraception) while taking chemo and for at least 30 days after your last dose. Please tell your care team if you become pregnant. If you plan to be sexually active during your treatment:

- You may need to take special steps to stay safe. Traces of chemo may be present in your vaginal fluid or semen for up to 48 hours after treatment.
- Do not breastfeed without talking with your care team first.
- It is safe to hug and kiss.

For more information, please read the Sexual Health section of this manual. You can also talk with your care team.

Is it safe to be sexually active during my treatment?

Please ask your care team this question, as this depends on the type of treatment you are on. Because traces of chemotherapy may be present in vaginal fluid or semen for up to 48 hours after treatment, you made need to take special steps to stay safe.

Can I travel with my chemotherapy?

Traveling with chemo is usually fine but check with your care team to make sure it is OK. Ask your care team for a letter that says you need to travel with your medications and that it's safe for you to do so. The letter should list the names of your medications.

Can I travel with my chemotherapy? continued

Some chemotherapy requires special storage, so you may need to make plans, such as traveling with a cooler. Always seal your chemotherapy medications in plastic bags. Keep medications in your carry-on bag. Do not put them in your checked bags.

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Step 4: Transplant

The day you receive stem cells is “transplant day.” We call this day zero. The process of getting stem cells doesn’t take long, but it is a significant event. You will either receive your donor cells in the clinic, in the Fred Hutch Hospital located at UW Medical Center – Montlake or at a unit of UW Medical Center – Montlake.

Donor marrow or cells are thawed and given to you through your central line. During the infusion, your nurse will check your blood pressure, pulse, respiration, and temperature. You may be connected to a heart monitor, so nurses can observe your heart rate and rhythm.

The length of the infusion depends on the volume, or amount of stem cells to be given. The infusion takes 30 minutes to 2 hours to complete. You may receive stem cells on more than one day because of the donor collection process.

During the infusion you will rest in bed and can read, watch television, or visit with family or friends. You may experience nausea, vomiting, shortness of breath, flushing, chills, or a mild fever. Your care team will work with you to control your symptoms.

Hospital admission and guidelines

You may be hospitalized during your transplant. If needed, your inpatient care will either be provided at Fred Hutch Hospital or a specialized unit of UW Medical Center-Montlake. Both are located at UW Medical Center-Montlake and provide the same high-level quality of care. The Transplant care units are located on 7 NE and 8 NE in the Cascade Tower, 1959 Pacific Avenue N.E., Seattle, WA 98195. If your admission to the hospital is scheduled in advance, you will be notified of the time and date to go to the hospital. At times, you may need to wait for an available hospital room.

Your phone number

Each patient room has a phone. This phone number can be used by your friends and family to reach you in the hospital. You will be responsible for giving this number out to your friends and family. Although staff will not give out this number, calls received at the nurses' station can be transferred into your room.

- To make an outside call, dial: 9 + phone number.
- To call within Fred Hutch Hospital or UW Medical Center-Montlake, dial: 8 + 4-digit extension number or dial "6190" and ask the hospital operator to connect you.

Mail

Volunteers will deliver patient mail daily to the rooms. An outgoing mailbox is located at the nurses' station.

Parking and transportation

You can park in the Triangle Garage or the Surgery Pavilion Garage. Staff at the front desk of your unit can validate your ticket to reduce your parking fee.

Valet parking is offered in front of UW Medical Center-Montlake on weekdays from 7:30 a.m. to 5:30 p.m. The cost is the same as parking in the Triangle Garage. There is no extra fee for valet services.

The hospital offers free shuttles to Roosevelt clinics, Harborview Medical Center, and Fred Hutch. Staff at the front desk of your unit can give you a schedule and tell you where to catch the shuttle.

All Fred Hutch Hospital and UW Medical Center-Montlake garages (Surgery Pavilion and Triangle) and the Fred Hutch clinic garage offer same-day reciprocal parking. Simply bring your receipt from a participating garage to your next appointment that day, and it will be honored. You can get a validation sticker at the nurses' station.

Food services

Nutrition Services will provide meals and snacks. You will receive a menu that is designed to follow your diet. Food safety is important, so it is preferred that your food and beverages be served from the hospital kitchen. If you feel you require foods from outside the hospital, talk with your dietitian or provider.

We may keep a record of your food and fluid intake. These records allow the dietitian to determine the amount of calories, protein, and fluids you eat and drink. Your dietitian and provider use this information to assess if you need additional IV fluid or nutrition support.

During your hospital stay, family members and visitors are encouraged to visit the Plaza Café on the first floor. There are also espresso bars located on the first and third floors. Family members should not eat from your tray. Family members can order from a guest menu.

Television

As part of an ongoing commitment to patient education, Fred Hutch Hospital and UW Medical Center-Montlake regularly offer a wide selection of health care information. You will get a program guide that lists the channels that are offered, as well as movie guides.

Smoking policy

Fred Hutch Hospital and UW Medical Center-Montlake are smoke- and tobacco-free facilities. If you are a patient and you smoke or use tobacco, you may request nicotine patches during your hospital stay. We are here to support you if you would like information about how to quit.

Your daily routine

You may wonder what a normal day is like while you are staying in the hospital. The nurse will explain this to you when you arrive, but in the meantime, here is what you can expect:

Routine blood tests

Around midnight the nurses will draw daily routine blood tests from your central line. We will disturb you as little as possible, but our medical team needs to review your laboratory findings as early in the day as possible. Some routine tests will be drawn other times of the day as well.

Vital signs

Your temperature, pulse, respirations, oxygen saturation, and blood pressure (vital signs) will be taken every 4 hours. Sometimes they are taken more often if we need to monitor you more closely.

Physical exams

The nurses and providers will need to listen to your heart, lungs, and abdomen (belly) with the stethoscope. The nurse will look at your mouth daily and more often when you are likely to experience mucositis (swelling in your mouth).

Daily weight

Your weight will be checked every morning to monitor the amount of fluid in your body. You may need to have your weight checked twice a day.

Bathing

You are required to take daily baths or showers to help cleanse bacteria from your body. This may help lower the chance of infection. Your nurses will work with you to fit your bath or shower into your schedule.

Central line care

Your central line dressing will be changed as needed to guard against bacterial growth. This gives us a chance to inspect the skin around the central line.

Measuring output

Your urine (pee), stool (poop), and vomit will be measured and tested. Tests will be done on a regular basis. Please do not get rid of urine, stool, or vomit. The nurse will do it for you.

Exercise

We encourage you to arrange a time to take a walk and exercise in the halls with the nurse. Your provider may have physical therapists help you keep your activity level up.

Nutrition

Dietitians will talk to you about your food likes and dislikes and recommend foods based on your oral (mouth) and/or gastrointestinal (G-I) symptoms. Nutrition support, either through a feeding tube or through your central line, is recommended if you are not able to eat.

Medications and IV fluids

Many medications, such as antibiotics and anti-nausea medications, will be given through your central line. Fluids will be given if you cannot drink enough to meet your body's needs.

Rounds

Every morning, your provider and other members of the team will do rounds, a group discussion with each patient. This is to check on your progress and make changes in your therapy, if needed. This is a good time to ask any questions you may have and to discuss your plan of care. Every hour during the day and every 2 hours at night, a nurse or patient care technician (PCT) will visit your room to check on your well-being, monitor your comfort and pain, help you to the bathroom, and make sure you can reach the things you need.

Transfusions

You will get blood and platelet transfusions as needed until you are able to make your own blood cells. Your blood counts will be checked every morning.

Making the transition to the Fred Hutch clinic

A transition nurse from the Fred Hutch clinic will meet with you and your caregiver to help plan your discharge from the hospital. Your team nurse will coordinate your care until you are discharged to your home provider.

Visitor guidelines

There are no set visiting hours in the hospital. Please check with your care team to learn the current visitor policy. There may be limits on visitors due to COVID-19 or during respiratory virus season. We encourage families to keep their own health in mind and to get a good night's sleep. A nurse will contact family members at home if any problem occurs. Family members should make sure that the nurses' station has their correct phone number on file for emergencies.

Any family member or visitor who has a fever, any respiratory virus symptoms (such as a runny nose, cough, sneezing, sore throat), or who is not feeling well, should not visit. Even minor colds and infections carry a risk to the patient.

Child visitors

Children are known to get many viruses. Please evaluate the health of children, and their exposure to other children who may have been ill, before letting them come to the hospital.

Children with any symptoms of respiratory virus infections should not visit. Since allergy symptoms and respiratory virus symptoms are very similar, children should not visit even if you think their symptoms are allergy related. Child visitors must follow these guidelines:

- Children must wash their hands like any other visitor.
- Children who are ill or might be ill are not allowed to visit.
- Children (or adults) who have been exposed to chickenpox and have not had chickenpox are not allowed to visit.
- If children have received live-virus oral polio vaccine, they cannot have contact with the patient for at least 6 weeks. If a child needs a polio vaccination, the inactivated polio vaccine can be given by injection.
- Children may not go into the room of another patient.
- The hallway is not a play area for children. No running, screaming, or yelling is allowed. Children are not allowed to play with hospital equipment such as wheelchairs and stretchers.

Preventing infection

You and your family members are not allowed to visit other patient rooms. This helps to prevent the spread of infection. You are encouraged to walk around the unit, but should avoid other patients, their families, and the areas where people gather. Family members or other visitors should not use the bathrooms in the patient rooms. They should use the public restrooms on the unit instead. Here are some additional infection prevention steps:

- Clean your hands often by washing with soap and water or by using alcohol hand sanitizer. At the very least, everyone should wash or use hand sanitizer when they enter and exit your room. Clean hands are safe hands.
- Keep surfaces clear of personal items. Some organisms can survive a long time on the surfaces and equipment in your room. It is very important that these surfaces can be cleaned daily by our Environmental Services (ES) staff. The ES staff cleans bed rails and other items close to you if you are not in the room. To help them do a complete cleaning, please leave your room, if possible. You can take a shower, walk, or sit in a chair.
- Do not keep a lot of personal items in the room. To help keep your room as clean as possible, we allow you to have cards and pictures posted on the wall of the room. Place other items in the bedside cabinet. If someone brings you gifts that you don’t need at the hospital, we encourage family members to take them home after you have seen them.
- Clean or wash your belongings. ES staff does not clean your belongings. Each day, a family member or friend should wipe off your belongings with a cloth or paper towel dampened with soap and water. Items such as clothing or quilts should be washed regularly or when they get soiled.
- Place used tissues in the trash can, not on other surfaces such as the bedside table or floor.

Families and other visitors need to take special safety steps during respiratory virus season. Families and visitors will need to sign in at the nurses’ station desk daily. They will be asked if they have flu and cold symptoms to help determine if they are sick. Sick people are not allowed to visit. This is for the safety of all patients who have weakened immune systems, and for staff who could risk infecting these patients if they catch a cold or the flu.

Fresh flowers and plants

Fresh or dried flowers and plants are not allowed on the hospital unit because of the organisms that grow on them and in their dirt or water, which can cause infections. Non-latex balloons and silk flowers are OK. Make sure there is no moss around silk flowers. Only artificial moss is allowed.

Other information

Money and valuables. Do not leave money and valuables in your room because of the risk of theft.

Getting help from a nurse. Please press the "nurse call button" if an alarm rings in your room. You will have medications and fluid running on infusion pumps. These pumps have alarms that will beep for various reasons. Family members should not turn off the pump alarms.

Recording intake and output

Input is what you eat or drink. Output is what you release through urine, stool, or vomit. If you have any food or drink, tell the nurse what you had and the amount. It is important to keep accurate records of your fluid intake and output. Never empty a urinal, bedpan, or vomit container.

Medications

Family members should never give you medications without instructions from the nurse.

Release of medical information

You can get medical records for your hospital stay from Health Information Management at UW Medical Center-Montlake. There is no charge to send copies to your provider.

Step 5: Waiting for engraftment

What is engraftment?

About 10 to 28 days after transplant, new stem cells start to grow. This is called engraftment. We monitor your blood counts daily as the graft strengthens.

Waiting and watching

While waiting for engraftment, there's a lot of "waiting and watching." During this time, you can record your daily blood counts, if you'd like. We will give you a special chart to track this.

In addition to watching for the first signs of your new immune system working, staff members are monitoring you very closely for early signs of complications so they can begin treatment right away, if needed.

After transplant with lower dose conditioning, a rising white count does not necessarily mean engraftment. We measure engraftment through a DNA blood test called chimerisms. The test measures the amount of donor cells versus your cells. Your own bone marrow can recover if the donor cells are rejected. This is uncommon but a real possibility.

Infection risk and other complications

Read the Infection Prevention section of this manual carefully to learn how to protect yourself from infection. Following the guidelines in the Infection Prevention section is the most important thing you can do to help prevent infections.

Until the new cells engraft, you are at high risk for infections, bleeding, and fatigue.

If you are unable to eat and drink while you wait for your cells to engraft, you may receive intravenous (IV) nutrition until you can eat and drink enough to maintain your weight. Possible complications during this time include:

- **Viral, bacterial, and fungal infections.** These can be serious problems after a transplant. You will take medications such as antibiotics, antifungals, and antivirals to help prevent certain infections during your treatment.

- **Pneumonia.** Pneumonia may occur in the first months after transplant. We will watch for early signs of pneumonia.

Sources of infection

Infections can come from a few different places, including:

- **Bacteria on your own body.** Bacteria normally grows on everyone's skin and in their bodies. Many of these bacteria are important for proper functioning of our bodies. Our immune system controls the growth of the bacteria, but if they overgrow, they can cause infection. You will give regular samples of blood, urine, skin, or other tissues so your team can monitor the bacteria you have growing in your body that may be causing infections. These samples are called "cultures." Culture results help providers prescribe the right antibiotic when you have an infection. It is not unusual for you to have negative culture results and still look and feel like you have an infection.

- **Bacteria and viruses from other people.** Washing your hands often is the best way to protect yourself from infection.

- **Respiratory viruses, like the common cold or the flu that become pneumonia.** These viruses include parainfluenza, adenovirus, and respiratory syncytial virus (RSV). If you develop symptoms of an upper respiratory infection, such as a stuffy nose, sore throat, cough, chills, fatigue, or fever, we will get a nasal swab to determine if there is a specific viral infection. You will be in isolation as soon as symptoms develop and remain in isolation until the cultures are negative and you no longer have symptoms. Family members or friends with cold or flu symptoms should stay away from you until they are well.

Other complications

- **Cytomegalovirus (CMV)** infection is a member of the herpes family and is very common. Between 50% to 80% of the US population has had a CMV virus infection, according to the Centers for Disease Control (CDC). CMV infections are rarely serious in otherwise healthy children and adults and usually cause only mild symptoms, if any.

  Once a person has a CMV infection, the virus is usually inactive in the body but can be reactivated and cause serious illness in people who have weakened immune systems. You will be monitored for CMV weekly with a blood test called CMV PCR. If you have CMV, it can be treated with antivirals.

Other complications, continued

- **Gastrointestinal (GI) problems.** High dose chemotherapy and radiation can cause mild to severe sore mouth and throat, nausea, vomiting, and diarrhea. We can prescribe pain medications to help with the symptoms and may recommend intravenous nutrition. These side effects get better with engraftment.
- **Taking antibiotics** can increase your risk for two serious problems:
    - ***Clostridioides* infections.** C. diff is a type of bacteria. When you take antibiotics, some of the good germs in your gut are destroyed. This allows the C. diff bacteria to grow. Diarrhea is one sign of C. diff infection. Tell your care team right away if you have new diarrhea while you are taking an antibiotic or within a few weeks after stopping an antibiotic.
    - **Antibiotic-resistant infections.** This type of infection is harder to treat with antibiotics. Taking antibiotics may increase your risk of getting this type of infection in the future. Your care team will watch you for any signs of antibiotic resistance. To help prevent antibiotic-resistant infections, take antibiotics only when needed and prescribed by your provider. If your provider prescribes an antibiotic, finish taking all of the pills as instructed.
- **Lung problems.** We will do daily physical exams and take regular chest X-rays to monitor for breathing difficulties caused by fluid overload, pneumonia, or side effects of chemotherapy or radiation.
- **Skin problems.** Chemotherapy and radiation may cause a mild redness like a sunburn or darker red, dry, and peeling skin.
- **Kidney problems.** Kidneys are organs that produce urine, remove bodily waste, and process some medications out of the body. Some medications affect kidney function. Your care team will closely monitor your kidney function through blood and urine tests and body weight.

Blood counts

What are they?

Blood counts are numbers that show the amount of blood cells circulating in the blood stream. Blood will be drawn from your central line to check the level of your counts. The blood counts that are monitored closely are the total number of white blood cells (ANC), the hematocrit, and the platelet count. You can record your daily blood counts while you wait for engraftment, if you'd like. We will give you a special chart to track this.

How do chemotherapy and radiation effect blood counts?

The amounts of chemotherapy and radiation used in conditioning cause the bone marrow to stop producing cells for a time. Your blood counts will be low during this period, and you may need a blood transfusion. After your blood counts are drawn, your provider will determine your transfusion needs. When your stem cells begin to engraft, your blood counts should start to rise. The actual time for recovery of cells will vary from person to person.

This chart explains what is being counted in a blood count and when a blood transfusion is recommended.

Type of blood cells	What they do	Normal ranges	Transfusion guidelines
Hematocrit (HCT) % red blood cells per volume of whole blood erythrocytes	• Carry oxygen to the body • Give color to the skin • Give energy to the body	37% to 52%	Transfuse: • If HCT less than 26% • If patient symptomatic
Platelets (PLTS) thrombocytes	• Prevent bleeding • Help blood to clot	150,000 to 500,000/ mm3	Transfuse: • If less than 10,000 • For bleeding • If otherwise indicated
White blood cells (WBC)	Fight infection	5,000 to 10,000/mm3	Not applicable
Absolute neutrophil count (ANC) neutrophils polys bands segs granulocytes	Type of WBC that is first to respond to potentially fatal infections	Over 1,000	• Very rare occurrences • Only if life threatening infection is present with no signs of white cell recovery

What is a blood transfusion?

When your blood count is low, the provider will order blood transfusions to increase your blood counts. This is a bag(s) of concentrated blood cells, transfused over 2 to 4 hours. This blood has been matched with yours to decrease the chance of reaction. Even though your blood is a match with the transfused blood, you may still have a reaction, such as fever, chills, hives, itching, and/or breathing problems. If you have any of these symptoms during transfusion or within the next 24 hours, report them right away to your nurse.

All blood products are tested for infectious diseases such as hepatitis, HIV (human immunodeficiency virus or AIDS), and West Nile. If you are cytomegalovirus (CMV) negative, you will receive CMV safe blood, also known as leuko-reduced blood products.

Emotional impacts

It is common to feel scared during the time you are not protected by a fully functioning immune system. You may experience intense concerns about physical symptoms and worry about making it through transplant. You may feel like you are on an emotional roller coaster. You may feel like you have lost control of your life as you cope with daily monitoring and medical procedures. All of these are common feelings during transplant and coping with them can be a challenge. Please reach out to your social worker or Spiritual Health clinician if you need help coping. They are here to help you.

Step 6: Recovery after engraftment

What to expect

As your new immune system is growing and developing, our goal is to support your recovery and manage any complications you may experience.

Most people feel very tired as they are recovering. You may find it difficult to focus on reading a book, watching television, or keeping up a conversation. During this time, it is important to have reasonable expectations of what you will be able to do.

It takes time to recover. Balancing periods of rest with light exercise is important for your recovery and helps prevent the complications of bedrest, such as blood clots and muscle weakness. Progress may seem slow. You may feel frustrated because you want to get well and put this experience behind you.

One of the best ways to cope is to take one day at a time. Work with your care team to set manageable goals to achieve each day. Keep track of the daily goals you achieve, so you can see the progress you are making. We will teach you and your caregiver how to manage symptoms that might arise and how to seek medical care quickly.

As you recover and no longer need close monitoring and treatment, the team will help you prepare to leave and return to the care of your regular physician. While you may be eager for this next step, you may also feel nervous and worried.

Possible complications

Two possible complications you may have are graft-versus-host-disease and failure to engraft. Both are described below.

Graft-versus-host disease (GVHD)

GVHD is when the donor cells you receive attack your tissues and organs.

Acute GVHD could be mild to severe. Symptoms include:

- Rash (can include itching or be painful)
- Loss of appetite
- Nausea and vomiting
- Diarrhea
- Liver damage
- Abdominal cramping

Milder cases may not need treatment or might require steroids, such as prednisone (a pill) or methylprednisolone (given through an IV in the hospital).

For more severe GVHD, high dose steroids are given. The goal of steroid treatment is to control symptoms of GVHD. The dose is reduced over weeks or months depending on your response. We want to limit the number of days that you take high-dose steroids to reduce your risk for serious infections and other side effects.

For GVHD of the stomach, you may also be prescribed beclomethasone. For GVHD of the intestines, you may also get budesonide. Sometimes these special steroids are called "B and B." The use of B and B generally allows the doses of prednisone to be tapered more quickly. For GVHD of the skin, you may be prescribed ultraviolet light called PUVA or steroid creams.

Failure to engraft

Generally, it takes a number of weeks after the transplant to find out if the graft was successful. It takes longer for some patients to engraft than others. Blood counts normally go up and down after transplant. At first, there may be signs of engraftment such as increasing blood counts, but later the blood counts may decrease. Certain medications can also impact the production of blood cells.

If you are diagnosed with failure to engraft (the graft did not work), you will be offered other therapies that may include:

- Increasing the production of blood cells (through research studies that focus on this)
- Not taking medications that get in the way of bone marrow function
- Receiving more marrow or stem cells, if they are available

Transitioning back to Fred Hutch

You may be hospitalized during your transplant. If needed, you will stay at Fred Hutch Hospital or a specialized unit at UW Medical Center-Montlake. Both are located at UW Medical Center-Montlake and provide the same high-level quality of care. See the **Hospital admission and guidelines** section for information about hospitalization.

Before you are discharged, a Transition nurse will meet with you and your caregiver to help with plans for discharge and your transition back to the Fred Hutch clinic. You and your caregiver will learn and practice the skills you need to manage your care at home. You and your caregiver are welcome to attend any Fred Hutch online classes a second time to refresh your memory on anything you learned before transplant.

Before you are released from the hospital, a transition nurse will schedule your next clinic visit. You will be scheduled to see a provider or provider's assistant and your team nurse at the clinic at least once a week, and other times as needed. This visit includes an exam and time for you to share your questions and concerns with staff.

At your first clinic visit after discharge, you will get your usual weekly schedule for clinic times, blood draws, and routine chest X-rays. You will have a Nutrition visit scheduled. You may need to be at the clinic for care other than your scheduled weekly visit. Your blood will be drawn at the clinic in the morning, 2 to 7 times a week. You will have bone marrow aspirations around days 28 and 80 to check the status of your new marrow. You may get spinal taps to receive treatment to your central nervous system. Any medications given through an IV, infusions, growth factors, study drugs, and blood product transfusions are also given in the clinic.

After you're discharged from the hospital, your care team will tell you to:

- **Exercise daily.** Regular exercise is important to your recovery. You may need physical therapy to maintain your muscle strength.
- **Wear sunscreen.** Use sunscreen with sun protection factor (SPF) 30 when you are outside and apply it to all exposed skin areas. Even if it is not sunny out, it is important to protect your skin from the sun's rays. Your skin is sensitive after a transplant, and there is an increased risk of skin cancer. You must use sunscreen for the rest of your life.
- **Manage your symptoms.** Review the **Managing care at home** section for more information on how to manage symptoms. Refer to the **Quick Reference Guide** in the pocket of this manual. When in doubt, call us. Keep your emergency card with you.

You may need to be readmitted to the hospital to manage symptoms that cannot be safely taken care of at home or in the clinic. As soon as you are medically stable, your care team will work with the Transition nurse to shift your care back to the clinic.

The average person who gets an allogeneic transplant stays in Seattle 100 days after stem cells are infused.

Departure evaluation

Before leaving Fred Hutch and around day 80 after transplant, you will learn about chronic GVHD and get a series of tests to check for signs and symptoms of it. Chronic GVHD usually starts as early as day 80 after transplant and can last a lifetime. Tests can find early signs of GVHD, so if needed, you can start treatment before problems develop. The tests take around a week to complete and include a physical exam and:

- Pulmonary (lung) function tests
- Skin biopsy
- Final bone marrow aspiration
- Blood tests
- Oral (mouth) exam
- Gynecologic exam
- Eye exam

Departure conference and clinic visit

About 2 weeks after your GVHD departure evaluation, you and your family will have a conference with the attending provider and primary nurse. You will get the results of your tests and be given recommendations and instructions for care and monitoring at home, including information about long term follow-up. You will also have the opportunity to ask any questions about your condition or your return home. After this conference, you will have one final clinic visit with your attending provider, primary provider or provider's assistant, and nurse.

Long-term follow-up (LTFU) departure class

You will attend the LTFU Departure Orientation class taught by an LTFU nurse. You can also find a video of the class online by visiting FredHutch.org/patient-education-videos and scrolling down to "Blood and Marrow Transplant." After you are discharged from our care, LTFU staff are available to you and your provider to answer questions and concerns during business hours for the rest of your life.

Discharge papers

You will get a packet of information to take with you and give to your referring provider. It includes a summary of all your care and recommendations for your further care. These papers will be given to you during your final clinic visit.

Step 7: Long Term Follow-Up

How to take care of yourself in the first year

> *"The most important advice I could ever give to someone dealing with life after transplant is: waste no time wishing you could get back exactly to where you were before transplant. Your life will instantly become more fulfilling and enjoyable the moment you stop being, say 70% of what you used to be, and becoming 100% of what you are now!"*
>
> *— BMT Survivor*

The long-term recovery phase may take a year or longer. This is the time to gradually get back to your life patterns at work, school, or at home, and make adjustments in relationships with your family and friends.

It may also mean learning to adjust to the therapy you may need for chronic or long-term complications. Former patients have noted that the interruption of life plans, the changes in relationships, and preparing to re-enter work and family life can be difficult.

You may experience a sense of loss or discouragement. Some people explore a deeper meaning in their lives. You may want to seek therapy to help you cope with chronic health issues and emotional responses to the challenges of treatment and recovery. Therapy can help you gain tools for coping with chronic illness or feelings of loss, anxiety, stress, worry, and depression.

Reestablishing your life may vary from difficult and challenging to easy and smooth. Some patients discover they have a more positive view of their life, greater compassion for others, and improved relationships with family. The majority of patients report that their quality of life is now the same or better than before transplant.

On the other hand, some patients struggle and become discouraged as they cope with the various life changes. Despite the intensity of the transplant experience, most patients make adjustments in their lives and maintain a positive outlook for the future.

Please see the section **Day-to-day care the first year and beyond** for more information on Long Term Follow-Up.

Managing care at home

Infection prevention guidelines

Even though you are well enough to recover at home, your immune system is still recovering. You will need to protect yourself from infection for up to 1 year or longer after your transplant (see table at the end of this section for more information on timing). You and the people around you should follow the guidelines in this section carefully for 6 months to a year to prevent infections.

What is an infection?

Infections are caused by germs that enter the body and multiply. Typical germs that can infect transplant patients are bacteria, viruses, and fungus (molds and yeast).

During and after your transplant, your immune system will be weak, so you will be at a higher risk for getting infections. Infections in people who are receiving a transplant can be more serious than in people who are healthy.

It is critical to limit exposures that might increase your risk for getting an infection, and to get help when you develop infectious symptoms. It is not possible to prevent all infections, but there are simple steps that you and your caregiver can take to help prevent many common infections. While this section cannot cover all scenarios or possible situations, it includes basic information on how to prevent infections.

Cleaning your hands

Cleaning your hands is one of the best ways to prevent infections, especially during the first year after your transplant and while taking immunosuppressive medicines (medicines that weaken your immune system). Cleaning your hands is also called "hand hygiene."

You and anyone you interact with, including all members of your household and your care team, should clean their hands often. You and your caregiver should also keep your nails short (do not wear fake, acrylic or gel nails) because germs can collect under them. You can wear nail polish as long as it isn't chipped (germs can collect under chipped nail polish). Do not be afraid to ask visitors or any healthcare staff if they cleaned their hands before they meet with you.

When to clean your hands

It is important to clean your hands often throughout the day, especially when you are in public places, such as the clinic, restaurants, and stores. Make sure you clean your hands:

- Before eating
- Before and after preparing food
- After touching raw meat
- After handling garbage bags
- Before touching your eyes, nose, or mouth
- After sneezing, coughing, or blowing your nose
- After using the restroom
- Before and after any central venous catheter care, intravenous infusions, or wound care
- Before taking oral medicines
- Before entering and leaving an exam room
- Before entering and leaving the clinic or hospital
- Before and after getting on a shuttle
- After touching public surfaces such as furniture, handrails, door handles, counters, elevator buttons, phones, or pens
- After touching pets or animals
- After going outdoors

Ways to clean your hands

There are 2 ways to clean your hands properly:

1. Wash them with soap and water. Use soap and water when your hands are visibly dirty or after using the restroom. Soap and water should also be used after touching someone with a gastrointestinal infection like C. diff or norovirus.
2. Use alcohol hand sanitizer, such as Purell®, that contains at least 60% alcohol. As a general rule, it is OK to use hand gel with alcohol when your hands do not look dirty.

Hand sanitizer may not prevent some gastrointestinal infections, such as C. diff and norovirus. People with these infections and their caregivers should wash their hands with soap and water instead.

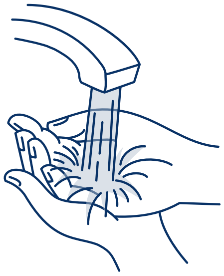
How to clean your hands

Cleaning your hands correctly is important. Read the steps below and practice them. Make the process a habit.

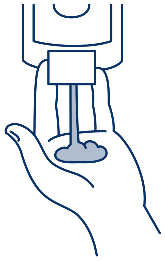
Using soap and water

1. Wet your hands with warm water.
2. Pump soap into your palm.
3. Lather up by rubbing your hands together for 20 seconds. Cover all surfaces of your hands and fingers.
4. Rinse your hands thoroughly.
5. Dry your hands with paper towel.
6. Use a towel to turn off the faucet.
7. Throw your dirty towel in the trash.

1. **Wet**



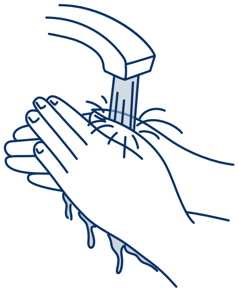
2. **Soap**



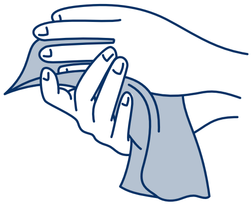
3. **Wash**

for 20 seconds

4. **Rinse**



5. **Dry**



6. **Turn off water**

with a paper towel

Using alcohol sanitizer:

1. Place 1 or 2 pumps of sanitizer into your dry palm.
2. Rub your hands together. Cover all surfaces of your hands and fingers until they are dry. Make sure you get sanitizer between your fingers and on the back of your hands.

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.

Maintain your personal hygiene

Maintaining your personal hygiene (keeping yourself clean) is an important part of preventing infection. Follow the personal hygiene guidelines below:

- Take a shower or bath once a day. Use soap. Wash your hair. Rinse thoroughly.
- Cover your central line when showering or bathing to keep your line dry. Follow the central line instructions in this manual to learn how to cover your central line.
- Change your clothes once a day.
- If you wear contact lenses, clean your hands and make sure the contacts are cleaned according to instructions before you put them in.
- Have a towel that is just for you. Change the towel daily.
- Do not self treat for infections. For instance, if you have a vaginal infection or discharge, tell your care team. DO NOT douche unless it is part of your prescribed treatment plan.

Keep your home clean

Your goal is to decrease the number of microorganisms (bacteria, viruses, and fungus) present and avoid spreading organisms on the surface of objects into the air. To do this:

- Clean the kitchen and bathroom with a bleach solution at least once a week and as needed. You can make your own bleach solution by mixing 4 teaspoons bleach with 1 quart (4 cups) water. If you do this, make a fresh solution each time you use it. This keeps the solution effective. Instead of making your own solution, you can buy a pre-made bleach solution such as "Clean-Up Cleaner with Bleach" spray made by Clorox®, or use Clorox wipes.

- Clean these areas in the kitchen:
  - o Sinks, which can be very dirty because grime and mold often stick to their surfaces
  - o Faucets and faucet handles
  - o Countertops
  - o Cutting boards
  - o Refrigerator and microwave handles
  - o Stovetops
  - o All areas that hands have touched or where food has been prepped

- Air conditioning (AC) and fans can bring dust and mold into your home. If you have AC, get it inspected and cleaned regularly. This includes getting the filters changed according to manufacturer instructions. If you have fans, wipe (or remove) the dust from fan blades and motors regularly.

Avoid activities with high risk for infection

The following activities can put you at risk for a life-threatening infection, especially during the first 6 months to 1 year after transplant. Follow these guidelines carefully:

- Avoid crowded areas such as movie theaters and sporting events where you can't control the distance between you and other people.

- Take your temperature. Take your temperature every morning and every night. Call the clinic or after-hours clinic if you have a temperature taken by mouth that is greater than or equal to 38.3°C or 100.9°F, or a temperature of 38.0°C 100.4°F for 1 hour. When taking your temperature under the arm, call if the temperature is 37.9°C or 100.3° F. Do not take Tylenol® until you have talked with a nurse or physician. **Report a shaking chill without a fever.**

- Avoid shaking hands with others. If you do shake someone's hand, clean your hands afterwards.

Avoid activities with high risk for infection, continued

- Avoid close contact with people who have respiratory illnesses, such as a cough or cold. Be especially careful around children who go to school or daycare. They are often exposed to other children who are ill. You should not live in the same home with someone who is ill.
- Avoid getting a manicure at a spa or salon. It is OK to paint your own nails or have a friend or family member paint them.
- Avoid direct contact with soil, plants, and activities such as gardening, raking, mowing, and farming. These activities create and spread tiny plant and soil particles into the air, which increases exposure to fungi and bacteria. Avoid working in green houses. Ask friends and visitors not to bring fresh flowers and potted plants as gifts. Do not keep any plants or flowers in your home.
- Avoid wood-burning fireplaces because wood contains fungus. If a wood stove is your only source of heat, have someone else touch the wood and manage the fire.
- Avoid all hot tubs.
- Avoid house cleaning that causes dust and mold to be stirred up in the air. This includes activities like vacuuming, dusting, and scrubbing down showers. If your house needs to be cleaned, ask someone else to do it and leave the house when they clean if you can. Ask them to clean with wet washcloths or wipes because they capture dust. Do not use feather dusters. Once you have the energy, it is OK to iron, wash clothes, dry clothes, and wash dishes.
- Avoid dusty or moldy areas and construction sites, including homes or buildings that are being repaired or remodeled. Construction can disturb soil and create bursts of airborne dust that have fungal spores called Aspergillus. Aspergillus is widespread in nature, especially in decaying matter, water, and soil. If you have a weakened immune system, Aspergillus can cause infections in your lungs, skin, sinuses, or brain. If you live near construction, keep your windows closed. Keep your car windows closed when driving past construction sites.
- Avoid using a humidifier or diffuser because bacteria live in the water.
- Avoid swimming in recreational water such as ponds, rivers, lakes, swimming pools, and hot tubs.

- Avoid human or animal feces (poop).
    - o Do not change a baby's diaper; if you must change a diaper, wear gloves, and wash your hands after you throw the diaper away.
    - o Do not empty and clean litter boxes.
    - o Do not clean up after pets.
    - o Do not touch bird droppings.
    - o Do not clean a fish tank.
- Avoid tobacco and marijuana use. The use of these substances, along with exposure to environmental tobacco smoke (second-hand smoke), increases your risk for bacterial and fungal infections.

Prevent infections from animals

- Wash your hands immediately after petting animals.
- You do not need to get rid of your pets. Avoid getting any new pets during treatment.
- Avoid sleeping with your pets.
- Ask someone else to do most of the pet care.
- If you have a cat, do not place the litter box in kitchens, dining rooms, or other areas where you prepare food and eat. Have someone clean the litter box during the first year after transplant. Keep your cats inside and do not adopt or handle stray cats.
- Reduce the amount of direct contact you have with animals, especially animals that are sick.
- Avoid contact with reptiles (turtles, snakes, lizards), ducklings, or chicks to prevent exposure to bacteria called Salmonella. If you have other pets, please discuss this with your care team.

Always notify your team if you have been exposed to an infection or if your caregiver or family member is ill or has recently been diagnosed with an infection.

Wearing a mask at the Fred Hutch clinic

Should I wear a mask at the Fred Hutch clinic?

Yes. According to the CDC, people who are immunocompromised should wear a well-fitted mask in indoor public places and in crowded outdoor settings.

Wearing a well-fitting mask:

- Makes you less likely to spread respiratory viruses, such as the flu, respiratory syncytial virus (RSV), and COVID-19
- May help protect you from respiratory viruses
- Helps make sure you do not touch your nose or mouth with dirty hand hands throughout the day, which can increase your likelihood of infection.

It is important to recognize that masks are not a replacement for social distancing and hand hygiene.

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

Wear a mask if you are coughing, sneezing, have a cold, the flu, or if you are on respiratory isolation. When worn correctly, masks help decrease the spread of respiratory viruses and bacteria. If you have a cold or the 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.
- Avoid high-traffic areas in the clinic, such as the Bistro, crowded elevators and classes, and Fred Hutch shuttles.
- Use hand sanitizer or wash your hands often.

What type of mask should I wear in the clinic?

You should wear a medical grade face mask. These masks have a strap that goes behind your ears. The mask should fit snugly and move in and out slightly when you breathe. Medical grade facemasks are made of soft materials and comfortable to wear. We offer free medical grade masks at clinic entrances.

How do I put on my mask?

1 Wash your hands with soap and water or hand gel (if soap and water aren't available).

2 Hold the mask by the ear loops and place a loop over each ear.

3 Mold or pinch the stiff edge to the shape of your nose.

4 Pull the bottom of the mask over your mouth and chin. Avoid touching the front of the mask.

How do I take off my mask?

1 Wash your hands with soap and water or hand gel (if soap and water aren't available).

2 Hold both of the ear loops and gently lift and remove the mask. Avoid touching the front of the mask. Only touch the ear loops.

3 Throw the mask in the trash and wash your hands with soap and water or hand gel.

4 Wash your hands with soap and water or hand gel (if soap and water aren't available).

Important notes about wearing a mask:

- Wash your hands each time you put on and take off the mask.
- Avoid touching the front of your mask while you're wearing it. If you do, wash your hands.
- Do **not** pull the mask down to expose your nose or mouth. Adjust the mask using the cords around your ears.

Mouth care

To prevent infection, it's important to perform mouth care (also called oral care). Brush your teeth morning and night with toothpaste. Ask your provider or nurse if it is OK to gently floss your teeth. Tell them if your gums bleed or if you have new sores in your mouth. Your provider or nurse may give you a special mouthwash to help clean your mouth. Most people who are going through a transplant see a dental specialist. They can answer your questions about dentures, bridges, retainers, or anything else about mouth care.

Vaccinations for family and friends

Although no vaccination is completely effective in preventing a disease, vaccinations are the most effective way to prevent the following diseases:

- Influenza (the flu)
- COVID-19
- Varicella (chicken pox), if you have not already had chicken pox
- Measles (for those born after 1957)
- Mumps (for those born after 1957)
- Rubella
- Tetanus
- Diphtheria
- Pertussis ("whooping cough")
- Pneumococcal
- Polio
- Shingles (for people over 50 years old)

Your family members (including children), caregivers, and close contacts should be up to date on all of these vaccines unless they cannot have them for medical reasons.

Some vaccines, such as MMR (measles, mumps, and rubella), varicella, and shingles (Zostavax®), are live virus vaccines. It is often safe for people in your household to receive these, but make sure you discuss the timing of these vaccinations with your team. Some of these live vaccines pose a very small risk of spreading in your home.

If a family or household member develops a rash after receiving the chicken pox or shingles vaccine, notify your provider or nurse.

It is very important that family members and household contacts receive the flu (influenza) shot every year. The flu vaccine is the best way to prevent the flu. The clinic offers the flu vaccine at no charge to family and household contacts. If your family or household contacts get the nasal spray flu vaccine (Flumist®), avoid contact with that person for 5 days because the nasal spray vaccine contains a weakened live flu virus that could spread to you.

Due to the risk of pertussis (also known as whooping cough) in transplant patients, make sure that your family, caregivers, and visitors check with their provider to see if they are up to date on this vaccine (also known as Tdap - tetanus/diphtheria/acellular pertussis).

What does the clinic do to prevent infections?

Infection prevention is a very high priority at the clinic and the basis for preventing major complications after transplant. All infections cannot be avoided, but here are some of the steps we take to keep you safe:

- All staff clean their hands while performing patient care. If you want to confirm that the staff caring for you have cleaned their hands, please ask them. Staff know that we all need to work together to prevent infections. By asking, you are helping us maintain a high standard of care.
- All healthcare workers in the clinic are required to wear a procedure or medical grade mask when interacting with patients for an extended period of time.
- We use isolation precautions (special steps used in healthcare settings) to stop germs from spreading. For instance, if you have an infection that could spread, you will be taken to an exam room right away, and staff will clean their hands more often and wear protective equipment, like gowns, gloves, and masks. If you are in isolation, make sure to remind staff when you arrive at clinic or are admitted to the hospital.
- We take cold and flu season very seriously. When you check in for your clinic appointments, at certain times of the year you and your family/caregiver may be asked if you have cold or flu symptoms like a cough or runny nose. If you have symptoms, you will be placed in isolation to prevent the spread of cold and flu viruses.

Infection prevention guidelines for certain activities

These are general guidelines. If any of the guidelines apply to you, you must discuss them with your provider. See key at the end of the table to learn what the numbers in parenthesis "(x)" mean.

	Time after transplant	
	1 to 6 months	**6 months to 1 year**
Handling animals, birds, reptiles, and fish		
Small cage rodents (gerbils, rabbits, hamsters, guinea pigs, hedge hogs, prairie dogs, ferrets)	No	OK
Cats/dogs	OK, but do not sleep with, feed, bathe, or groom pets.	OK, but do not sleep with, feed, bathe, or groom pets.
New pets in patient's household	No	No
Pet birds (parakeets and parrots)	No	OK
Reptiles and amphibians (snakes, turtles, frogs, lizards, iguanas)	No	No
Farm animals (pigs, horses, cows, llamas)	No. Stay out of barns full of hay.	OK
Poultry & wild birds (pigeons, baby chicks, chickens, ducks, geese, other wild birds, etc.)	No	No
Exotic, wild, and game animals (deer, elk, squirrels, bear, and monkeys)	No	No
Animal trophy mounts in the house	OK	OK
Cleaning feces, litter boxes, utensils, or cages/tanks, etc.	No	No
Going to zoos and petting zoos	Do not visit	No
Visiting public aquariums (3)	Do not touch marine life in handling tanks.	OK (3)
Fishing (fresh and salt water)	OK to handle if wearing gloves but do not bait hooks or clean fish.	OK

	Time after transplant	
	1 to 6 months	**6 months to 1 year**
Hunting (wild game and birds) and sport shooting (2)	No	OK (2). Wear latex gloves when handling game; do not clean or skin game.
Horseback riding	No. Stay out of barns full of hay.	OK
Other activities		
Golfing (2) (sun protection required; do not golf with a central line in place)	No	OK
Attending spectator events and going places with crowds (3)	No	OK (3) but do not shake anyone's hands.
Sexual activity	OK	OK
Working with mechanical equipment (oil changes, working on cars & engines, etc.)	OK	OK
Camping and hiking	OK	OK
Using down comforters with a cover	OK	OK
Going to school in person	No	No
Using hot tubs (avoid all hot tubs) (6)	No	OK (1)
Swimming (1) (do not swim with a central line or venous catheter in place)	No	OK (1) but avoid putting your head under water and diving; use sunscreen.
Gardening (digging in soil); mowing the lawn; raking leaves	No	No
Having plants in the home (do not touch or handle the plants) (4)	OK	OK
Making/kneading yeast breads (5)	OK	OK
Doing carpenter work	No	No
Occasional woodworking (sawdust)	No	OK

Key:

(1) No swimming if you have a catheter, central line or history of sinusitis. Swim in chlorinated and well-maintained pools. It is OK to swim in lakes, rivers, and the ocean if the water is tested routinely for safety by local state and health departments. Avoid small bodies of standing water such as small lakes and ponds. Swimming in pools used

by non-toilet trained babies and children is not recommended. Water aerobics is OK.

(2) Shooting rifles/shotguns and golfing is not recommended if you have a catheter or central line.

(3) Recommend caution and an understanding of the risk involved when participating in public events or going to locations with large crowds.

(4) If you have a real Christmas tree, use water solution of 1 part bleach solution in 10 parts water in the tree stand.

(5) Wash hands thoroughly with soap and water after kneading dough.

(6) Avoid all public hot tubs.

Overview of medications

This section gives information about cyclosporine, tacrolimus, prednisone and mycophenolate mofetil (also called MMF or CellCept®). Each of these are immunosuppressants used to treat GVHD. Immunosuppressants help prevent your body from rejecting a transplant but they also lower your body's ability to fight infections.

Cyclosporine

Forms and doses

- Cyclosporine comes in 3 forms:
  - **Capsules:** 25 mg or 100 mg doses
  - **Liquid:** taken by mouth in a 100 mg/milliliter concentration. You will be told how many milliliters make up your dose. For example, 250 mg of cyclosporine = 2.5 ml. Know your dose and ask the nurse or pharmacist to show you how to find the dosage mark on the measuring device. It is important to take the correct amount of the drug.
  - **Infusion** through a vein (intravenous or IV)
- Your blood levels of cyclosporine will be checked at least once a week to make sure that your dose is correct. The goal is to maintain a level that is effective without causing serious side effects.

Fluid goals

- Cyclosporine can damage kidney function. Drinking lots of fluids helps flush your kidneys and keeps them functioning normally. The level of creatinine in your blood is a measure of kidney function. Creatinine levels increase if kidney function decreases.

- You will need to drink more fluid while on cyclosporine to keep your kidneys functioning normally. Your dietitian can tell you how much to drink each day. Write down your fluid goals here:

______________ cups/day (______________ ml/day)

Magnesium supplement

Cyclosporine decreases the amount of magnesium in your body. You will probably need to receive magnesium in your intravenous fluid or parenteral nutrition (PN)*. As you are able to eat and drink, your physician will prescribe magnesium pills to take several times each day. Magnesium pills will cause loose or soft bowel movements (poop). If you develop diarrhea, tell your care team. Most people taking cyclosporine cannot get enough magnesium from food alone and will still need a supplement. You can get magnesium from these foods:

Excellent sources:	**Good sources:**
Bran cereals	Dried apricots
Nuts	Brown rice
Beet greens	Dates
Tofu	Soybeans
	Shrimp

*PN is parenteral nutrition, the medical term for infusing a form of food through a vein (intravenously or IV).

How to prepare a liquid dose of cyclosporine

1. Wash your hands with warm, soapy water.

2. Use the measuring device that came with your prescription. Follow the manufacturer's instructions for measuring the cyclosporine. To protect your family from getting the drug on their skin and to prevent oily stains on clothing or furniture, clean up any drops or spills of the medicine.

3. Squirt the cyclosporine into the liquid you're mixing it with. Stir well. It is best to use a glass container and rinse it with more liquid to make sure you take the whole dose.

4. Drink right away.

5. Dry the syringe with a clean paper towel and replace it in the clear case. To avoid cloudiness, do not rinse the syringe with water or other cleaning agents. If the syringe needs to be cleaned, dry it completely before using it again.

6. Wash your hands with warm, soapy water.

Beverage and food recommendations

- Most people prefer to take **liquid** cyclosporine with a flavored drink.
- **Do not take oral** cyclosporine with drinks that contain the enzyme bergamottin, such as grapefruit, tangelos, honeybell oranges, Sunny Delight®, Fresca®, Squirt®, or Earl Grey tea. Please ask your dietitian, pharmacist, or nurse if you have questions about taking oral cyclosporine with other fruit juices or drinks.
- **It is good to eat breakfast or a small snack before taking your morning dose of oral cyclosporine.** Some people find that taking cyclosporine by mouth on an empty stomach can cause nausea. If you have eaten dinner within 2 to 3 hours, you may not need to eat again right before taking your evening cyclosporine dose. If cyclosporine continues to cause nausea, talk with your nurse, physician, or dietitian.

Blood draws

On the morning of your blood draw, do not take your morning cyclosporine until after your blood draw. If you do not plan to go home after the blood draw, bring your cyclosporine with you to the clinic.

Storage

- Store cyclosporine liquid and capsules at room temperature. Do not store cyclosporine in the refrigerator or freezer. Do not expose it to heat or strong light.
- Throw away partly used bottles of cyclosporine 2 months after opening it.
- Keep your cyclosporine with you when you travel. Store the bottle in a plastic bag to protect your purse, carry-on bag or clothing.

Refills

- Call the Fred Hutch Pharmacy when your supply of cyclosporine gets low. Allow 24 hours for refills.
- When you are discharged for home, your local physician will prescribe cyclosporine and you can get it from your local pharmacy. Plan ahead with your physician and pharmacist. Do not wait until you are completely out of medicine to get a refill.

IV cyclosporine

- Infused as prescribed. Cyclosporine can cause burning in hands and feet. If this occurs, call the Transplant clinic or the after-hours clinic.

- Infuse cyclosporine in the white port only. Do not infuse it into the blood draw side of your central line.
- Keep IV cyclosporine in the refrigerator.

Tacrolimus

Forms and doses

- Tacrolimus comes in 3 forms:
  - o **Capsules:** 0.5mg, 1mg, and 5mg doses
  - o **Liquid** taken by mouth
  - o **Infusion** through a vein (intravenous or IV)
- Your blood levels of tacrolimus will be checked at least once a week to make sure that your dose is correct. The goal is to maintain a level that is effective without causing serious side effects.

Fluid goals

- Tacrolimus can damage kidney function. Drinking lots of fluids helps flush your kidneys and keeps them functioning normally. The level of creatinine in your blood is a measure of kidney function. Creatinine levels increase if kidney function decreases.
- You will need to drink more fluid while on tacrolimus to keep your kidneys functioning normally. Your dietitian can tell you how much to drink each day. Write down your fluid goals here:

______________ cups/day (______________ ml/day)

Magnesium supplement

Tacrolimus decreases the amount of magnesium in your body. You will probably need to receive magnesium in your intravenous fluid or parenteral nutrition (PN)*. As you are able to eat and drink, your physician will prescribe magnesium pills to take several times each day. Magnesium pills will cause loose or soft bowel movements (poop). If you develop diarrhea, tell your care team. Most people taking tacrolimus cannot get enough magnesium from food alone and will still need a supplement. You can get magnesium from these foods:

Excellent sources:	**Good sources:**
Bran cereals	Dried apricots
Nuts	Brown rice
Beet greens	Dates
Tofu	Soybeans
	Shrimp

*PN is parenteral nutrition, the medical term for infusing a form of food through a vein (intravenously or IV).

Food and drink recommendations

- Most people prefer to take **liquid** tacrolimus with a flavored drink.
- **Do not take oral** tacrolimus with drinks that contain the enzyme bergamottin, such as grapefruit, tangelos, honeybell oranges, Sunny Delight®, Fresca®, Squirt®, or Earl Grey tea. Please ask your dietitian, pharmacist, or nurse if you have questions about taking oral tacrolimus with other fruit juices or drinks.
- **It is good to eat breakfast or a small snack before taking your morning dose of oral tacrolimus.** Some people find that taking tacrolimus by mouth on an empty stomach can casue nausea. If you have eaten dinner within 2 to 3 hours, you may not need to eat again right before taking your evening cyclosporine dose. If tacrolimus continues to cause nausea, talk with your nurse, physician, or dietitian.

Blood draws

On the morning of your blood draw, do not take your morning tacrolimus dose until after your blood draw. If you do not plan to go home after the blood draw, bring your cyclosporine with you to the clinic.

Storage

- Store tacrolimus liquid and capsules at room temperature. Do not store tacrolimus in the refrigerator or freezer. Do not expose it to heat or strong light.
- Throw away partly used bottles of tacrolimus 2 months after opening it.
- Keep your tacrolimus with you when you travel. Store the bottle in a plastic bag to protect your purse, carry-on bag or clothing.

IV tacrolimus

- Infuse as prescribed. Tacrolimus can cause burning in hands and feet. If this occurs, call the Transplant clinic or the after-hours clinic.
- Infuse tacrolimus in the white port only. Do not infuse it into the blood draw side of your central line.
- Keep IV tacrolimus in the refrigerator.

Sirolimus

Sirolimus comes in tablet and liquid form.

- If you use the tablet, do not crush, chew or cut the tablets.
- If you use the liquid, mix with 2 ounces (4 tablespoons) of water or orange juice; stir well and right after drink mixing
- Your blood levels of sirolimus will be checked at least once a week to make sure that your dose is correct. The goal is to maintain a level that is effective without causing serious side effects.

Food and drink recommendations

- Sirolimus is taken by mouth, once a day, with or without food.
- Avoid drinks containing the enzyme bergamottin. This includes grapefruit juice or the juice of grapefruit hybrids such as: tangelos, honeybell oranges, Sunny Delight®, Fresca®, Squirt®, or Earl Grey tea.
- Drink fluids daily as recommended by your dietician to help flush your kidneys.

Blood draws

On the day of your blood draw, do not take your sirolimus dose until after your blood draw. If you do not plan to go home after the blood draw, bring your sirolimus with you to the clinic.

Storage

- Store tablets at room temperature and away from light, excess heat, and moisture (not in the bathroom).
- Store liquid medication in the refrigerator, away from light and closed tightly. Throw away any unused liquid 1 month after the bottle is opened. Do not freeze. If needed, you may store the bottles for up to 15 days at room temperature.

Side effects

- **Elevated lipid levels (cholesterol and/or triglycerides) may occur.** Your care team will check fasting lipid levels routinely. If your lipid levels rise, your doctor may prescribe medication to treat this. You may need to adjust your diet. Your care team will discuss this with you, if necessary.
- **Decreased platelets, red blood cells, and white blood cells may occur.** Your care team will check your blood counts routinely. Report any signs of infection, fever, excessive fatigue, and unusual bleeding or bruising.
- **Liver damage may occur.** Your care team will check your liver function tests routinely. Most patients with liver damage do not experience symptoms. Report yellowing of your skin or eyes to your care team.

Prednisone

Side effects

Prednisone can cause changes in mood, sleep, and blood glucose levels.

Forms and doses

Prednisone comes in 2 forms:

- **Tablets**. You may need to use several different milligram sizes of tablets to take the prescribed total dose. You may also need to cut pills in half to take the prescribed dose.
- **Infusion** through a vein (intravenous or IV)

Food and drink recommendations

Never take oral prednisone on an empty stomach. Take your morning dose of prednisone after breakfast or at least with a glass of milk or a smoothie. If you have eaten dinner within 2 to 3 hours, you do not need to eat again right before taking your evening prednisone dose.

Nutrition recommendations during prednisone therapy

- **Eat a protein-rich diet while taking prednisone.** You may experience muscle loss while taking prednisone, even if your weight is stable or increasing. A protein-rich diet and regular exercise may help to maintain your muscles. Your dietitian will give you a protein goal.
- **Eat a calcium-rich diet while taking prednisone.** Calcium goal: 1,500 mg daily. Prednisone can cause bone loss. Vitamin D and calcium, as well as exercise, can help

minimize this loss. Your dietitian will assess your current calcium intake and recommend supplements if needed. Calcium carbonate (such as Tums®) or calcium citrate are recommended supplements.

- **Prednisone may increase your blood glucose (sugar) level, similar to diabetes.** A normal fasting blood glucose level is 60-110 mg/dl. If your fasting blood glucose level is above normal, your dietitian may advise you to make some diet changes. This may include changing the amount of carbohydrates you eat. Levels of blood glucose usually return to normal when you stop prednisone.
- **You may need more potassium in your diet while taking prednisone.** Prednisone causes some people to "waste" potassium into their urine (pee). If your blood potassium level is below normal your physician may prescribe a potassium supplement and recommend a high potassium diet. Please ask your care team for the "potassium handout" that includes dietary suggestions.
- **Prednisone can cause your body to retain (hold onto) fluids.** A high salt intake diet can worsen fluid retention. Limit added salt and salty foods such as canned, instant, and frozen soups and meals, soy sauce, cured meats, and packaged sauces, and seasonings. In general, processed foods contain too much salt.

Ask your dietitian for more information about diet recommendations during prednisone therapy.

Mycophenolate mofetil (also called MMF or CellCept®)

Side effects

MMF can cause nausea, vomiting, constipation, abdominal cramps, diarrhea, muscle pain, headache, and swelling of the feet or lower legs.

Forms and doses

- MMF comes in 3 forms:
    - o **Tablets or capsules:** 250 mg and 500 mg doses. Swallow the tablet and capsules whole. Do not break, crush, or chew or open tablets or capsules.
    - o **Liquid** taken by mouth. Do not mix the liquid suspension with any other medicines.
    - o **Infusion** through a vein (intravenous or IV).
- Your MMF dosing may be given every 8 or 12 hours.

Blood draws

You may need to have your blood drawn to check the levels of MMF in your body. If you do, you would need to get several blood draws over an 8 to 10 hour period on these days.

Food and drink recommendations

- MMF is absorbed best on an empty stomach. If you are having problems with nausea, take the medication with some crackers.
- Do not take MMF within 2 hours of eating or drinking high calcium foods such as:
  - Milk (cow's milk, almond milk, or soy milk with calcium added)
  - Cheese
  - Yogurt
  - Calcium or magnesium supplements

Storage

- Keep tablets and capsules in a closed container at room temperature away from extreme heat, moisture, and direct sunlight.
- Store the liquid form that you take by mouth in the refrigerator. Throw away any unused liquid 60 days after you get it from the pharmacy because it expires.
- Do not refrigerate intravenous (IV) infusions of MMF. MMF cannot be mixed with saline flushes. Lines need to be flushed with 50ml of dextrose 5% water **before** and **after** each infusion. Discuss this with your nurse or pharmacist to make sure you understand this instruction.

Sample transplant medication schedule

Bring this sheet to your first visit. Include all of your medications. Put an “H” in the column if you gave the medicine at home.

Medication	Dosage/ directions	AM							PM											
		6	7	8	9	10	11	12	1	2	3	4	5	6	7	8	9	10	11	12
☐ **Bactrim:** ☐ **Dapsone:** Discontinue day –2: ____	☐ 1 DS tablet x 1/day ☐ 50 mg x 1/day																			
Acyclovir: Begin day –4: ____	____ mg x 2/day																			
Fluconazole: Begin day –4: ____	____ mg x 1/day																			
Multivitamin	1 tablet x 1/day																			
Cyclosporine: Begin day –3: ____	____ mg x 2/day																			
MMF (Mycophenolate Mofetil): Begin day 0 (4–6 hours after stem cells finished):	____ mg x 2/day																			
Kytril: Take day 0, ½ hour before TBI: ____	1 mg ____ ____																			
Every 4 hours as needed: Ativan 0.5 to 2 mg Benadryl 25 to 50 mg Compazine 10 mg																				

Suggested medication schedule

Bring this sheet to your first visit. Include all of your medications. Put an “H” in the column if you gave the medicine at home.

Medication	Dosage/ directions	AM							PM											
		6	7	8	9	10	11	12	1	2	3	4	5	6	7	8	9	10	11	12

Food safety guidelines

Foodborne illness is any illness caused by eating a food that is contaminated with a bacteria, virus, mold, or parasites. Examples of organisms that can cause a food borne illness are *E. coli, Salmonella* and *Listeria*. Sources of foodborne illness may be the food handler (person preparing the food), the environment (such as a contaminated work surface), or the food itself.

Bacteria and other organisms are common in foods. Most of these organisms are of little risk to the average healthy person. However, people getting chemotherapy, radiation, or a stem cell transplant are at increased risk for infections, including foodborne illness. By following safe food practices, you and your caregiver can reduce the risk of foodborne illness.

We recommend you follow the immunosuppressed patient diet and food safety guidelines discussed below during the first 3 months after chemotherapy or transplant. If you have any questions about food safety and diet guidelines, talk to your dietitian.

Steps to food safety

- Wash hands and surfaces often.
- Avoid cross-contamination of foods.
- Keep foods at a safe temperature.

Tools for food safety

- Food and refrigerator thermometers
- Hand soap
- Clean towels (cloth or paper)
- Bleach solution for washing countertops, cutting boards and other items. To make bleach solution:
  - o Mix 4 teaspoons bleach with 1 quart (4 cups) water.
  - o Remake this solution daily.

Hand hygiene

- Wash your hands often with soap and warm, running water and rubbing motion (friction) for 20 seconds before and after every step in food preparation. This is critical before and after handling raw meat, seafood, and poultry.
- Wash your hands before eating and after using the rest room, handling garbage, and touching pets.
- Dry your hands with a paper towel or cloth hand towel that is changed daily.

Kitchen cleanliness

General

- Replace dishcloths and dishtowels daily. Wash using the hot cycle of your washing machine.
- Sanitize sponges daily and after contact with raw meat, fish, and eggs. You may soak them in the bleach solution for 5 minutes, heat them in a microwave on high for 1 minute, or run them through the dishwasher.
- Use liquid dish soap and very warm water when hand-washing dishes, pans, and utensils. Air-dry dishes instead of towel-drying them.
- Wash counters, utensils, and can openers with soap and hot water immediately after use. After washing, they can be sanitized using the bleach solution.
- Keep the refrigerator clean. Clean spills immediately. Wash shelves and doors weekly using the dilute bleach solution.
- Make sure food storage areas remain clean.
- Rotate food stock so older items are used first. Check expiration dates. Do not use foods past the expiration dates.
- Throw away any bulging, leaking, or cracked cans, or those deeply dented in the seam area. Do not taste these foods.
- Keep appliances free of food particles (including the microwave, toaster, can opener, blender, and mixer blades). Blender blades and the bottom ring should be removed from the blender after each use and washed in hot, soapy water.
- Keep food storage areas clean. Do not store any food supplies under the sink. Do not store chemicals and cleaning solutions over or near food supplies.

Cutting boards

- Wash cutting boards with hot, soapy water after each use; then rinse and air-dry or pat dry with fresh paper towels. Non-porous acrylic, plastic, or glass boards and solid wood boards can be washed in a dishwasher (laminated boards may crack or split).
- Sanitize both wooden and plastic cutting boards with the dilute bleach solution. This should be done every time the board is used for raw meat, fish, and poultry. Sanitize cutting boards used for other purposes at least once weekly. Flood the surface with the bleach solution and allow it to stand for at least 2 minutes, then rinse and air-dry or pat dry with fresh paper towels.
- Replace worn cutting boards, including boards with cracks or grooves.

Safe food handling: from the grocery store to your home

Grocery store

- Shop for shelf-stable items first (shelf-stable refers to unopened canned, bottled, or packaged food products that can be stored at room temperature before opening; the container may require refrigeration after opening).
- Select frozen and refrigerated foods last, especially during the summer months.
- Check “sell by” and “use by” dates on dairy products, eggs, cereals, canned foods, and other goods. Select only the freshest products.
- Check packaging dates and “use by” dates on fresh meats, poultry, and seafood. Do not purchase if they are outdated.
- Do not use damaged, swollen, rusted, or deeply dented cans. Check that packaged and boxed foods are properly sealed.
- Select fruits and vegetables that are not moldy, bruised, or damaged. Fresh fruits and vegetables should look fresh. Wilted salad greens may be an indication that the product is old and not properly handled.
- Avoid unpasteurized juice (unless prepared at home with washed produce).
- Choose shelf-stable salsa rather than salsas found in the refrigerator section of the grocery store.
- Avoid unpasteurized milk, yogurt, cheese, and other unpasteurized milk products, including Mexican-style cheese made from unpasteurized milk (such as queso fresco).

- Do not use foods with any mold present, including blue cheese.
- Avoid unrefrigerated, cream- and custard-filled pastry products, such as fresh bakery cream pies, eclairs, cream-filled donuts, and pastries. Commercial, shelf-stable items such as Danish pastries are allowed. Follow the “use by” date and store them according to the manufacturer’s guidelines after opening.
- Avoid foods from “reach in” or “scoop” bulk food containers. Avoid food from any type of bulk food container if it will not be cooked before you eat it.
- Do not taste unpackaged food samples.
- Choose eggs that are refrigerated in the store. Do not use cracked eggs. Pasteurized eggs, liquid pasteurized egg products (such as Egg Beaters®) and powdered egg whites may be used in recipes calling for raw eggs in foods that will not be cooked.
- Place meat, poultry, and fish in plastic bags. Ask to have these items placed in separate bags from the fresh produce and ready-to-eat foods when at the checkout stand.
- Never leave perishable food (food that spoils easily) in the car. Refrigerate or freeze it promptly.

Home

- Wash the tops of canned foods before opening. Clean the can opener after each use.
- Throw away eggs with cracked shells.
- Throw away foods older than their “use by” expiration dates.
- Throw away entire food packages or containers with any mold present, including yogurt, cheese, cottage cheese, fruits (especially berries), vegetables, jelly, bread, cereal, and pastry products.

Fruit and vegetable handling

All fresh produce (whether organic, natural, or general produce) may carry dangerous bacteria or other organisms that can cause food borne illness. Bacterial contamination can occur in the fields from the use of natural fertilizers (such as animal manure) or from human contact during produce harvesting, transporting, and in the grocery store. **The term "organic" or "natural" refers to growing without the use of chemical fertilizers or pesticides and has no relationship to the cleanliness or safety of the produce.**

Use the following guidelines for handling **all** raw produce, including organic, organically grown, **"natural,"** and general produce:

- Refrigerate fruits and vegetables promptly.
- Do not purchase produce that has been cut at the grocery store (such as melon or cabbage halves). This is particularly true for produce that will not be cooked before you eat it.
- Rinse produce thoroughly under **clean, running water** just before use, including produce that is to be peeled (such as bananas, melons, and oranges) or cooked. Do not wash fruits and vegetables with soaps, detergents, or chlorine bleach solutions. Produce can absorb these cleaning agents.
- Commercial produce rinses (such as Fit® Fruit and Vegetable Spray) are not recommended since they have not been shown to be more effective for removing bacteria off the produce than washing under running water.
- Scrub produce that has a thick, rough skin or rind (such as cantaloupe or potatoes) or has visible dirt on the surface using a clean vegetable scrubber.
- Rinse leaves of leafy vegetables (such as lettuce, spinach, and cabbage) individually under running water.
- Packaged salads, slaw mixes, and other prepared produce, even when marked pre-washed, should be rinsed again under running water; a salad spinner or colander can be used to make this easier. Check for **"use by"** dates.
- Do not eat any raw vegetable sprouts (avoid **all** types, including alfalfa sprouts, clover sprouts, mung bean sprouts, etc.) due to high risk of Salmonella and *E. coli* contamination.
- Throw away fruits and vegetables that are slimy or show mold.

- If you're canning foods at home, review these guidelines: bit.ly/usda-home-canning-guide. Be sure the procedure is appropriate for the acidity of the food, size of the bottle, and elevation above sea level. Look for mold and leaks. Check seals. **If you suspect a home-canned food may not have been properly processed (for example, if the lid bulges or if the food has any bad odor or unusual characteristics after opening), throw it away. Use home canned foods within 1 year of canning as chemical changes may occur.**

Avoid cross contamination

- Use a clean knife for cutting different foods (for example, use different knives for cutting meat, produce, or bread).
- During food preparation, do not taste the food with the same utensil used for stirring. Use a clean utensil each time you taste food while preparing or cooking.
- In the refrigerator, store raw meat separately from ready-to-eat foods.
- When grilling, always use a clean plate and utensils for the cooked meat.

Keep foods at safe temperatures

Proper thermometer use

- Test thermometer accuracy by placing it into boiling water; it should read 212° F.
- Read the manufacturer's instructions. Insert the meat thermometer into the middle of the thickest part of the food to test for doneness. The entire part of the stem, from the dimple to the tip, must be inserted into the food. For thin foods, insert the thermometer sideways.
- Place a refrigerator thermometer on a shelf toward the back of the refrigerator. It should read 40°F or less.

Refrigeration

- Keep the refrigerator temperature at or below 40°F.
- Keep the freezer temperature at or below 0°F.
- Never leave perishable food (food that spoils easily) out of the refrigerator for more than **2 hours.** Throw away food left out longer than 2 hours.
- Marinate foods in the refrigerator.

Refrigeration, continued

- Thaw foods in the refrigerator, never on the counter.
- Thaw meat, fish, or poultry in the refrigerator away from raw fruits and vegetables and other prepared foods. Place on a dish to catch drips. Cook defrosted meat right away; do not refreeze. If you are in a hurry, you can thaw meat in the microwave. **The meat must be cooked immediately after thawing.**
- Cool hot foods uncovered in shallow containers in the refrigerator. Cover storage containers after cooling. Make sure the covers seal tightly.
- Throw away all prepared food after 72 hours (3 days). Use labels or masking tape to write dates on containers.
- Freeze foods that will not be used within 2 to 3 days.
- **Never taste food that looks or smells strange.**
- Cook meat until it is no longer pink, and the juices run clear. These are signs that the meat may be cooked to a high enough temperature. The only way to be sure that the meat has been cooked to the proper temperature is to use a food thermometer (See table on the next page).
- Thoroughly heat until steaming (165°F) all hot dogs and “ready to eat” luncheon meats, cold cuts, and “deli-style” meats before eating.
- Do not eat raw, lightly cooked, or soft-boiled eggs.
- Do not eat uncooked foods containing raw or undercooked eggs, such as raw cookie dough, cake batter, or salad dressings containing raw or coddled eggs.
- If a food won’t be cooked, and the recipe calls for raw eggs, you can use pasteurized eggs or liquid pasteurized egg products (such as Egg Beaters®).
- Keep food at safe temperatures:
  - o Keep hot food **above** 140°F
  - o Keep cold food **below** 40°F.

Recommended minimum cooking temperatures

Product	Cooking temperature or appearance
Eggs, egg dishes, casseroles	
Eggs	Cook until yolk and white are firm.
Casseroles, foods containing eggs, custards, egg sauces	160°F
Veal, beef, pork, lamb, rabbit, goat, game	
Whole pieces meat	145°F
Ground veal, beef, lamb, pork, rabbit, goat, game	160°F
Poultry (chicken, turkey, duck, goose)	
Chicken and turkey: whole bird and dark meat (leg, thigh, wing)	165°F
Breast, roast	165°F
Ground chicken, turkey	165°F
Stuffing (always cook in separate container outside of bird)	165°F
Ham	
Fresh (raw)	145°F
Pre-cooked (to reheat)	140°F
Seafood	
Fin fish (such as salmon, cod, halibut, snapper, sole, bass, trout)	145°F or cook until opaque and separates easily with a fork.
Shrimp, lobster, crayfish, crab	Cook until flesh is pearly and opaque.
Scallops	Cook until flesh is milky white or opaque and firm.
Clams, mussels, oysters	Cook until shells open during cooking (may be high risk food for people with low white count or who are immunosuppressed)
Leftovers, hot dogs, luncheon meats	
Leftovers	165°F
Hot dogs, luncheon meat	Steaming hot

Microwave cooking

- Microwave cooking can leave cold spots in food where bacteria can survive. Rotate the dish a quarter turn once or twice during cooking if there is no turntable in the appliance.
- When heating leftovers, use a lid or vented plastic wrap to cover them. Stir several times during reheating. When the food is heated thoroughly (to a minimum of 165°F), cover and let sit for 2 minutes before serving.

Dining out safely

- Eat early to avoid crowds.
- Ask that food be prepared fresh in fast food establishments (for example, a hamburger should be fresh off the grill, not one that has been sitting under heat lamps).
- Ask if fruit juices are pasteurized.
- **Avoid raw fruits and vegetables when dining out.** Eat these items when prepared at home, where you can wash them thoroughly and prepare them safely.
- Ask for single-serving condiment packages. Do not use public self-serve condiment containers, including salsa.
- Avoid salad bars, delicatessens, buffets and smorgasbords, potlucks, and sidewalk vendors.
- Be sure that utensils are set on a napkin or clean tablecloth or placemat, rather than directly on the table.
- Check the general condition of the restaurant. Are the plates, glasses, and utensils clean? Are the restrooms clean and stocked with soap and paper towels? How clean the restaurant looks may tell the amount of care taken while preparing the food.
- If you want to keep your leftovers, ask the server to bring you a box that you can put the food in yourself, rather than having your food put into a box in the restaurant kitchen. Be sure to take home and refrigerate the leftovers immediately.

Other foods

- Heat soft cheeses such as feta, Brie, Camembert, blue-veined, Stilton, or Mexican-style cheese (queso fresco) before eating.
- Avoid soft-serve ice cream, soft-serve frozen yogurt, and milkshakes made from soft-serve ice cream.

- Cut tofu into 1-inch cubes or smaller and boil 5 minutes in water or broth before eating or using in recipes. (Note: This process is not needed if using pasteurized tofu or shelf-stable tofu such as Mori-Nu® silken tofu.)
- Choose shelf-stable salsas and salad dressing (shelf-stable refers to unopened canned, bottled, or packaged food products that can be stored at room temperature before opening; the container may require refrigeration after opening). Avoid fresh fruit or vegetable salsas and salad dressing found in the refrigerated section of the grocery store.
- Do not consume raw honey or honeycomb. Choose **Grade A** honey.

Diet guidelines for immunosuppressed patients

Your immune system may not work as well because of chemotherapy, radiation therapy or medications that suppress your immune system. This means that you are at increased risk of developing a food-related infection. The purpose of this diet is to help you avoid specific foods that are more likely to contain infection-causing organisms, while allowing maximum healthy food choices. Choose foods from the “May eat” column and don’t choose foods in the “Do not eat” column. You may want to discuss the safety of these or other foods with your dietitian or care team.

In general, we recommend this diet for:

- **General oncology and cellular immunotherapy patients**: follow this diet when you have a low white blood cell count. A low white blood cell count refers to a neutrophil count less than 1000 mm3 or when chemotherapy is held due to low neutrophil count.
- **Autologous transplant patients:** follow this diet during the first 3 months after chemotherapy or transplant.
- **Allogeneic transplant patients:** follow this diet until you are off all immunosuppressive therapy such as cyclosporine, prednisone, tacrolimus, Myfortic®, sirolimus, or MMF.

Food groups	You may eat	Do not eat
Dairy	• All pasteurized, grade "A" milk and milk products including eggnog, yogurt, ice cream, frozen yogurt, sherbet, ice cream bars, milkshakes, processed cheese slices and spreads, cream cheese, cottage cheese and ricotta cheese • Dry, refrigerated, or frozen pasteurized whipped topping • Commercially packaged hard and semi-soft cheeses such as cheddar, mozzarella, parmesan, Swiss, Monterey Jack, etc. • Cooked and pasteurized soft cheeses such as brie, goat, Camembert, feta, farmer cheese. Though not completely risk free, the risk of getting food borne illness from cooked soft cheeses is low. • Commercially sterile ready-to-feed and liquid-concentrate infant formulas (avoid powdered infant formulas if a ready-to-feed or liquid concentrate alternative is available)	• Non-pasteurized or raw milk and milk products made from non-pasteurized or raw milk. • Cheeses from delis • Cheese containing chili peppers or other uncooked vegetables • Cheeses with molds (such as blue, Stilton, Roquefort, gorgonzola) • Mexican-style soft cheese such as queso fresco, queso blanco (unless it is made with pasteurized milk and cooked) • Avoid soft-serve ice cream, soft-serve frozen yogurt, and milkshakes made from soft-serve ice cream.

Food groups	You may eat	Do not eat
Meat and meat substitutes	• All meats cooked to well done (see temperature guide) or canned meats (beef, pork, lamb, poultry, fish, shellfish, game, ham, bacon, sausage, hot dogs) • Eggs cooked until both white and yolk are firm • Pasteurized eggs and egg substitutes (such as Egg Beaters®), and powdered egg white (all can be used uncooked) • Commercially packaged salami, bologna, hot dogs, ham, and other luncheon meats, heated until steaming • Canned and shelf-stable[1] smoked fish (refrigerate after opening) • Pasteurized or cooked tofu[2] • Refrigerated smoked seafood such as salmon or trout if cooked to 160°F or contained in a cooked dish or casserole	• Raw or undercooked meat, poultry, fish, game, tofu[2] • Raw or undercooked eggs and non-pasteurized egg substitutes; no eggs over easy, soft-boiled eggs, or poached eggs. • Meats and cold cuts from delicatessens • Hard cured salami in natural wrap • Uncooked refrigerated smoked seafood such as salmon or trout labeled as "nova-style," "lox," "kippered," "smoked," or "jerky" • Pickled fish • Tempe (tempeh) products

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[1] Shelf-stable refers to unopened canned, bottled, or packaged food products that can be stored before opening at room temperature; container may require refrigeration after opening.

[2] Shelf-stable tofu and pasteurized tofu do not need to be boiled. Unpasteurized tofu must be cut into 1-inch cubes or smaller and boiled at least 5 minutes in water or broth before eating or using in recipes.

Food groups	You may eat	Do not eat
Fruits and nuts	• Well washed[3] raw fruit; foods containing well washed raw fruits • Cooked, canned, and frozen fruit • Pasteurized juices and frozen juice concentrates • Dried fruits • Canned or bottled roasted nuts • Shelled, roasted nuts, and nuts in baked products • Commercially packaged nut butters (such as peanut butter, almond butter, or soybean butter)	• Unwashed raw fruits • Unroasted raw nuts • Roasted nuts in the shell • Non-pasteurized fruit and vegetable juices • Fresh fruit salsa found in the grocery refrigerator case • Non-pasteurized items containing raw fruits found in the grocery refrigerator case
Entrees and soups	• All cooked entrees and soups	• All miso products (such as miso soup and miso paste)

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[3] Rinse under clean, running water before use, including produce that is to be cooked or peeled (such as bananas, oranges, and melon).

Food groups	You may eat	Do not eat
Vegetables	• Well washed[3] raw vegetables • All cooked fresh, frozen, or canned vegetables, including potatoes • Shelf-stable[1] bottled salsa (refrigerate after opening) • Cooked vegetable sprouts (such as mung bean sprouts) • Fresh, well washed[3] herbs and dried herbs and spices (added to raw or cooked foods)	• Unwashed raw vegetables or herbs • Fermented vegetables such as kimchi or sauerkraut • Fresh, non-pasteurized vegetable salsa found in the grocery refrigerator case • Non-pasteurized items containing raw vegetables found in the grocery refrigerator case • All raw vegetable sprouts (alfalfa sprouts, clover sprouts, mung bean sprouts, all others) • Salads from delicatessens and restaurants
Bread, grain, and cereal products	• All breads, bagels, rolls, English muffins, muffins, pancakes, sweet rolls, waffles, French toast • Potato chips, corn chips, tortilla chips, pretzels, popcorn • Cooked grains and grain products, including pasta and rice • All cereals, cooked and ready-to-eat	• Raw (not baked or cooked) grain products (such as raw oats)

Food groups	You may drink	Do not drink
Beverages	• Boiled well water[4] • Tap water and ice made from tap water[5] • Commercially bottled distilled, spring, and natural waters[6] • All canned, bottled, and powdered beverages • Instant and brewed coffee and tea; cold brewed tea made with boiling water • Herbal teas brewed from commercially-packaged tea bags • Commercial nutritional supplements, both liquid and powdered • Commercially sterile ready-to-feed and liquid-concentrate infant formulas (avoid powdered infant formulas if a ready-to-feed or liquid concentrate alternative is available)	• Unboiled well water • Cold-brewed tea made with warm or cold water • Non-pasteurized fruit and vegetable juices • Mate tea • Kombucha • Wine, unpasteurized beer (Note: All alcoholic beverages should only be consumed following health care provider approval)

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[4] Bring tap water to a rolling boil and boil for 15-20 minutes. Store boiled water in the refrigerator. Get rid of water not used within 48 hours (2 days).

[5] Recommend using boiled or bottled water if using a water service other than city water service. Please see *Water Safety Guidelines* in "Food Safety Guidelines."

[6] See *Water Safety Guidelines* in "Food Safety Guidelines" for approved bottled water treatments.

Food groups	You may eat	Do not eat
Desserts	• Refrigerated commercial and homemade cakes, pies, pastries and pudding • Refrigerated cream-filled pastries • Cookies, both homemade and commercially prepared • Shelf-stable[3] cream-filled cupcakes (such as Twinkies®, Ding Dongs®) and fruit pies (such as Poptarts® and Hostess® fruit pies) • Canned and refrigerated puddings • Ices, popsicles, and similar products • Candy, gum	• Unrefrigerated cream-filled pastry products (not shelf-stable[3])
Fats	• Vegetable oils and shortening • Refrigerated lard, margarine, and butter • Commercial, shelf-stable[3] mayonnaise and salad dressings including blue cheese and other cheese-based salad dressings (refrigerate after opening) • Cooked gravy and sauces	• Fresh salad dressings (stored in the grocer's refrigerated case) containing raw eggs or cheeses listed as "Do not eat" under "Dairy"
Other	• Commercial pasteurized Grade A honey[7] • Salt, granulated sugar, brown sugar • Jam, jelly, syrups (refrigerate after opening) • Ketchup (or "catsup"), mustard, BBQ sauce, soy sauce, other condiments (refrigerate after opening) • Pickles, pickle relish, olives (refrigerate after opening) • Vinegar	• Raw honey; honey in the comb • Herbal and nutrient supplement preparations (refer to the **Herbal and nutrient supplements** section) • Brewer's yeast, if uncooked

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[7] Honey products are **not** allowed for any child less than 1 year of age and not allowed for children with SCIDS until 9 months posttransplant.

More nutrition tips

The chemotherapy you will receive during your marrow or stem cell transplant will affect your nutrition in many ways. You may find that you are not eating the way you normally do because of nausea, mouth and throat soreness, lack of appetite, or changes in the way foods taste. Use these tips to help you:

- Keep in mind that your calorie needs are higher during your transplant. Keep your body nourished even when you do not feel like eating.
- You will be using some medications that can be hard on your kidneys, so it is important to drink lots of fluids. Fluids include all beverages, smoothies, yogurt, ice cream, popsicles, and soups. Your dietitian will give you a goal for daily fluid intake.
- You need protein for repair, growth, and fluid balance. Regularly include high protein foods such as eggs, milk, dairy products, meat, poultry, fish, beans, nuts, or high protein smoothies.
- Eat smaller, more frequent meals. Snack often, and keep beverages handy at all times. Use a water bottle to keep beverages close all day long.
- Foods will probably taste differently for a while. This will pass, but you may need to adjust the way you eat. Drink beverages with meals or snacks if your mouth is dry. And remember, what does not taste good today might taste good tomorrow.
- Tell your provider or nurse if you are having nausea, vomiting, diarrhea, constipation, heartburn, or mouth and throat pain.
- A dietitian can answer questions you might have or help you find the foods that will work for you.

Nourishing food suggestions

If you do not feel hungry or you have a sore mouth and/or taste changes, eating can be challenging. To make it easier, we have some suggestions for stocking a kitchen with ingredients for fast, healthy, and flavorful meals and snacks:

For the refrigerator

- Yogurt
  - Look for at least 10 grams protein per serving
  - Consider getting plain yogurt and adding your own fruit and sweetener (such as honey)
- Ginger Ale, can be taken hot or cold
- Lemons and limes to flavor your water
- Premade, pasteurized smoothies
- Nut butters (peanut, almond, or cashew)
- Eggs
- Cottage cheese: easy to eat and protein-rich
- Single-serve cheese packages:
  - String cheese or cheddar
  - Babybel® or Laughing Cow® cheese rounds

For the freezer

- Frozen/microwavable meals. For example:
  - Whole-wheat macaroni and cheese
  - Pot pies or single-serve casserole dishes
  - Oven-baked sweet potato wedges
- Frozen Magic Mineral Broth — freeze in ice cube trays for single servings. Ask your dietitian for recipe.
- Whole fruit popsicles or sorbets

Tips on eating if you have thick, viscous saliva:

- Switch to mostly liquid foods.
- Drinking more fluids will help loosen mucous.
- Club soda, seltzer, hot tea with lemon, or sucking on lemon drops may help break up the mucous.
- Milk and dense liquids are sometimes hard to swallow when there is extra mucous.
- If you have nausea in the morning from mucous build up, try eating a lighter breakfast.
- Avoid thick nectars and juices, cream soups, and bread products.

Some foods to try:

Beverages	**Proteins**
• Seltzer water, diluted nectars, juices • Thinned fruit smoothies • Tea with lemon • Clear broth • Sugar-free lemon drops, sour candies	• Moist, cooked fish and chicken • Thin, broth-based soups
Breads and cereals	**Fruit and vegetables**
• Hot cereals thinned with milk or water	• Blended fruits or vegetables diluted to a thin consistency • High moisture fruits such as melon

Tips on eating if your mouth and throat are sore:

- A soft, bland diet will cause less irritation.
- Avoid rough, acidic, and spicy foods.
- Popsicles and slushies (frozen beverages) may help to soothe your mouth and throat and quench your thirst.
- Try smaller bites of foods that don’t take much chewing.
- Avoid extreme hot and cold food temperatures.
- Canned fruits are usually softer than fresh, raw fruits and cause less discomfort.

Some foods to try:

Beverages and seasonings	Proteins
• Herbal teas • Diluted juices • Smoothies/shakes • Popsicles • Low-salt homemade or canned soups (can be put in the blender to change texture) • Herbs for seasoning: thyme, basil, oregano, bay leaf	• Moist, cooked fish and chicken • Thin, broth-based soups
Breads and cereals	**Fruit and vegetables**
• Hot cereals thinned with milk or water	• Blended fruits or vegetables diluted to a thin consistency • High moisture fruits such as melon

Tips on eating if your mouth is dry:

- Dry foods like meats and breads will be easier to swallow if served in a liquid, such as gravy or broth.
- Dip cookies in milk or cocoa or eat with ice cream.
- Pour sauces over cake and gravy over breads.
- Citric acid, found in citrus fruits and fruit juices, may help to stimulate saliva; try adding lemon to tea, water, and soda.
- Do not eat dry crackers, unless dipped in broth or gravy.
- Do not eat foods that are hot in temperature.
- Keep beverages handy when eating any food to keep your mouth moist between bites.

Some foods to try:

Beverages/other	Proteins
• Beverages with meals • Tea with lemon, lemonade • Sherbet • Sugar-free sour candies • Biotene® gum, toothpaste, mouth rinse • Oral Balance® mouth gel	• Tender, moist fish and chicken with gravy or sauce • Casseroles • French dip sandwiches • Milk, milkshakes, malts • Eggnog

Breads and cereals	Fruit and vegetables
• Cooked cereals • Dry cereals soaked in milk	• Vegetables with sauces • Melon, peaches • Canned fruits • Fruit juices and nectars

Food record

Please write down everything that you eat and drink in a food record. You can get this from your dietitian or from the 6th floor front desk staff. Keeping a food record will help you and your dietitian make sure you are getting the nutrients you need.

Follow these steps for your food record:

- Use a new food record each day.
- Record your name and date.
- Write down the time you eat or drink each food.
- Note if the food is vomited up and what time.
- Answer the questions on the back of the food record.
- Bring your completed food record sheet to each nutrition appointment.

How to record fluids on your food record:

- Include water, juice, milk, soup, ice cream, sherbet, gelatin, soda, and yogurt.
- Record fluids as cups, ounces (oz.), or milliliters (mL).
- Describe drinks clearly, such as: 2% milk or whole milk.
- Include how much sugar you add when sweetening tea or other drinks.
- List each ingredient of special drinks (such as homemade milkshakes).

How to record solids on your food record:

- Cereal: Measure with a measuring cup. Include the amounts of milk and sugar added. If you use milk to prepare cooked cereal, include how much milk and what type of milk in the food record.
- Condiments and snacks: Include these, as they are important sources of calories. Please write them out on your record. Be specific about the amount you use, such as 1 teaspoon or 2 tablespoons. Examples are:
  - o Butter or margarine (on toast, sandwiches, potatoes, oatmeal, etc.)
  - o Mayonnaise or salad dressing
  - o Syrup, jam, or honey
  - o Olives or pickles
  - o Nuts or sunflower seeds
  - o Potato chips or other kinds of chips
- Fruits and vegetables: State whether fresh or canned. Measure cooked ones with a measuring cup or state number (such as 3 French fries). Estimate raw foods, such as “one medium tomato” or “3 carrot sticks” or “½ large banana.”
- Meat, cheese, and eggs: State how meat or eggs are prepared (fried, roasted, broiled, etc.). State whether you eat the skin of poultry.
- List portion size by the dimension or cup: 1 hamburger patty, 3” diameter x ½” thick; ¼ cup grated cheddar cheese.
- Some foods can be listed by the piece: 1 scrambled egg, 1 small chicken thigh without skin, 5 potato chips.

How to record soups:

State whether homemade, canned, or dehydrated. State if creamed soups are made with milk or water.

How to record mixed items:

List recipes for casseroles, pasta dishes, sandwich ingredients, and contents of tacos, pizzas, hamburgers, and hotdogs.

How to record special products, frozen dinners, etc.:

Cut out and tape the nutrition panel from TV dinners, protein powders, canned foods, or other products we may not be familiar with onto your food record.

How to record brand name foods:

Include these, as the brand name can be helpful. Examples are:

- ¾ McDonald’s Big Mac®
- 1.6 oz Butterfinger® candy bar

How to record food when eating out:

State fast food or restaurant names and the foods and beverages you eat.

Herbal and nutrient supplements

During your first appointment, your dietitian and provider will ask if you use any herbal and nutrient supplements, including cannabis (marijuana). Stop using all herbal and nutrient supplements at this time. These supplements may:

- Decrease the effectiveness of medications used during transplant or chemotherapy.
- Cause bacterial or fungal infections.
- Cause serious toxic side effects to the liver, blood, kidneys, heart, and other body organs.

Herbal and nutrient supplements are not regulated by the U.S. Food and Drug Administration. As a result, the dosage may vary from the dose listed on the label and the product might contain ingredients not listed on the label.

Herbals and botanicals

- Herbal and botanical supplements include a variety of products created directly from plants. They may be sold as tablets, capsules, liquid extracts, teas, powders, and topical preparations. There are no regulations for the cleanliness or purity of these products. There is a danger the products may contain organisms that can be life-threatening to a person with a decreased immune system. Even boiling water may not kill some organisms that can contaminate these products.
- Avoid all herbal and botanical products during chemotherapy when you have a decreased immune system. Talk with your provider about any supplements you are taking. They will consider how the product affects your kidneys, liver, and other organs, your risk of infection, and any interactions it may have with other medications.
- Some herbals may decrease blood clotting. If you have low platelet counts:
    - Do not take garlic or gingko biloba supplements. It is OK to cook with garlic.
    - Do not use any product that is given as an injection into the central line or as an injection under the skin.
- Several herbal and botanical supplements have very dangerous side effects and should not be taken under any circumstance. Do not take:
    - Alfalfa
    - Black Hellebore
    - Borage
    - Chaparral
    - Chinese herbs
    - Coltsfoott
    - Comfrey
    - DHEA
    - Dieter's Tea (senna, aloe, rhubarb root, buckthorn, cascara, castor oil)
    - Echinacea
    - Ephedra or Ma Huang
    - Garlic
    - Germander
    - Ginko
    - Ginseng
    - Grape Seed
    - Groundsel or Life Root
    - Heliotrope or Valerian
    - Hemlock
    - Kava kava
    - Laetrile (apricot pits)
    - Licorice root
    - L-tryptophan
    - Lobelia
    - Marijuana/THC/CBD
    - Maté Tea
    - PC-SPES, SPES
    - Pau d'arco
    - Pennyroyal
    - Sassafras
    - St. John's Wort
    - Yohimbe/Yohimbine

Vitamin and mineral supplements and antioxidants

You will be prescribed a multi-vitamin and mineral supplement that provides nutrients at levels close to the Dietary Reference Intakes (DRI). In some instances, you may wish to take higher doses of specific vitamins, minerals, or antioxidants. While higher doses are not suggested, the list on the next page outlines the DRI and maximum amounts (called safe upper limits in the chart) of supplements recommended. Higher doses may be toxic or interact with other medications.

Dietary reference intakes and safe upper limits

Micronutrient	Dietary Reference Intakes	Safe Upper Limits
Vitamin A	2,800–3,000 IU/ 700–900 RE or mcg	10,000 IU; 3,000 RE or mcg
Vitamin C (Ascorbic Acid)	Females: 75 mg Males: 90 mg (+ 35 mg if patient is a smoker)	If undergoing high dose cytoreduction or if on nephrotoxins: 500 mg; otherwise, 2,000 mg
Vitamin D6 (Calciferol)	600 IU	2,000 IU
Vitamin E (as Alpha-Tocopherol)	33 mg or IU	If undergoing high dose cytoreduction: 400 mg or IU; otherwise 1,000 mg or IU Patients on anticoagulation therapy should have INR's or prothrombin times measured 1–2 weeks after starting Vitamin E therapy
ß-Carotene	No DRI	25,000 IU or 15 mg
Folic Acid (Folate)	400 mcg	1,000 mcg or 1 mg
Vitamin B_1 Thiamin	1.1–1.2 mg	None established
Vitamin B_2 Riboflavin	1.1–1.3 mg	
Niacin (mg of Niacin equivalents)	14–16 mg	35 mg
Vitamin B6 Pyridoxine	1.3–1.7 mg	100 mg
Vitamin B_{12} (Cobalamin)	2.4 mcg	None established
Biotin	30 mcg	
Pantothenic Acid	5 mg	
Iron	8–18 mg	Iron supplementation is not recommended posttransplant
Selenium	55 mcg	If undergoing high-dose cytoreduction, limit intake to DRI; otherwise: 400 mcg
Calcium	1,000-1,200 mg	2,500 mg

Recommended vitamin brands

Ask your dietitian for brand names of recommended vitamins. We do not recommend vitamins that contain iron and/or extra vitamin C.

Antioxidants

- Antioxidants (vitamin C, vitamin E, and ß-carotene) taken in high doses may protect against certain types of cancer, but taking antioxidants during radiation and chemotherapy may reduce the effectiveness of these treatments in destroying cancer cells.
- Stop taking antioxidants before chemotherapy and radiation.
- You may also need to stop taking antioxidants after transplant due to interactions with medications, immunosuppressive therapy, or other vitamins and minerals in your body. Check with your dietitian before taking any supplements after transplant.

B vitamins

Taking high doses of B vitamins (thiamin, niacin, riboflavin, pyridoxine (BR6R), folate, cobalamin (BR12R), biotin, and pantothenic acid,) may have a negative effect. Check with your dietitian before taking any B vitamins.

Specific recommendations

As your immune system begins to recover and strengthen, you may be able to include herbal supplements and vitamins in your diet, depending on the type of transplant you had. Some people wish to start using the supplements they were taking before transplant. **It is very important to check with your health care team before taking any vitamin or herbal supplement, as some may put your recovering immune system at risk.**

Water safety guidelines

Public water quality and treatment varies throughout the United States, so always check with the local health department and water utility about the safety of household and community tap water and ice for people who are immunosuppressed.

Tap water

Tap water is water from your home faucet. It is considered safe if your water is from a city water supply or a municipal well serving highly populated areas.

Well water

Well water from private or small community wells is not considered safe for people who are immunosuppressed and at risk for infection. Water from a private or community well must be heated to a rolling boil for 15–20 minutes. This water should be stored in the refrigerator and may be used up to 48 hours (2 days).

Examples of ways well water could become contaminated:

- Construction occurs near the well
- Well depth is shallow
- Well is located near a dairy farm or large numbers of livestock
- Flooding has recently occurred in the well area

Municipal wells

Drinking well water from municipal wells serving highly populated areas is considered safe because the water is tested for bacterial contamination more than 2 times each day.

Private and small community wells

The quality of well water from these sources cannot be guaranteed.

Not considered safe

Common home water filtration devices do not remove bacteria or viruses. If the well water supply is **chlorinated** per guidelines provided by your local health department, the chlorinated water treated with one or more of the following is considered safe to consume:

- Reverse osmosis treated
- Distillation
- Filtered through an absolute 1 micron or smaller filter (NSF Standard #53 for cyst removal). See **Water Filters** (below).

Safe water sources

Use the following safe water sources if your water is **not from a city water or municipal well supply:**

Bottled water

Acceptable forms of bottled water have been processed to remove organisms known to cause stomach or intestinal infection. Bottled water labels reading "well water," "artesian well water," "spring water," or "mineral water" do not guarantee that the water is safe to drink. Water labeled as having been treated with one or more of the following is considered safe:

- Reverse osmosis treated
- Distillation
- Filtered through an absolute 1 micron or smaller filter (NSF Standard #53 for cyst removal)

To be sure that a specific brand of bottled water has undergone one of the above processes, contact the International Bottled Water Association (IBWA) at 1-800-928-3711, or visit their home page at bottledwater.org. If the IBWA does not have information on a specific brand, call the bottling company directly.

IBWA follows more strict manufacturing practices in its water bottling process than those practices currently mandated by the United States Food and Drug Administration. Therefore, water bottled by a member of the IBWA may be preferable to water produced by non-member bottlers.

Water filters

Most water filtration devices will not make the water safe if the water supply has not been chlorinated. If you choose to install water filters on household faucets, only purchase filters certified by National Sanitation Foundation (NSF) International. The following specifications must also be met:

1. The filters must be designed to remove coliforms and Cryptosporidium. Any of the following are acceptable:
    - Reverse osmosis filter
    - Filters with an absolute pore size of filter 1 micron or smaller
    - Filters that are tested and certified by NSF Standard #53 for cyst removal
2. The water tap filter must be installed immediately before the water tap.
3. You must follow manufacturer directions for filter maintenance and replacement.

Portable water filters (such as a Brita® or Pur® system) as well as refrigerator-dispensed water and ice machine systems do not meet filtration standards. Portable water systems filter out chemical impurities, not bacteria. If a portable water system (such as a Brita® pitcher) is used in combination with a safe water supply (to improve water flavor and remove chlorine and other impurities), change the system's filters frequently according to manufacturer's guidelines.

For a list of approved filtration systems, call the NSF International, at 1 (800) 673-8010 or visit their home page at NSF.org (go to the section "Home Water Treatment Devices").

Caregivers

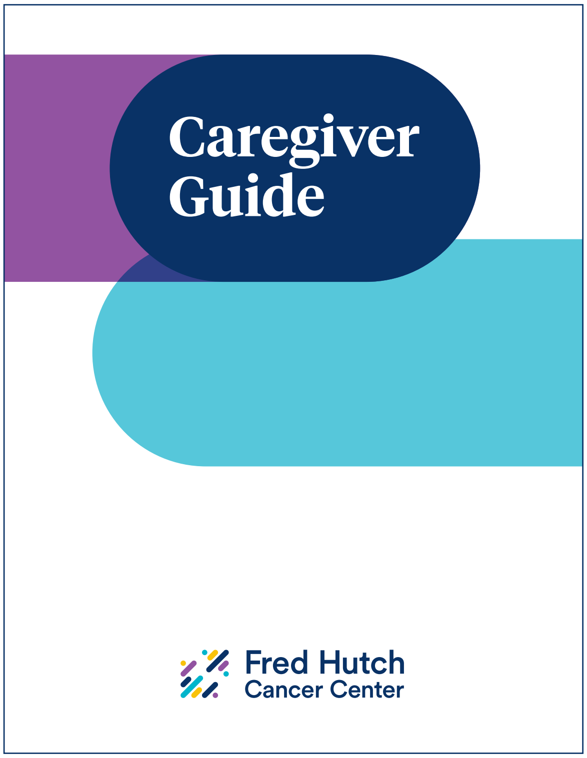
“There are only four kinds of people in this world:
Those who have been caregivers
Those who are currently caregivers
Those who will be caregivers
Those who will need caregivers”
—Introduction to Rosalynn Carter’s book *Helping Yourself Help Others.*

This section explains the role of caring for a person undergoing transplant and the responsibilities that come with it. It is written for caregivers, but is important for you to read too, so you have an idea of what your caregiver will be doing.

What is a caregiver?

Being a caregiver means helping with the daily needs of another person. Being a caregiver can change daily. Some days you may find that you are able to balance all of the demands that come with being a caregiver and other days it can be difficult to find the time to do it all.

Caregiving can take a toll on your body, emotions, spirituality, and finances. It’s important to take care of yourself so that you can cope with these changes. By eating healthy, exercising, relaxing, getting enough sleep, and asking for help, you will have more energy to take care of someone else and prevent personal health problems.



Caregiver Guide

Fred Hutch
Cancer Center

We encourage you to read our Caregiver Guide that we put together with the help of Fred Hutch caregivers to help support you as you take on this important role. In it, you will find tips on how to be an effective caregiver and advice on how to continue caring for yourself while caring for someone else. Ask your care team for a copy or find it at FredHutch.org/caregiver-guide.

Examples of caregiving responsibilities

Making arrangements

- Transportation
- Financial
- Appointments

Giving emotional support:

- Being physically present
- Offering encouragement
- Helping your loved one find ways to cope

Providing physical care:

- Bathing, dressing, or shaving
- Identifying changes in condition
- Getting medical care if needed
- Reporting symptoms to care team
- Making sure medications are taken
- Recording medications taken
- Getting medical supplies
- Helping with at home medical care, such as central line care

Doing chores:

- Cleaning
- Preparing food
- Shopping

Advocating for the patient:

- Gathering information and making sure it is given to care team
- Helping with decision-making

Supporting other people in the patient's life:

- Sharing information with children, other family members, and friends
- Providing or arranging childcare

The changing role of a caregiver

Patients' needs change throughout the transplant process, which means your role as a caregiver will change, too. Below are our recommendations for the levels of support a patient will need during the inpatient and outpatient phases.

Inpatient phase (when patient is in the hospital): This is when patients do not require caregivers but do appreciate and benefit from emotional support from family and friends.

Outpatient phase (also called ambulatory): This refers to when the patient is living "at home" and coming to the clinic several days a week and sometimes daily. Family caregivers are very important in providing care during this phase. The 3 levels of support during this phase are:

- **Consistent support:** This is when the caregiver is present most of the time and **takes breaks less than 3 to 4 hours.** When patients are left alone, they should have access to the phone, food, and fluids, and be able to contact emergency services, operate pumps, and get to the restroom.
- **Intermittent support:** This is when the caregiver does not need to be around most of the hours within a 24-hour period. A caregiver is available 2–3 times per day to help with dressing changes, medications, transportation, and talking through information provided during conferences or clinic visits.
- **Minimal support:** Patients do not require a caregiver but do benefit from emotional support during clinic visits and conferences.

Tips for coping with care at home

Coping with care at home can be challenging. Use these tips to help you throughout your time as a caregiver:

- Ask your care team questions. Do not assume. If you are not sure about something, call us.
- Remember that you are a member of the care team and your input is important. Keep your nurse and provider informed.
- Review the symptom sheets provided and call for help if needed.
- Review tips for self-care in our Caregiver Guide. Ask your care team for a copy or visit FredHutch.org/caregiver-guide.
- Develop a home care plan. See the **Develop a home care plan** section for details.
- Ask your family and friends for help before you are too tired.
- Keep a list of what friends can do and give them tasks. For example, one person could drive you to an appointment, another could make a meal, and another could go to the grocery store. Some people have more time than others. This is where your list would be helpful.
- Organize your day into manageable segments.
- Develop a schedule each day or week with the caregiver who is providing the care. This process allows family members or friends to agree with the goals for the day or week. If everyone is working with the same schedule and goals, the tension within a family usually decreases.
- Set up a caringbridge.com website to keep people informed.

Remember, your care team is here to support you. Tell your provider, nurse, social worker, or Spiritual Health clinician if you need more support.

Develop a home care plan

A home care plan is a schedule of regular care that is organized to meet the patient's most pressing needs like bathing, medication management, grocery shopping, and laundry. Nursing staff, including Transition Services, will work with you to develop a unique home care plan with the following in mind:

- A Fred Hutch nurse is available by phone 24 hours a day to answer your questions about care at home, including side effects and symptom management.
- Many patients rely on family members and friends during the different stages of transplant.
- You and the person you're caring for should create a schedule and division of tasks together, to make sure you agree on what is being decided.
- Patients can take care of themselves as long as they feel well enough to do so. Some patients, for instance, choose to do all their care themselves and only use their caregiver when they are not feeling well. When a new person (even if it's the patient) takes over line care, they should review the procedure with a nurse. The patient, as well as the caregiver, can learn to operate the home infusion pump.
- The home care plan should meet the safety needs of the patient. Some patients and families are interested in hiring a homecare agency. Some people are interested in hiring a caregiver either full-time or part-time. If these are options you wish to explore, please contact Transition Services.
- Each patient and family organizes their routines differently. Some people like to develop a very complete schedule during the outpatient steps of transplant. Some people like to keep a logbook of activities, infusions, and medications.

Taking care of the caregiver

As a caregiver, taking care of yourself is important. Because treatment can last months, we encourage you to ask the patient's family members, friends, or professional home health care for help. You can find a list of home health care options and general information about being a caregiver in our Caregiver Guide at FredHutch.org/caregiver-guide.

Here are some helpful tips from Rosalynn Carter's book, *Helping Yourself Help Others:*

- Listen to your friends. Be open to others' observations.
- Let go. Know your limits.
- Focus on your loved ones' strengths.
- Learn relaxation techniques.
- Take care of your health: exercise, rest, stay hydrated, and don't forget to eat.
- Maintain a life outside your caregiving role.
- Insist on private time.
- Build a caregiving team.
- Rely on your sense of humor.
- Appreciate the benefits of leisure time.
- Help your loved one find an online support group.
- Seek professional help.
- Appreciate your own efforts.
- Seek spiritual renewal.

Symptom Sheets

Anemia

Anemia is a condition that occurs when you don’t have enough healthy red blood cells to carry oxygen throughout your body. It is found through blood tests that measure your red blood cell count, hemoglobin, and hematocrit. Anemia can be mild or severe. It may require a blood transfusion, iron infusion, or other medication. Treatment is based on what is causing the anemia.

Causes

What causes anemia?

- Cancer and its treatment
- Bleeding
- Diet lacking in certain vitamins
- Other chronic health conditions

When to get help

Call 911 immediately if you have:

- Chest pain
- Severe shortness of breath
- Patient is not conscious
- New severe pain
- Seizures

Call the clinic or after-hours clinic now if you experience:

- Dizziness
- Shortness of breath
- Unusual tiredness or weakness (fatigue)
- Pounding in your head
- Pulsing or ringing in your ears
- Unusually pale skin
- Irregular heartbeat

What you can do at home

- Get plenty of sleep, ideally between 7–8 hours of sleep daily.
- Rest between short periods of activity to save your energy.
- Move slowly when getting up from a sitting or lying position. Sit up for several minutes before standing. This can help prevent dizziness, fainting or “passing out.”
- Monitor yourself for any bleeding like nose and gum bleeds, or bloody stool (poop), urine (pee), and sputum (mucus).
- Your care team may refer you to a Fred Hutch dietician.
- Call your care team as soon as you have symptoms of anemia. Don’t wait until your next visit to tell them.

Anxiety

Anxiety means feeling worried, nervous, or scared about a real or possible situation. It is common to experience anxiety when you or your loved one has been diagnosed with cancer. Too much anxiety can lead to other problems such as panic, insomnia, or even physical symptoms, and can get in the way of your ability to get through treatment. Many types of treatments can reduce anxiety.

What causes anxiety?

- Concern about a health condition or serious illness, such as cancer
- Certain medications, alcohol, or drugs
- Stress or depression
- Not getting along with loved ones
- Financial concerns

When to get help

Call the clinic or after-hours clinic now if you experience:

- Thoughts that you might harm yourself or others
- Excessive worry
- Feelings of nervousness or tenseness
- Difficulty sleeping
- Panic
- Irritability or anger
- Fear or feeling like something bad is going to happen
- Mood swings that you can't control
- Physical symptoms, such as
  - Upset stomach
  - Sweaty palms
  - Shaking
  - Rapid heartbeat

What you can do at home

- Recognize that anxiety during treatment is normal. Getting help for it is normal, too.
- Think about what's triggering the anxiety. For example, if you're anxious about a medical procedure, ask yourself what about the procedure is upsetting. Staff may be able to help you find ways to cope with your anxiety.
- Learn what you can — information helps, and your care team can help you find the best resources. For example, if you are worried about pain or discomfort, ask your care team how to manage symptoms and side effects.
- Think about doing things that you enjoy or help you relax. For example, imagine you are at the beach or in the mountains.
- Focus on your breath to keep your mind from wandering. Inhale deeply and slowly through your nose for four seconds. Exhale deeply and slowly through your mouth for four seconds. Continue this deep breathing for 30 to 60 seconds.
  - Watch our playlist of mind-body relaxation videos at FredHutch.org/mind-body-relaxation-playlist.
  - Read Fred Hutch's Mind-Body Relaxation Resources handout, which is available at FredHutch.org/patient-education.
- If your anxiety doesn't improve after taking these steps, discuss it with your care team or request an appointment with a social worker. They can help you explore other options.

Bleeding

Bleeding is when you lose blood. You may experience unusual or abnormal bleeding or bruising at some point during your treatment. Bleeding can be internal, where you can't see it, or external (like from a cut), where you can see it. If you notice any unusual bleeding or bruising, it is important to tell your care team.

What causes bleeding?

Bleeding may be caused by:

- Cancer and its treatments
- Low platelet count due to chemotherapy or other factors
- Blood disorders, like problems with clotting
- Gastrointestinal (GI) ulcers
- Blood thinners and other medications or supplements
- Injuries and wounds

When to get help

Call 911 immediately if you have:

- Uncontrolled, constant bleeding
- Patient is unconscious

Call the clinic or after-hours clinic now if you experience:

- New or increased bleeding or bruising
- Blood in your vomit (could be red or look like coffee grounds)
- Blood in your stool (poop); the blood could be bright red or black
- Blood or blood clots in your urine (pee)
- Blood in your mouth or gums
- Nosebleed that won't stop after 30 minutes
- Many, tiny, red or purple spots on your skin or in your mouth (the size of a pinpoint)
- A fall, with or without injury
- Any new or increased confusion
- Lightheadedness
- Unusually pale, cold, or moist skin
- Irregular heartbeat
- People who menstruate: Changing your pad more than you normally do or using more than one pad in an hour. Do not use tampons or a menstrual cup.

Note: If you need to go somewhere for treatment while bleeding, apply pressure to the site that's bleeding. Avoid any unnecessary movement.

What you can do at home

Prevent bleeding

- **Do not take over-the-counter medications or supplements** without first talking to your care team. Certain medications can increase your risk of bleeding. Examples include aspirin, ibuprofen (Advil®), naproxen (Aleve®), Alka-Seltzer®, or cold medications that contain these medications. This is not a full list of medications that can increase your risk of bleeding.
- If you take medication for high blood pressure, take it as prescribed; high blood pressure can trigger bleeding.
- If you are told your platelet count is low:
  - Use a soft bristle toothbrush.
  - Do not use razorblades because you may cut yourself; use an electric razor instead.
  - Be extra careful to avoid falls.
  - Do not exercise intensely; follow activity guidelines from your physical therapist or care team.
  - Do not get a deep massage.
  - Do not blow your nose hard or scratch the inside of your nose.
  - Use pads if you are menstruating. Do not use tampons or a menstrual cup.
  - Do not have sexual intercourse if you have had breakthrough bleeding (any vaginal bleeding) within 2 weeks.
  - Do not have anal sex until your platelets are stable.
  - Do not put anything in your rectum, including suppositories, enemas, or thermometers.

Control bleeding if it starts

- Apply pressure to your bleeding site. For example, for a nosebleed: Press your nostrils together firmly with your fingers or wrap ice in a soft cloth and press it firmly against your nostrils.
- Hold pressure on bleeding site for 5 minutes before checking to see if the bleeding has stopped.
- Try to stay calm if you can. Breathing exercises, such as inhaling for 4 counts and exhaling for 4 counts (repeatedly) can help.

Body image changes

Cancer treatment can change how you look and feel. The way you feel about these changes is known as your body image. Your body image can affect how you feel about yourself physically, mentally, and emotionally. It is important to recognize when you are struggling with your body image so you can take steps to feel better.

What causes body image changes?

Many things can trigger the way you feel about your body. Some may be temporary while others are permanent. Some of these changes include:

- Weight loss
- Weight gain
- Muscle loss
- Hair loss
- Surgery that can change the way you look
- Infertility
- Changes with sex or intimacy
- Scars
- Skin or nail changes

When to get help

Call the clinic or after-hours clinic now if you experience:

- Extreme sadness, anxiety, or anger
- Losing interest in activities that you used to enjoy because of your body changes
- Not taking care of yourself (not exercising, not showering, not getting dressed)
- Discomfort around others because your body has changed

What you can do at home

- Tell your family, friends, and care team how you feel.
- Spend time with people who make you feel good.
- Talk to others who have had similar struggles. Consider joining a support group. Ask your care team to connect you to a Fred Hutch social worker for more information on support groups.
- Laugh! Humor is a fine way to cope. Treat yourself to funny movies, TV shows, books, or people.

- Explore options for creating a positive body image:
    - Visit Look Good, Feel Better's website at lookgoodfeelbetter.org. Look Good, Feel Better has lots of resources, including online classes, to help improve the quality of life and self-esteem of people undergoing cancer treatment.
    - Call Fred Hutch's retail store, Shine to make an in-person or virtual appointment at (206) 606-7560. They have specialty products and trained staff who can help you with:
        - Breast prostheses (artificial or fake breast worn on the outside of your body) and bras
        - Wigs, hats, and hair alternatives
        - Skin care products
        - Compression garments
        - Sexual intimacy items

      You can also visit Shine's website for more information at FredHutch/shine.org. If you don't live in the Seattle area, feel free to call Shine. They can help you find a local resource.
- Exercise daily but check with your care team before starting an exercise routine. Exercise is one of the simplest and most effective ways to reduce stress, increase stamina, and give you an overall sense of well-being.
    - Begin slowly with low-intensity exercise, such as walking. Your body will tell you what your limits are. A good rule of thumb is that you should never be out of breath. You should be able to talk while exercising.
    - Vary your exercise routine. Ask your care team for advice on how to exercise safely. They can also help you if you're having trouble getting started. Your care team may refer you to a physical therapist.
- Talk with your care team or social worker if these tips don't help improve your body image. They are here for you and can help you find other helpful resources.

Breathing problems

Breathing problems can feel like you can't "catch" your breath, you can't take a full deep breath, or you need to breath more quickly or deeply than you usually do. Sometimes they can occur quickly and be frightening, especially if you've never experienced them before. Other times, they can be mild and bothersome when doing daily activities.

What causes breathing problems?

Breathing problems can be caused by:

- Cancer
- Cancer treatments, such as radiation and chemotherapy
- Infection in your lungs
- Fluid in your lungs
- Other chronic conditions like asthma and heart conditions

When to get help

Call 911 immediately if you are:

- Not breathing
- Feeling like you can't breathe
- Having severe trouble breathing
- Choking
- Having chest pain
- Having difficulty speaking
- Swelling in your face and neck

Call the clinic or after-hours clinic now if you experience:

- Shortness of breath
- Feeling like you can't get enough air
- Trouble breathing when lying flat
- Chest tightness or wheezing with breaths
- New or recurrent cough
- Uncontrollable or continuous cough
- Blood or green/yellow mucus when you cough
- Getting "winded" more easily than normal

What you can do at home

- Sit up during the day instead of lying down if you can. Standing up and moving around is even better.
- Exercise daily if you can but check with your care team before starting an exercise routine. Exercise helps expand your lungs and improve the flow of oxygen in your body.
- Take deep breaths while sitting up. This helps expand your lungs and improve the flow of oxygen in your body.
- Practice mind-body relaxation. For a playlist of exercises, visit FredHutch.org/mind-body-relaxation-playlist.
- Do not smoke or be around smoke. Ask your care team about Fred Hutch's Living Tobacco-Free Services if you'd like to cut back or quit using tobacco. This service is free of charge to Fred Hutch patients and families.
- Avoid wearing any tight clothing that makes it harder to breathe.
- Avoid contact with anyone with a cold, fever, runny nose, cough, or who is sneezing or has other signs of a respiratory infection.
- Use a fan and keep the room cool.

Change and uncertainty

What does change and uncertainty feel like?

The treatment process is filled with change and uncertainty. Your life may suddenly feel less secure than it once was and you don't know what the future holds. This can cause worry, stress, and sadness. It is important to recognize and get help when feelings like this became severe or get in the way of your everyday life.

What causes feelings of uncertainty?

- Serious illnesses
- Changes in your life

When to get help

Call the clinic or the after-hours clinic now if you experience:

- Feeling like harming yourself
- Feelings of dread and anxiety most days
- Sweaty palms, shaking, rapid heartbeat, and other physical symptoms of anxiety.
- Feeling down, depressed, or hopeless
- Wide mood swings that you cannot control

What you can do at home

- Identify the changes that are taking place in your life. Ask your care team to explain all of your treatment options. Discuss these changes and options with your family.
- Write down and ask lots of questions. Keep track of answers and other information in a notebook or electronic device.
- When planning for the future, think about both short-term and long-term goals.
- If new decisions or plans need to be made, be flexible and consider all of your options.
- Share your feelings of worry or uncertainty with someone who listens.
- Get help when you need it. If you aren't feeling better after taking these steps, discuss it with your care team or request an appointment with a social worker. They can help you find other options.

Constipation

What is constipation?

Constipation is when it's hard to have a bowel movement (poop). You may be constipated if you have:

- Small, lumpy, hard, or dry poop
- Pain or difficulty pooping, often with straining and hemorrhoids
- Bloating, fullness, and being unable to fully empty your bowels; you may also feel nauseated

What causes constipation?

- Certain medications, such as opioid pain relievers or anesthesia (medication that prevents pain during surgery)
- Cancer and its treatments
- Changes in the body from other health conditions
- Inactivity or reduced activity
- Lack of fluids (dehydration)
- Changes in your usual diet
- Recent surgery

When to get help

Call the clinic or after-hours clinic now if you have:

- Not pooped for 3 days or more
- Uncontrolled nausea or vomiting that prevents you from eating or drinking
- Distended (swelling or expanded) belly area, pain in your belly area or you can't pass gas
- Leaking poop
- Constipation that does not improve within 24 hours after taking medications as prescribed by your care team
- Back pain
- Rectal bleeding
- Fever

  - o Temperature taken by mouth between 100.4-100.8°F (38-38.2° C) for one hour or more, or a temperature that is 100.9°F (38.3°C) or above
  - o Temperature taken under the arm between 99.5-99.9°F (37.5-37.7° C) for one hour or more, or a temperature that is 100° F (37.8°C) or above

If you develop a fever, talk with your care team before taking any medications to lower your fever (such as acetaminophen/Tylenol® and ibuprofen/Advil® or Motrin®).

What you can do at home

For your safety, do not take any medications to help with constipation without talking to your care team first.

Treat constipation or manage symptoms

- Your provider may prescribe medications called laxatives to manage your constipation. Sometimes two or more laxatives are prescribed together. Make sure to take each laxative as instructed by your care team.
- Commonly prescribed laxatives include:
  - o **"Gush" osmotic laxatives,** such as Polyethylene glycol (MiraLAX® or other brands) or lactulose, which help soften poop
  - o **"Push" stimulant laxatives,** such as Sennoside (Senna) and Bisacodyl (Dulcolax® or other brands), which help move poop through your bowel

Belly cramping is a common side effect of both types of laxatives.

- If these laxatives don't work, your care team may talk to you about other options, such as: Magnesium Citrate, Milk of Magnesia®, or other prescription medications.

Caution: Even though suppositories and enemas are available at your pharmacy without a prescription, **do not use them unless prescribed by your care team.** They may be unsafe for you.

Maintain nutrition and fluid intake

- Drink plenty of fluids to stay hydrated, such as water, juice, soup, broth, and smoothies. Regular fluid intake helps you poop and is especially important as you increase the fiber in your diet. Talk to your team about how much fluid intake is right for you.
- Increase dietary fiber by including vegetables, fruits, legumes, nuts, seeds and whole grains on a regular basis. Increase the amount of fiber in your diet slowly to prevent excess gas or bloating. See the table below for foods suggestions for constipation.
- Discuss fiber supplements, such as Metamucil® and Citrucel®, with your care team **before you take them** because some make constipation worse.
- Try to eat meals, especially breakfast, at the same time each day. This helps get your bowels back on a regular schedule
- Include regular, daily exercise, if possible. Exercise helps the bowels move. Even walking slowly will help. Try to walk for 5 to 15 minutes once or twice a day.
- If you would like to see a Fred Hutch dietician, ask your care team. A dietitian can talk to you about foods that may help.

Food suggestions for constipation

Try these	Limit these
Grains	
• Whole grain and seed breads or muffins (>3 grams fiber per serving) • Whole grain cereals: All Bran®, Fiber One®, raisin bran (>3 grams fiber per serving) • Hot whole grain cereal: oatmeal • Whole wheat pasta • Brown or wild rice, bulgur wheat, quinoa	• Frozen dinners, instant mashed potatoes and chips • Refined grains and breads, white rice, regular pasta, pizza • Low-fiber cereals such as Rice Krispies®, corn flakes

Try these	Limit these
Protein	
• Legumes such as beans, lentils, split peas • Yogurt (with live cultures) • Trail mix with nuts, seeds • Lean meats • Cold water fish such as wild salmon, halibut, and sardines	• Large quantities of meat and cheeses or peanut butter
Fruit and vegetables	
• Raw or cooked vegetables: carrots, acorn squash, spinach, avocados, beets • Cruciferous vegetables: cabbage, broccoli, brussels sprout (eat in moderation if gas is an issue) • Raw, whole fruits: apples, pears, cherries, grapes, tangerines, oranges, peaches, plums • Berries: raspberries, blueberries and strawberries • Dried fruits: raisins, figs and prunes • Prune juice	• Bananas
Other	
• Trail mix, whole grain snack foods • Air-popped popcorn • Fluids	• Caffeine and alcohol • Pastries, rich cakes, candy • Concentrated sweets

Dehydration

Dehydration happens when your body doesn't have enough fluids, such as water. Your body doesn't function well without enough fluids.

What causes dehydration?

Dehydration can be caused by:

- Chemotherapy, radiation, and other cancer treatment
- Certain medications, such as diuretics (also called water pills)
- Diarrhea, vomiting and other side effects of treatment
- Fever
- A lot of sweating
- Not eating or drinking enough

When to get help

Call the clinic or the after-hours clinic now if you experience:

- Irregular heartbeat
- Sunken eyes, increased dark cricles or hollowing around your eyes
- Dizziness or lightheadedness
- Fainting
- New or increased confusion
- Decreased urination, dark or strong smelling urine
- Increased weakness
- Not eating and drinking as much as normal, weight loss
- Dry or cracked skin, skin that "tents" (stays up) when lightly pinched
- Constipation (no poop for 2–3 days)
- New or increased vomiting or diarrhea

What you can do at home

- Stay hydrated with fluids, such as water, tea, juice, soup, and smoothies. Your care team will tell you the amount of fluids that's right for you.
- Drink small amounts of fluids frequently throughout the day. Sometimes iced fluids are easier. In addition to water, drink coconut water, broths, soups, smoothies, or store bought electrolyte drinks.

- Avoid caffeine and alcohol.
- Suck ice chips to relieve dry mouth if you can’t drink enough liquid.
- Remember that food contains fluid. Try to eat fruits, vegetables, soups, gelatins, Popsicles, and other moist foods. Fruits, especially cantaloupe, strawberries and watermelon and vegetables like lettuce, cabbage, celery, and spinach, have a high fluid content.
- Try to eat small meals several times a day.
- Keep a food and fluid diary.
- Use lotion often to soften dry skin.
- Try to get rid of the cause of dehydration, such as vomiting, diarrhea, or fever. Read the Nausea and Vomiting and Fever symptom sheets in this manual.
- Apply lubricant to lips to avoid painful cracking.

Depression

When you or your loved one are coping with a serious illness, it is common to sometimes feel sad, down, and depressed. But too much depression can lead to other problems such as anxiety, physical symptoms, or even suicidal thoughts. These can get in the way of your ability to get through treatment.

People experience depression in all different ways. Often, people don't feel like doing the things they typically enjoy or lose their motivation. Some people have a hard time sleeping, can't concentrate, or don't feel like eating.

What causes depression?

There are several causes of depression, including:

- Serious illnesses, such as cancer
- Medication, alcohol, or medications
- Stressful life events
- The chemistry in your brain
- Family history of depression

When to get help

Call the clinic or after-hours clinic now if you experience:

- An ongoing sad, anxious, or "empty" mood
- Uncontrollable crying or tears
- Feelings of hopelessness or pessimism
- Feelings of guilt, worthlessness, or helplessness
- Loss of interest or joy in hobbies or activities
- Feelings that interfere with the ability to care for yourself
- Decreased energy, fatigue, or being "slowed down"
- Difficulty concentrating, remembering, or making decisions
- Difficulty sleeping, early-morning awakening, or oversleeping
- Appetite and/or weight changes
- Thoughts of death, self-harm or suicide attempts
- Restlessness or irritability
- Aches or pains, headaches, cramps, or digestive problems without a clear physical cause and/or that do not ease even with treatment

What you can do at home

- Try to do things that you used to enjoy.
- Be kind to yourself.
- Try to be active and exercise.
- Break up large tasks into small ones, set priorities, and do what you can as you can.
- Spend time with other people and talk to a trusted friend or relative.
- Discuss important decisions with others who know you well.
- Avoid drinking alcohol or taking drugs or medications that are not prescribed for you.
- Your care team may refer you to a social worker, psychiatrist or psychologist who can help you with counseling. They may also suggest medication to help you manage depression.

Diarrhea

Diarrhea is when you have more stools (poop) in a day than is normal for you. Your poop may also be loose or watery. The normal frequency and consistency of poop is different for each person. It is important to tell your care team if you are experiencing diarrhea because it can cause your body to lose large amounts of water. This can lead to dehydration and loss of important electrolytes.

What causes diarrhea?

- Cancer and its treatments
- Certain medications, including antibiotics, laxatives, and some supplements
- Infections of the gastrointestinal (GI) tract
- Changes in your diet
- Stress or anxiety
- Food intolerances or sensitivities
- Other chronic conditions of the stomach or bowel

When to get help

Call the clinic or the after-hours clinic now if you are experiencing:

- New or increased amount of loose or watery poop. Specifically, if you have 4 or more poops than you normally do in a day
- Uncontrolled (constant) diarrhea:
  - Even though you're taking your anti-diarrhea medications
  - That continues for more than 2 days
  - That suddenly gets worse
- Whole pills visible in your poop
- Signs of dehydration
  - Feeling very tired, weak, or dizzy
  - Feeling like your heart is racing
  - Peeing less than normal or dark-colored pee (the color of apple juice or darker)
  - Increased thirst, dry mouth

  - Dry or cracked skin, skin that “tents” (stays up) when lightly pinched
- Poop that is bloody, dark red, black or has mucous
- Stomach cramping, pain, or bloating
- Trouble eating and drinking as much as normal
- Fever:
  - Temperature taken by mouth between 100.4-100.8°F (38-38.2° C) for one hour or more, or a temperature that is 100.9°F (38.3°C) or above
  - Temperature taken under the arm between 99.5-99.9°F (37.5-37.7° C) for one hour or more, or a temperature that is 100° F (37.8°C) or above

If you get a fever, talk with your care team before taking any medications to lower your fever (such as acetaminophen/Tylenol® and ibuprofen/Advil® or Motrin®).

What you can do at home

For your safety, do not take any medications to help with diarrhea without talking to your care team first.

Treat diarrhea or manage symptoms

- Your provider may prescribe medication called antidiarrheals to manage your diarrhea at home. Take each medication as instructed by your care team.
- Commonly prescribed antidiarrheal medications include:
  - Loperamide (Imodium® or other brands)
  - Atropine sulfate/diphenoxylate hydrochloride (Lomotil®)

Maintain nutrition and fluid intake

- Tell your care team if you continue to have diarrhea after taking your antidiarrheal medication. Do not change the amount of medication or take any new medications before speaking with your care team.
- Stay hydrated with fluids, such as water, juice, soup, broth, smoothies, and store-bought electrolyte drinks. Your care team will tell you the amount of fluids that’s right for you.
- Try to eat small meals several times a day.
- Include food sources of probiotics (like yogurt).

- Limit foods that may worsen symptoms such as spicy, greasy or sugary foods.
- Limit drinks that may worsen symptoms such as alcohol, caffeine and acidic drinks like tomato and citrus juices.
- Ask your care team if you would like to see a dietitian; they can talk to you about other foods that may help.

Protect your skin and prevent infection

- Wash your hands often.
- Diarrhea can cause skin irritation, keep affected area clean and dry.
- Use dampened, unscented toilet paper or baby wipes to gently clean yourself after each bowel movement.
- Do not use ointment or creams on anal or stoma area unless directed by your care team.

Dizziness and lightheadedness

Dizziness and lightheadedness can feel like loss of balance or feeling woozy or faint. Some people feel like the room is spinning.

What causes dizziness and lightheadedness?

There are several possible causes of dizziness and lightheadedness, including:

- Standing up or sitting too quickly
- Lower than normal blood pressure or a drop in blood pressure
- Anxiety, sleeping problems
- Anemia (low number of red blood cells)
- Dehydration
- Low blood sugar (hypoglycemia)
- Ear infection or inner ear problems
- Fatigue
- Motion sickness
- Medications for blood pressure, anxiety, sleep, pain

When to get help

Call 911 immediately if you:

- Cannot wake the patient

Call the clinic or after-hours clinic now if you experience:

- Dizziness and/or lightheadedness:
  - After starting a new medication
  - That does not go away when lying down
  - That causes you to lose balance or fall
- Shortness of breath
- Headache
- Fever and/or chills
- Feel your heartbeat is irregular or pounding
- Low blood sugar (less than 70)
- Nausea or vomiting
- Diarrhea
- Shakiness

What you can do at home

- Stay hydrated with beverages, soups, and smoothies. Ask your care team what your fluid goal for each day should be. Avoid alcohol and caffeine. Read the Dehydration symptom sheet in this manual for more information on staying hydrated.
- Change positions slowly: Move from lying down to sitting up slowly. Sit on side of bed or couch for at least a minute before standing. Stand for a minute or more before walking.
- Eat regularly throughout the day.
- Prevent falls:
  - o Make sure the path is clear and has plenty of light.
  - o Wear sturdy, non-skid shoes, such as tennis shoes. Avoid walking with bare feet or wearing footwear that adds to your risk for falls such as slippery slippers and socks, high-heels, and flip-flops.
  - o Remove any throw rugs or loose power cords on the ground.
  - o Remove things you can trip over (like paper, books, clothes, and shoes) from stairs and places where you walk.
  - o Always use handrails when walking up or down the stairs.
  - o Read the Fall Prevention symptom sheet in this manual for more information.
- Create regular rest and sleep routines. Read the Sleep Problems and Healthy Sleep Habits symptom sheet in this manual for more tips on healthy sleep routines.
- Keep a diary to monitor your fatigue levels. Take note of what you think may be causing increased fatigue. Read the Fatigue symptom sheet in this manual for more information.

Exercise and blood value guidelines

Sometimes it is not safe to exercise during cancer treatment, especially if you have a blood cancer. Your blood values for platelets (called platelet count), hematocrit, and hemoglobin tell us what type of exercise is safe for you. The charts below explain exercise guidelines you should follow based on the range of your blood tests.

Exercise guidelines based on platelet counts

Platelets are a type of cell found in your blood that help your blood clot.

Platelet count range	Exercise guideline
50,000–100,000	Cardiovascular exercises and strength training with weights/elastic tubing are OK. Do not exercise if you have any signs of bleeding (i.e. from the nose). Contact your care team if you have any signs of bleeding.
20,000–49,999	**If you have no signs of bleeding**, cardiovascular exercise and strength training with weights/elastic tubing are OK as long as you are not straining or holding your breath. Straining can increase your blood pressure and risk for stroke or major bleeding. **Talk to your provider before getting a massage.** Gentle comfort massage is typically OK as long as your skin is not fragile or prone to easy bruising for other reasons (such as chronic steroid medications). Deep tissue massage is not OK.

Platelet count range	Exercise guideline
Less than 20,000	You may have an increased risk of bleeding with certain types of exercise. The bleeding could become serious and even life threatening. **Do not** do any intense cardiovascular exercise (power walking, running, cycling, dancing, etc.) or strength training with weights or elastic tubes.
10,000–19,999	Strength training **without** weights/elastic tubing or strain, and cardiovascular exercise **without** strain are OK if you are steady on your feet and have no signs of bleeding.
Less than 10,000	**Do not** do any cardiovascular exercise and strength training until your platelets are in a safe range. You may walk around your room and go to the bathroom with help from a caregiver if you are steady on your feet and have no sign of bleeding.

Exercise guidelines based on hematocrit (Hct) and hemoglobin (Hgb)

Hct is the number of red blood cells in your body. Hgb is the amount of oxygen your blood can carry. Exercising when your Hct and Hgb are too low may cause shortness of breath, muscle fatigue, or dizziness.

Hct/Hgb range	Exercise guideline
Hct less than **25%** Hgb less than **8.0**	Talk to your doctor, physical therapist, or occupational therapist about what type of exercise is safe for you. They may recommend restrictions in strength training or cardiovascular exercise.

When your Hct or Hgb are below these ranges, you may need a red blood cell transfusion. It can be difficult to predict how much a transfusion will increase the level of Hct and Hgb, so a follow-up blood count is recommended.

Fall prevention

People at any age with cancer are more likely to fall due to their cancer or cancer treatment. They are also more likely to be injured when they fall because they could bleed, bruise, or break their bones more easily. Some falls can lead to serious injury, hospitalization, or even death.

Common risk factors for falling

You may be at risk for falls because of:

- Medications, such as chemotherapy and anti-nausea medications
- Dehydration (when your body loses too much water and other fluids that it needs to work normally)
- Low blood pressure
- Muscle weakness or fatigue
- Numbness or tingling in legs or feet
- Feeling unsteady or dizzy
- Confusion
- Poor vision or hearing

If you have a history of confusion with any medications for nausea or pain control, tell your care team. We want to prevent falls both in the clinic and at home. Review this information with family members and friends who are part of the team to keep you safe.

When to get help

Call 911 immediately if you:

- Have fallen and are bleeding
- Lose consciousness for any amount of time
- Think you have a broken bone
- Have fallen and hit your head
- Have fallen and have low platelets
- Have fallen and are on anti-coagulant medications (blood thinners)

Do not try to get up yourself because you might get hurt.

Call the clinic or after-hours clinic now if you:

- Have fallen, even if you think that nothing is wrong. Report all falls.

What you can do at the clinic

- Wear closed-toed, closed-heel, non-slip footwear.
- Keep shoes on at all times in the clinic, even when on the exam table or bed.
- Bring your walker, cane, wheelchair, or scooter to the clinic with you.
- Some walkers have a seat for resting. Do not move the walker while seated. Use a wheelchair if you need to be seated and pushed.
- Get in and out of your car slowly. Use valet service when available.
- Wear your eyeglasses or hearing aids.
- Bring a caregiver to help escort you through your appointments.
- Do not rush to get to an elevator.
- Use handrails and benches that are available in reception areas and hallways.
- Never use an IV pole for support — ask for help if you need to move your IV pole.
- Keep your belongings within easy reach.
- Sit at the edge of the exam table or chair for a minute before standing.
- Ask for help when you go to the restroom after taking medications because certain medications cause dizziness or unsteadiness.

Let us know if you:

- Need help walking.
- Need a wheelchair.
- Have fallen in the last year.
- Have stumbled, tripped, felt dizzy, off balance, unsteady on your feet, or have felt weakness in your legs.
- Notice slippery, wet floors, or torn or lifted carpet in the clinic.
- If you fall or appear unsteady at Fred Hutch, staff may offer you a wheelchair or use a mechanical lift with a sling to transfer you.

What you can do at home

Use this checklist to help you prevent falls at home.

Floors

☐ Clear pathways of furniture and clutter.

☐ Remove rugs if possible. If not, secure with double-sided tape.

☐ Coil or tape cords against the wall.

Stairs and steps

☐ Remove objects from the stairs.

☐ Fix loose or uneven steps.

☐ Install overhead lighting at the top and bottom of the stairs.

☐ Firmly attach carpet to each step.

☐ Fix loose handrails or add new ones on each side of stairs.

Kitchen

☐ Move common items to lower shelves.

☐ Use a step stool with a hand bar. Never use a chair.

Bathrooms

☐ Use a non-slip rubber mat or self-stick strips on the floor of the tub or shower.

☐ Install grab bars inside the tub and next to the toilet.

Bedroom

☐ Place a lamp within reach of the bed.

☐ Add a night-light by the doorway.

General

☐ Use furniture with higher seats and armrests. These are easier to sit down and stand up from safely.

☐ Wear closed-toed, closed-heel, non-slip footwear around the house.

Other helpful tips

- Be honest with your care team. Tell them right away if you have slipped, tripped, or fallen. They can help you create a plan to prevent falls.
- Exercise can help build your strength and stamina. Ask your care team for a referral to physical therapy (PT). PT can discuss what exercise is safe for you and how to safely use a walker or cane.
- Get your vision checked.

Fatigue

Fatigue is one of the most common symptoms experienced by people with cancer. Fatigue is described as a lasting tiredness that gets in the way of normal life activities. Fatigue may continue long after cancer treatment is completed. If you are experiencing fatigue, it is important to talk to your team so they can help you cope with it.

What causes fatigue?

There are several possible causes for fatigue, including:

- Cancer treatment or other medications
- Cancer itself
- Poor sleep habits
- Stress
- Lower than normal number of circulating red blood cells (anemia)
- Decreased nutrition
- Nausea and vomiting
- Diarrhea
- Mouth sores

When to get help

Call 911 immediately if you are a caregiver and you:

- Cannot wake the patient

Call the clinic or the after-hours clinic now if you experience:

- Dizziness or confusion
- Difficulty catching your breath
- Too tired to get out of bed or walk to the bathroom
- Significant increase in fatigue
- Increased weakness
- Drowsiness
- Loss of balance

What you can do at home

- Exercise
  - The best way to lessen fatigue is exercise. If possible, exercise 3 to 5 hours per week. It doesn't need to be done all at once. You can exercise for 10 to 15 minutes at a time. This can be especially helpful when fatigue is severe. Ask your care team what type of exercise is best for you.
- Conserve energy:
  - Engage in light activity, like taking a walk, each day. Avoid overexerting yourself.
  - Take rest breaks throughout the day.
  - Plan activities, such as exercise, visits, or trips when you are feeling the most rested and energetic.
  - Organize work centers so that equipment is within easy reach.
  - Ask people to help. It helps you get tasks done and it makes those who want to help feel useful.
  - Arrange your household so that most activities can be done on one floor.
  - Plan activities that allow you to sit or lie down.
  - Wear a hip sack, carpenter's belt, or jacket or sweater with pockets to carry things.
  - Eat snacks between meals to keep up energy.
- Create regular rest and sleep routines:
  - Set up a regular daily schedule for sleep and wake times.
  - Avoid long naps during the day. Limit naps to 1–2 hours.
  - Play soft music, read, or mediate or pray.
  - Avoid watching TV or using your cell phone before bedtime.
  - See the Sleep Problems symptom sheet in this manual for more tips on healthy sleep routines.
- Keep a diary to monitor your fatigue levels. Take note of what you think may be causing increased fatigue.

Fever

You may experience fevers and/or chills throughout your illness and treatment. Fever and chills are signs of possible infection. You are at a high risk of fever after chemotherapy, radiation, and while on immunosuppressive medications. It is important to contact your care team right away if you develop a fever and/or chills because your body cannot fight infection when your number of white blood cells is low.

What causes a fever?

- Cancer treatment
- Cancer
- An infection

When to get help

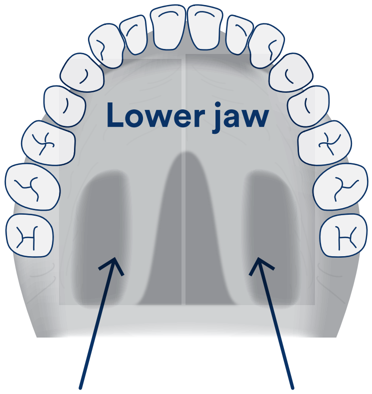
If you develop a fever, talk to your care team before taking any medications to bring down the fever (like acetaminophen [Tylenol®] and ibuprofen [Advil® or Motrin®]).

Call the clinic or the after-hours clinic now if:

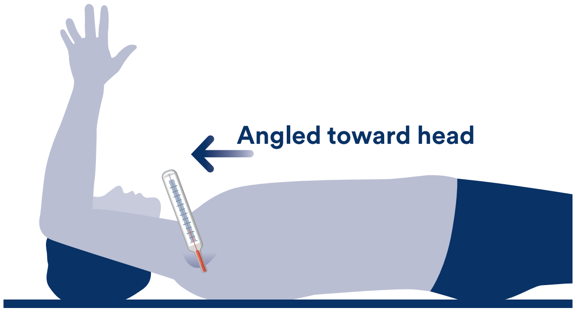
- Temperature taken by mouth is between 38 to 38.2°C (100.4 to 100.8°F) for one hour or more, or a temperature that is 38.3°C (100.9°F) or above
- Temperature taken under the arm is between 37.5 to 37.7°C (99.5 to 99.9°F) for one hour or more, or a temperature that is 37.8°C (100°F) or above
- Chills or shaking chills (even if temperature is normal)
- Cold symptoms (runny nose, stuffy nose, watery eyes, sneezing, coughing)
- New or worsening redness or swelling
- New or worsening pain, including in your belly, back, sinuses or mouth

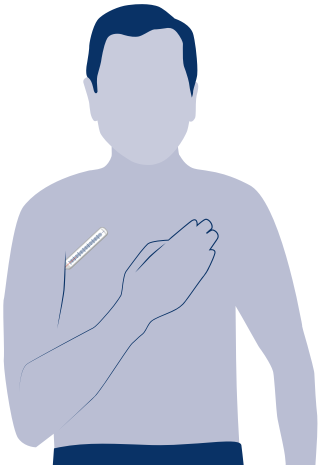
What you can do at home

- Monitor your temperature as directed by your care team.
- Taking your temperature orally (by mouth) is preferred.
  - o The best way to take your temperature is to place the thermometer into your mouth under your tongue in the sublingual pockets and keep your mouth closed. The sublingual pockets are in the lower jaw, under the tongue (see picture). If you have any questions, please ask your care team.



  - o To use an under-the-arm thermometer, lift your arm up. Place the tip of the thermometer as high up as possible in the middle of your armpit. Make sure the skin in your armpit completely surrounds the tip of the thermometer. Lower your arm snugly by your side (see picture).





  - o Temporal (touch/scan) thermometers are not preferred as temperature can vary based on how or where it is taken.
  - o Do not take rectal temperature as the thermometer may cause injury.
- Clean thermometer after each use with soap and water. You can clean it with an alcohol-based cleanser instead, if preferred.
- Keep a record of your temperature readings.

Conversion Chart for Temperature Taken by Mouth

Do not take acetaminophen (Tylenol®) or ibuprofen (Advil®, Motrin®) unless instructed by your care team. Call for chills or shaking chills, with or without a fever.

°F	°C		Directions for oral temperature (taken by mouth)
96.8	36.0	⬜	96.8 to 99.2°F (36.0 to 37.3°C) This is the normal temperature range. **Call for chills or shaking chills.**
97.8	36.6	⬜	
98.0	36.7	⬜	
98.2	36.8	⬜	
98.4	36.9	⬜	
98.6	37.0	⬜	
98.8	37.1	⬜	
99.0	37.2	⬜	
99.2	37.3	⬜	
99.4	37.4	🟨	99.4 to 100.3°F (37.4 to 37.9°C) Re-check in 30 to 60 minutes for a temperature in this range. **Call for chills or shaking chills.**
99.6	37.6	🟨	
99.8	37.7	🟨	
100.0	37.8	🟨	
100.2	37.9	🟨	
100.3	37.9	🟨	
100.4	38.0	🟥	100.4 to 100.8°F (38.0 to 38.2°C) **Call for chills or shaking chills.** **Call when temperature is in this range for 1 hour or more.**
100.6	38.1	🟥	
100.8	38.2	🟥	
100.9	38.3	🟥	Greater than or equal to 100.9°F (38.3°C) **Call when temperature is this high or higher.**
101.0	38.3	🟥	
101.2	38.4	🟥	
101.4	38.6	🟥	
101.6	38.7	🟥	
101.8	38.8	🟥	
102.0	38.9	🟥	
103.0	39.4	🟥	
104.0	40.0	🟥	
And above			

Hand-foot syndrome (HFS)

HFS is a skin reaction that often affects hands and feet, although it can also affect other areas where there is increased pressure or warmth, like the buttocks, groin, armpits, or under the breasts.

What causes hand-foot syndrome?

- Certain chemotherapy medications

When to get help

Call the clinic today or after-hours clinic now if you experience:

- Tenderness, swelling, redness or darkening on your palms or the soles of your feet; this can look like a sunburn
- Dry, peeling, cracking, or blistering on the skin of your palms or soles of your feet
- Numbness, burning, or tingling sensation in your hands or feet

What you can do at home

Prevent dryness and irritation:

- Apply unscented moisturizer that does not contain alcohol to your hands and feet often, especially in the creases. Examples include Bag Balm, Udderly Smooth Cream, lanolin creams (unless you're allergic to wool), Aveeno cream, Eucerin cream, and Lubriderm.
- Avoid heat. Bathe or shower in lukewarm water. Soak hands and/or feet in basins of cold water for 15 minutes, 3 to 4 times per day when possible. Take cool baths and put gel ice packs on affected areas.
- Avoid activities that cause irritation due to even slight rubbing or pressure on the skin. For example, avoid vigorous washing, gripping tools, typing, driving, playing musical instruments. Do not apply any adhesives or bandages such as band-aids because the adhesive (sticky part) will further irritate your skin.
- Avoid any unnecessary and vigorous exercise.
- Sit or lie on padded surfaces of chairs or mattresses. Raise your legs under cushions whenever possible.

- Place a pillow between your knees or wear pajamas if your legs rub together when you sleep.
- Avoid tight fitting shoes or gloves.
- Wear loose fitting clothing and shoes with comfortable soles. Do not walk barefoot.

Manage symptoms if they start

- Place palms or bottoms of feet on an ice pack or a bag of frozen peas to provide temporary relief of pain and tenderness. Alternate on and off for 15–20 minutes at a time. You may use gel insoles that can be cooled before putting them in your shoes.
- Apply moisturizer after the area has been cooled to increase your comfort.
- If your provider suggests a steroid cream, apply it after the skin has been cooled. Apply lotion over the top of the steroid cream to increase its effectiveness.
- If you develop blisters or open sores, apply gentle moisturizers on your hands and feet and contact your care team. They may suggest other treatment.
- Talk with your care team about how to change your activities of daily living (bathing, dressing, etc.) if the HFS is severe.
- Contact your care team about other over the counter (non-prescription) or prescription options to relieve your symptoms.

Low white blood cell counts (neutropenia)

White blood cells (WBCs) help protect your body from infections caused by bacteria, viruses, fungi and parasites. Neutrophils are a type of white blood cell (WBC) that are especially important because they are the first cells to respond to infection. When your neutrophil level is low, it is called neutropenia. When you have neutropenia, your body is more likely to get an infection.

Neutropenia often occurs several days after you receive cancer treatment. Your care team will tell you when your white blood cell count is likely to be at its lowest. During this time, you should carefully watch for signs and symptoms of infection that are listed below.

What causes neutropenia?

The common causes for neutropenia in people with cancer include:

- Certain diseases, including cancer, HIV, and hepatitis
- Cancer treatments, such as chemotherapy, radiation, immunotherapy, and targeted therapy

How do you test for neutropenia?

A blood test checks your absolute neutrophil count (ANC). If your ANC is below a certain level, you are considered to have neutropenia. If you have severe neutropenia, even a minor infection can become serious quickly. See chart below for details.

If your absolute neutrophil count is…	It is considered to be…
Between 2,500 and 6,000 cells/microL (written as 2.5–6.0 in our system)	Normal range for a healthy person
Less than ("<")1500 cells/microL (written as 1.5 thousand/microL in our system)	Mild neutropenia
<1000 cells/microL (written as 1.0 thousand/microL in our system)	Moderate neutropenia
<500 cells/microL (written as 0.5 thousand/microL in our system)	Severe neutropenia

When to get help

Call 911 immediately if you experience:

- Severe trouble breathing or patient is not breathing
- Chest pain
- You cannot wake the patient
- Signs of sepsis including:
    - Light-headedness
    - Pale, cold, or moist skin
    - Thirst
    - Rapid pulse

Call the clinic or after-hours clinic now if you experience:

- Temperature taken by mouth between 100.4–100.8°F (38-38.2° C) for one hour or more, or a temperature that is 100.9°F (38.3°C) or above
- Temperature taken under the arm between 99.5–99.9°F (37.5-37.7° C) for one hour or more, or a temperature that is 100° F (37.8°C) or above
  If you develop a fever, talk with your care team before taking any medications to lower your fever (such as acetaminophen/Tylenol® and ibuprofen/Advil®, Motrin®)
- Chills or shaking chills even if your temperature is normal
- Sore throat or new cold symptoms (runny nose, stuffy nose, watery eyes, sneezing)
- A general feeling of tiredness, unusual fatigue, or "flu-like" symptoms
- Change in cough or new cough
- Shortness of breath
- Stiff neck
- Diarrhea
- Vomiting
- New or worsening pain
- Painful or frequent urination
- Unusual vaginal discharge or irritation
- Rash or other skin changes
- Redness, soreness, or swelling in any area, including mouth, surgical wounds, central lines, and ports
- Changes in mental status

If you have to go to the emergency room

Tell emergency room staff right away that you are receiving chemotherapy or cancer treatment. Fevers and infections can become serious very quickly. You should be evaluated as soon as possible.

What you can do to help prevent infection

There is not much you can do to prevent neutropenia from occurring, but you can decrease your risk for getting an infection while you have it by following these guidelines.

Personal care

- Clean your hands frequently using soap and water or hand gel.
- Avoid crowded places and contact with people who are sick.
- Brush your teeth after each meal and at bedtime with a soft bristle toothbrush. Avoid using mouthwashes that contain alcohol or peroxide, which may dry and irritate your gums and the tissue in your mouth. Your care team may recommend saline rinses to prevent mouth sores.
- Do not share food, drink cups, utensils or other personal items, such as toothbrushes.
- Shower or bathe daily.
- Keep your skin clean and try to avoid cuts and scratches.
- Use unscented lotion for dry skin as needed to prevent your skin from becoming dry and cracked.
- Avoid smoking tobacco and cannabis products.
- Get the seasonal flu shot if recommended by your care team.

Food safety

- Cook meat and eggs all the way through to kill any germs — refrigerate leftovers within 2 hours. For more information on Food Safety, read the Food Safety section of this manual or watch the Food Safety video at FredHutch.org/food-safety-video or by scanning the QR code.
- Carefully wash raw fruits and vegetables — avoid salad bars, buffets, deli counters, bulk foods.

At home

- Monitor your temperature as directed by your care team. Read the Fever symptom sheet in this manual.
- Try and keep all your household surfaces clean — best to use bleach-based solution. To make this yourself, mix 4 teaspoons bleach with 1 quart (4 cups) water. Remake this solution daily.

- Avoid housework that may disturb dust or mold — try to have this cleaning done while you are outside of the home if possible.
- Avoid direct contact with a child or pet's bodily waste (urine, feces or vomit). If unable to do so, protect yourself by wearing vinyl or household cleaning gloves when cleaning up after your child or pet. Wash your hands immediately afterwards.
- Avoid gardening and fresh flowers or plants in the home because they can carry bacteria and fungus that can cause infection.
- Keep fans and air conditioners clean, and change air conditioning filters regularly.
- Avoid room humidifiers because bacteria can grow in water.
- Avoid swimming in recreational water — public pools, hot tubs, lakes, ponds, and the ocean.

Memory and concentration problems

Many people experience problems with memory and concentration during or after cancer treatment. These are called cognitive problems. A common term used to describe cognitive problems is “chemo brain” or “brain fog.”

What causes memory and concentration problems?

- Cancer and its treatment
- Side effects of cancer treatment such as pain, fatigue, sleep disturbance, depression, or anxiety
- Ongoing medical conditions, such as vitamin deficiencies and anemia

When to get help

Call the clinic or after-hours clinic now if you experience:

- Feeling disoriented or confused
- Difficulty concentrating on tasks
- Feelling distracted
- Slowness in thinking
- Memory problems
    - More forgetful in daily life, for example: forgetting where personal items, like keys or wallet are; forgetting appointments or tasks; forgetting the reason for going into a room
    - Trouble recalling details of recent conversations or events
- Difficulty finding words while talking or writing
- Trouble with decision-making or problem-solving

What you can do at home

- Keep items that you use a lot, like keys or wallet, in a designated spot in your home.
- Keep an appointment calendar in a planner notebook or on your computer or smart phone.
  - Use your smart phone or another device to sound an alarm when you need to do an activity or be someplace.
- Take breaks in between physical or demanding activities, so that you can get enough rest and maintain a good level of energy throughout the day.
- Prioritize activities. Identify what you must get done in the day in case you become too tired to complete other activities.
- Do one task at a time and keep distractions to a minimum, for example do important tasks in a quiet room.
- If needed, set an alarm to remind you when to take medications.
- Practice good sleep hygiene. Read the Sleep Problems symptom sheet in this manual.
- Manage stress by listening regularly to a relaxation recording or taking a meditation or yoga class.
- Keep your mind active.
- Socialize with friends and family.
- Read — join a book club or go to a book reading.
- Play challenging games, such as sudoku, card games, crossword puzzles.
- Take in-person or online continuing education classes.
- Try to learn new hobbies.
- Learn a new language.
- Exercise, but talk to your care team before starting an exercise routine.
- Eat a well-balanced diet.
- Be kind to yourself — changes are a normal part of cancer treatment.

Mucositis

Mucositis is inflammation or swelling of your mouth and gastrointestinal (GI) tract. Mucositis can lead to mouth pain, sores, or bleeding in your mouth. It can also cause thick saliva. Your experience may vary from mild discomfort to severe pain, which can make eating, drinking, and sleeping difficult. When severe, mucositis can increase your risk of infection. If you experience mucositis, it is important to notify your care team to discuss treatment strategies.

What causes mucositis?

- Chemotherapy
- Immunotherapy
- Radiation

When to get help

Call 911 immediately if you experience:

- Difficulty breathing
- Patient is not breathing

Call the clinic or after-hours clinic now if you experience:

- Pain that is not controlled by medication
- Redness or swelling in your mouth
- Bright red blood in your mouth
- White patches or sores on your gums or mouth
- Difficulty swallowing food or fluids
- Pain when eating or drinking

What you can do at home

Prevent infection and irritation

- Use a saltwater solution every 1–2 hours and before eating, drinking or taking medications by mouth to prevent infection, irritation and reduce thick secretions. You can use the solution as a rinse, freeze it into ice cube trays and suck on the ice, or freeze it in a cup and eat is as a slushy. Whichever you choose, spit secretions out often and especially before eating, drinking or taking medications by mouth.
    - o To make the saltwater solution: Mix 4 cups (32 ounces) of water with 3/4 teaspoon salt. If you have thick secretions in your mouth or the solution causes stinging or burning, add 1 tablespoon of baking soda to the solution.
- Brush your teeth twice a day with a very soft bristle toothbrush. If it becomes too painful or you bleed a lot, use a child's toothbrush. If toothpaste hurts your mouth, you may brush without it.
- Continue to floss daily as long as it is comfortable, and no significant bleeding occurs.
- Avoid using mouthwashes that contain alcohol or peroxide or are highly flavored. These can dry and irritate your gums and mouth tissues.

Control pain

- Your provider may prescribe pain medication, including a topical pain reliever or oral rinse to help numb and soothe your mouth. Take pain medication as prescribed. All oral rinses can be kept in the refrigerator or placed in an ice bath. This can be soothing and help reduce swelling or control bleeding.
- Apply lanolin creams or lip balms to chapped lips. Avoid Vaseline as it can increase dryness.
- Place ice packs on painful areas such as cheeks or lips for 10–15 minutes every 2 hours.
- Avoid hard, crunchy, spicy, and acidic foods. Hot foods may also be difficult to eat.

Stay nourished and hydrated

The following foods and drinks may feel good on your gums and mouth:

- Warm fluids: Soups, chicken or vegetable broth, tea
- Cool fluids: Smoothies, shakes, iced tea, ice water, diluted juices, popsicles

A Fred Hutch dietitian can help you create a list of other foods and drinks to try.

Nausea and vomiting

What are nausea and vomiting?

Nausea is a feeling of sickness of the stomach that often makes you lose your appetite. Nausea and vomiting are common side effects of many cancer treatments. These side effects can affect your quality of life and overall well-being and may lead to dehydration (loss of fluids).

You may experience nausea and vomiting at some time during your treatment. If you do, it is important to tell your care team. They can give you advice on how to maintain your nutrition and fluid intake and feel comfortable.

What causes nausea and vomiting?

- Chemotherapy and other medications
- Constipation
- Radiation
- Pain that won't stop
- Poor kidney and liver function
- Infections of the gastrointestinal tract
- Abnormal blood chemistry, such as high or low potassium, magnesium or calcium
- Graft-versus-host disease

When to get help

Call 911 immediately if you experience:

- Vomiting that leads to choking or difficulty breathing

Call the clinic or the after-hours clinic now if you experience:

- Uncontrolled (constant) nausea and vomiting:
  - Even though you're taking your anti-nausea medications
  - That gets in the way of your ability to eat or drink
  - That suddenly gets worse
- Projectile vomiting
- Blood or "coffee ground" appearing material in your vomit
- Medicine coming out in your vomit

- Weakness or dizziness
- Severe stomach pain
- Side effects from nausea medications that bother you
- Nausea that interferes with your ability to eat

What you can do at home

Prevent nausea and vomiting or manage symptoms

- Take your anti-nausea medicine as instructed.
    - Some anti-nausea medicines can cause sleepiness. Do not drive a car or operate any dangerous equipment if you feel sleepy. Consider having a caregiver/family member stay with you throughout this treatment period.
    - Do not drink alcohol while taking anti-nausea medicines. Alcohol can increase sleepiness.
    - Notify your care team if you continue to have nausea or vomiting after taking your anti-nausea medication. Do not change the amount of medication or take any new medications before speaking with your care team.
- Wear loose fitting clothes.
- Sit up after eating. Keep your head elevated for 30 to 60 minutes after eating.
- Lie down in a quiet place for 15–20 minutes and relax.
- Use distraction, relaxation, or deep-breathing techniques. Take a few slow deep breaths in through your nose and out through your mouth.

Maintain nutrition and fluid intake

- Eat small meals during the day to avoid feeling too full. Keeping a small amount of food in your stomach may also help prevent nausea.
- Eat and drink slowly so only small amounts enter your stomach at one time.
- Avoid eating your favorite foods when feeling nauseated so you don't develop a dislike for them.
- Avoid foods that are very sweet. Avoid fatty, fried, greasy, or strongly spiced foods.
- Eat low-fat, plain, and salty foods; these usually work best.
- Keep crackers at your bedside if nausea is a problem in the morning or after a nap.

- Drink cool, clear beverages. Drink between meals, rather than with meals. Slowly drink or sip liquids throughout the day — a straw may help.
- Avoid odors that bother you. If food smells make you sick, avoid being in the kitchen when food is being prepared.
- Avoid food served at extreme temperatures.
- Keep a wide range of foods available.
- Choose foods that are easy to digest such as yogurt, smoothies, broth, toast, and bananas. A Fred Hutch dietitian can help you create a list of other foods and drinks to try.

Pain

What is pain?

Pain is an unpleasant sensation that only you can feel. You may experience pain during your illness. Your care team will help you find the best way(s) to manage your pain based on what's causing it and where it is in your body.

A change or increase in pain does not necessarily mean that your cancer has returned or is progressing. On occasion, your care team may refer you to a physician who specializes in managing pain for people with cancer.

What causes pain?

- Cancer
- Side effects of cancer treatment
- Medical problem not related to cancer
- Acute injury (a sudden and severe injury, like a broken bone)

When to get help

Call 911 immediately if you experience:

- New severe pain
- Severe squeezing, pressure, or pain in your chest
- Severe sudden headache
- Unable to stay awake
- Patient is unconscious
- Weakness in your lower legs or loss of bowel or bladder control

Call the clinic or after-hours clinic now if you experience:

- New pain, pain that is getting worse, pain that isn't controlled
- New headache
- Burning in chest or stomach
- Pain (burning, stinging, aching), swelling or redness around your central line

- Irregular or pounding heartbeat
- Pain or burning when you pee
- Side effects of your pain medications that bother you, such as sleepiness, confusion or nausea
- Nausea/vomiting prevents you from taking pain medications

What you can do at home

- Take your pain medications as prescribed. These medications may include:
  - Over-the-counter medications
  - Prescribed opioid or non-opioid medications

  Do not take over the counter medications without talking to your care team first

  Remember to always follow the treatment plan. Take medications as prescribed and keep track of when you take them. Do not increase your dose of medication without talking to your care team first.
- Find a relaxation technique that works for you, such as meditation, guided imagery, hypnosis, listening to relaxing music, or massage.
- Continue activities that are meaningful to you. These activities may help you notice less pain or discomfort.
- Get enough sleep, eat a balanced diet, and exercise (if you can safely do this). These activities may improve your pain or your perception of the pain. For the same reasons, talk with your care team if you need more emotional support; not treating depression and anxiety may make your pain worse.
- Keep a pain journal. Write down the level of your pain intensity (0–10, with 10 being the worst pain) and the time and date you had it, as well as anything that makes your pain better or worse. Share this information with your care team.
- Before taking pain medication or opioids, ask your care team about ways to prevent constipation.
- Communicate openly with your care team about what is working or not working to manage your pain. It is our goal at Fred Hutch to provide you with the best possible treatment of your pain.
- Talk to your care team if you would like a referral to a Fred Hutch physical therapist, acupuncturist, or integrative medicine specialist.

Myths about opioids

- Some people think they will become addicted to opioids. Research has shown that although this can occur, it is very rare to get addicted to opioids if you use them exactly the way your care team prescribes them.
- Some people do not want opioids because they fear the side effects. Nausea, vomiting, sleepiness, constipation, and itching are common side effects, but they often get better the longer you take opioids or by adding other treatments. They can sometimes also be managed by changing your medication. Talk to your care team about ways to manage these side effects.

Resources

To learn more about pain and how to manage it:

- Watch these videos at FredHutch.org/patient-education-videos:
  - Pain: During and After Cancer Treatment
  - Mind-Body Relaxation Techniques
- Follow the instructions in Acupressure for Pain: FredHutch.org/acupressure-for-pain

Acupressure is a practice of Traditional East Asian Medicine that stimulates the same system of acupoints used with acupuncture, but you use your hands instead of needles. Acupressure has been used for thousands of years. You can do acupressure on yourself at any time, especially when you're experiencing certain side effects, such as nausea, vomiting, anxiety, stress, fatigue, and pain.

Peripheral neuropathy

Peripheral neuropathy is a nerve problem that impacts your sensory and motor nerves. If your sensory nerves are affected, you may have numbness, tingling, or burning sensations in your arms or legs. If your motor nerves are affected, you may have muscle weakness, cramping, or twitching.

Peripheral neuropathy usually begins in the hands or feet and gets worse over time. When you have peripheral neuropathy, you have a greater chance of injuring yourself.

What causes peripheral neuropathy?

- Some chemotherapy medications
- Other cancer treatments, like surgery or radiation
- Tumors pressing on nerves
- Infections that affect the nerves
- Spinal cord injuries
- Diabetes
- Alcohol abuse
- Shingles
- Low vitamin B1 (thiamine), B6 (pyridoxine), and B12 (cyanocobalamin) levels
- Some autoimmune disorders
- HIV (human immunodeficiency virus) infection
- Poor circulation (peripheral vascular disease)

When to get help

Call 911 immediately if you experience:

- Your legs won't move

Call the clinic or after-hours clinic now if you experience:

- A fall
- Sensation symptoms that are getting worse (pain, numbness, burning, tingling, etc)
- You can't control your muscles; for instance muscle twitching, cramping, foot drop (can't lift the front part of your foot), or muscle atrophy (loss or thinning of muscle)

- Abnormal blood pressure or symptoms of abnormal blood pressure, such as blurred vision and dizziness
- Changes in your bladder and bowel function (how you pee and poop)

What you can do at home

- Prevent falls
    - Always wear shoes and slippers that cover your whole foot when walking, even when at home.
    - Clear walkways, including stairwells, of objects that you could trip over such as small rugs, toys, or clutter.
    - Be careful of slippery, wet floors in the bathroom or kitchen areas of your home.
    - Be sure that you have ways to support yourself if you have problems with stumbling while walking. Handrails in hallways and bathrooms may help you keep your balance. A walker or cane can give you extra support.
- Wear clothing to protect your skin. Wear gloves when you clean, work outside or do repairs. Keep your hands and feet warm and well covered in cold weather. For example, consider keeping a pair of gloves in your car. Avoid extreme temperatures.
- Be careful when using hot, cold, sharp or potentially harmful objects, like scissors and knives. Use them only when you can give your full attention to the task.
- Protect yourself from heat injuries. Use hot pads when handling hot dishes, racks, or pans. Set hot water heaters between 105° to 120°F to reduce the risk of burning while bathing or washing your hands.
- Check your feet daily, looking carefully at your toes and the bottom of your feet for any injuries or open sores.
- Keep fingernails short to avoid tearing.
- Keep hands moisturized to prevent your skin from cracking from dryness.
- Use night lights or flashlights when getting up in the dark.
- Walk and stretch your arms and legs to help keep your muscles flexible.
- Gentle foot and hand massages can help relieve stiffness and discomfort.
- If you are not able to exercise, have fallen, or need assistance with walking, please talk to your care team about a referral to physical therapy.
- See the Fall prevention symptom sheet in this manual to learn more about how you can prevent falls.

Sexual health

What is sexual health?

Sexual health is how a person sees, feels, and thinks about themselves as a sexual being and their overall body image. It includes the unique ways a person expresses themselves sexually, including their behavior and relationships. It is deeply personal and varies among individuals.

What causes sexual changes and what type of changes might I experience?

Many things can impact your experience of intimacy and sexuality, including illness or any treatment that can change the way you look or feel. Some changes to your sexual health may be temporary while others are permanent. You may experience:

- Lack of sexual desire (also called lack of libido)
- Pain during sex
- Problems having an orgasm
- Physical changes in your body, including vaginal dryness or inability to get an erection

When to get help

Call the clinic if you experience:

- Pain, discomfort, or bleeding during or after sex
- Fear or anxiety about participating in sexual activities
- Lack of sexual desire that affects your relationship(s)
- Vaginal dryness, discharge, pelvic pain, or menopausal symptoms such as hot flashes or loss of menstrual cycle
- Pain during penetration or ejaculation, abnormal discharge, changes in your ability to get erections or ejaculate

What you can do at home

Pregnancy and cancer treatment
Cancer treatment can have harmful effects on pregnancy. If there is a chance you or your partner could become pregnant while undergoing cancer treatment, talk with your care team about birth control. Birth control (also known as contraception) is the use of any method, medicine, or device to prevent pregnancy.

Optimize positive feelings of intimacy

- Plan sexual activity for the time of day when you are feeling best. If you are taking pain medication, take it as prescribed so it will be in full effect during sex.
- Keep an open mind about the possibility of needing to adjust to physical and emotional changes that may affect how you feel about yourself.
- Talk with your partner(s) about what might feel good, what to avoid or if any kinds of touching causes irritation or pain.
- Consider other forms of intimacy—holding hands, snuggling, kissing, self-stimulation, and talking is safe at any stage of cancer treatment.
- Find a position or activity that puts as little pressure as possible on the sensitive or painful areas of your body.
- Use a water-based sexual lubricant to help dry skin areas be slippery and less painful.

Prevent infection

- Wash hands and genitals with fragrance free soap before and after any type of sexual activity.
- Pee before and after sex. This rinses out bacteria that may cause infection in the urinary tract.
- Use a water-based lubricant to keep the vagina, penis, or rectum from becoming irritated.
- If you have anal sex, use condoms and a water-based lubricant to help prevent infection and tissue irritation.
- Avoid sexual contact with people who have infectious diseases (colds, flu, cold sores) or sexually transmitted infections. Talk to your care team about avoiding intercourse when your white blood cell counts or platelets are low.

- Use a condom or other barrier protection during sexual activity to reduce the risk of infection. This includes oral, anal, and vaginal sex.

Why don’t I have much sexual desire?

Lack of desire and fatigue can be a normal response to the stresses of treatment, some medications, and changes in hormone levels.

Talking to your partner(s) or a therapist may help, and sometimes hormone replacement can be helpful. Talk with your care team so they can help you find what will work for you.

Other resources

Sexual intimacy products
Fred Hutch’s cancer specialty store, Shine, has trained staff to help you identify which products are most appropriate for you. Call (206) 606-7560 for more information or visit Shine’s website at FredHutch.org/Shine.

Brochures and books

Below are some recommended books that may be available at your local library, ordered through your local bookstore or purchased online.

- **Man Cancer Sex** by Anne Katz
- **Woman Cancer Sex** by Anne Katz
- **This Should Not Be Happening: Young Adults with Cancer** by Anne Katz
- **Intimacy After Cancer: A Woman’s Guide** by Sally Kydd and Dana Rowett
- **One Hundred Questions and Answers about Erectile Dysfunction** by Pamela Ellsworth
- **The Monster Under the Bed - Sex, Depression and the Conversations We Aren’t Having** by JoEllen Notte

Websites

Fred Hutch Education

- Sexual health handout
  FredHutch.org/sexual-health
- Vaginal dryness handout
  FredHutch.org/vaginal-dryness

LIVESTRONG

livestrong.com/sscat/sexual-health

American Cancer Society

- How cancer affects sexuality
  bit.ly/acs-cancer-and-sexuality
- Sex and the adult male with cancer
  bit.ly/acs-male-sexuality-cancer
- Sex and the adult female with cancer
  bit.ly/acs-female-sexuality-cancer

Look Good Feel Better

lookgoodfeelbetter.org

Fertility and cancer

What is fertility?

Cancer treatments can affect your fertility during and after treatment is complete. Fertility preservation is the process of saving or protecting eggs, sperm, or reproductive tissue so that a person can use them to have biological children in the future. It is important to understand your risks of infertility and options for preserving your fertility before you start treatment. A reproductive specialist can help you understand both.

Risk factors

Factors that affect your risk for infertility include:

- Age
- Type of cancer
- Type of treatment, such as surgery, chemotherapy, radiation or transplant
- Dose of treatments
- Previous chemotherapy or radiation exposure

How do cancer treatments affect fertility?

People who ovulate (when an egg is released from an ovary as part of the menstrual cycle):

- Often stop ovulating during and after treatment for a period of time
- May need to use medication that prevents ovulation for many years after treatment
- May go into early menopause

People who generate sperm:

- Often stop making sperm completely
- Often have very low sperm counts during and after treatment

Cancer treatments do not always affect fertility. To prevent pregnancy, use birth control during your cancer treatment and for at least 6 months after treatment is complete.

Fertility preservation options

For people who generate sperm, sperm banking is the standard approach to fertility preservation. The simplest way is to collect ejaculated sperm, but other methods can be used. Sperm can be safely stored for many years for later use.

For people who ovulate, the standard approach is to surgically harvest mature eggs from an ovary. Before harvesting, people who ovulate take hormones for up to 2 weeks to mature the eggs. Eggs may be frozen unfertilized, or they can be fertilized (by partner or donor sperm) and stored as embryos. These eggs or embryos can be safely stored for many years until a pregnancy is desired. Adoption and other family-building options may also be available after cancer treatment.

Regaining fertility

A small percentage of people, usually of younger reproductive age, regain their fertility after treatment. This may take months to years and can be hard to predict for each person. A reproductive specialist can assess your fertility and tell you if fertility techniques might help you get pregnant after cancer treatment.

Meet with a reproductive specialist

Meeting with a reproductive specialist can help you learn about your fertility preservation options before treatment and fertility techniques that are available to you after treatment.

If you are a Fred Hutch Cancer Center patient and are interested in meeting with a reproductive specialist, speak with your oncologist for a referral or contact the Fred Hutch Oncoreproduction Clinic directly at (206) 606-4100.

Because the initial consultation is billed under the diagnosis of family planning, most insurance plans will cover it. If you have specific questions about your benefits, please contact your health insurance company directly.

Costs and financing

Insurance coverage for fertility preservation varies. Work with your reproductive clinic and health insurance company to determine what may or may not be covered and what the costs will be. Ask them about financial assistance programs such as Livestrong Fertility. For more information, go to livestrong.org/how-we-help/livestrong-fertility.

Additional Resources

The Oncofertility Consortium
oncofertility.msu.edu
Phone (517) 884 6434

Alliance for Fertility Preservation
allianceforfertilitypreservation.org

University of Washington Sperm Cryopreservation Program
Phone (206) 598-1001
faculty.washington.edu/cmuller/MFL

Save My Fertility
savemyfertility.org

University of Washington Reproductive Care
Phone (206) 598-4225
uwmedicine.org/locations/reproductive-care-uwmc-roosevelt

Male Fertility Lab/Men's Health Center
Phone (206) 598-6358
uwmedicine.org/locations/mens-health-center

Sleep problems and healthy sleep habits

What causes sleep problems?

- Side effects related to cancer and its treatment
- Medications for conditions that aren't cancer
- Hormonal changes, such as menopause
- Anxiety and depression
- Pain
- Restless leg syndrome
- Sleep apnea
- Lifestyle habits including caffeine (especially later in the day), not getting enough exercise or getting too much exercise before bed time, too much noise or screen time.

When to contact your care team

Contact your care team if you are having difficulty sleeping, including trouble falling asleep or waking up too early.

What you can do at home

Many people have problems sleeping. When you don't get good sleep, it can affect your quality of life and ability to do daily activities. Sleeping well on a regular basis is important for your health. By practicing a few good habits, you can improve the quality of your sleep

Create a peaceful sleep space

- Create an inviting and soothing sleeping space
- Keep it dark, quiet, and cool (less than 68°F)

Quiet your body

- Avoid caffeine 6 to 8 hours before bedtime
- Avoid moderate to intense exercise for a few hours before bedtime
- Make time to slow down — take a warm bath with Epsom salts and aromatherapy, write in a gratitude journal, do gentle yoga, meditate, practice intimacy
- Check to see if your medications have sleep side effects

Use dusk and dark

- Dim lights a few hours before bed; sleep in total darkness
- Use blue light reduction applications, devices, or screen protectors on your electronic devices (such as on your smartphone, tablet, computer screen, TV)
- Go to sleep and wake up at the same time every day

Recognize your wakefulness

- Go to bed only when you feel sleepy
- When you are ready to sleep, create separation from the waking world (avoid watching the clock or using electronic devices)
- If you can't sleep, get up and sit in a comfortable spot until you feel sleepy again. Try progressive muscle relaxation with soft belly breathing or another mind-body exercise

Surrender to sleep

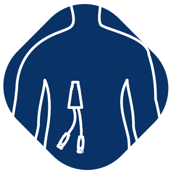
- Ask your primary care or integrative medicine provider if there are sleep aids that would be appropriate for you
- Instead of "going to sleep" think about "letting go of being awake"

Wake up mindfully

- Wake up slowly
- Notice your morning thoughts and memories of your dreams
- Set an intention for the day
- Turn on the lights, or use daylight or a light box to energize your morning

Resources

- Health Journey's guided imagery for sleep: healthjourneys.com
- American Cancer Society: Sleep Problems at cancer.org/treatment/treatments-and-side-effects/physical-side-effects/sleep-problems.html
- "Healing Sleep: Discover the Restorative Power of Sleep, Dreams, and Awakening" a book by Rubin Naimen, PhD



Central line care

What is a central venous catheter?

A central venous catheter is a small flexible tube inserted into a large vein in your chest. It is used to give you fluid, nutrients, medicine, and blood products. It may also be used to get blood samples. A central venous catheter is also called a central line, tunneled catheter, or central venous line. In this document, we will refer to it as a "central line." There are many types of central lines.

How is the central line placed?

Inserting the central line is a minor surgical procedure. It is done in a procedure suite or an operating room and takes about 1 hour. Your doctor will use local anesthesia to numb your neck and chest. You may also be sedated (given medication to make you sleepy).

During the surgery, your doctor will make 2 small incisions (surgical cuts). You will have 1 small incision at the bottom of your neck by your collar bone. This is where the central line enters your vein. The other incision will be in your upper chest. This is where the central line exits your body. The central line is threaded through a "tunnel" under your skin between these 2 sites. You will likely have a few stitches placed to help secure the central line. You will have a dressing (bandage) placed on top of each incision site.

A small cuff on the central line helps hold it in place in the tunnel underneath your skin. This cuff also acts as a barrier to help prevent bacteria on your skin from traveling up the central line tunnel and into your bloodstream.

Will it hurt?

Your shoulder and chest area may be sore for a few days after the central line is placed. You may be prescribed a mild pain reliever. It helps to move your shoulder and neck right after surgery to keep the area from getting stiff.

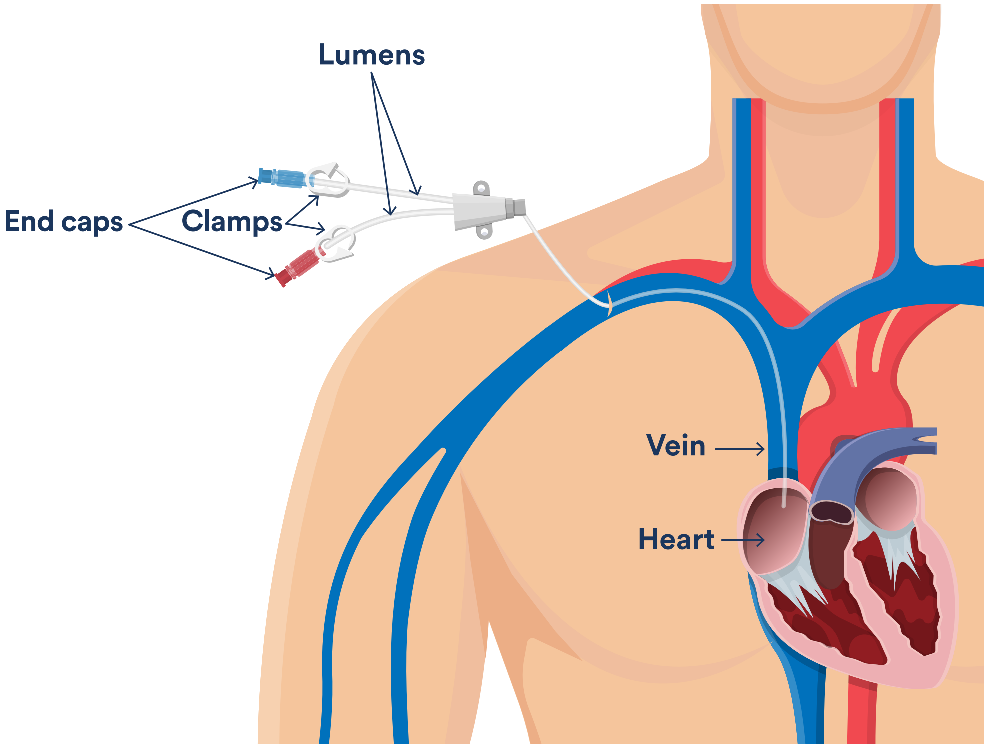
What instructions should I follow after my procedure?

- Do not take over-the-counter (non-prescription) pain medications, such as acetaminophen (Tylenol®) and ibuprofen (Advil®) without checking with your care team first.
- Secure the line by wearing a tight-fitting tank top/undershirt or sports bra for at least 1 night after placement.
- Do not lift anything heavier than 5 pounds for 3 days after your surgery. Do not participate in activities that use your chest muscles such as vacuuming, bowling, weightlifting, tennis, or golf while you have the central line. You may have sex, but do not pull on the catheter. If you have any questions about your activities, please ask your care team.

How do I care for my central line?

The day after your surgery, you will have an appointment to get your dressing (bandage) changed for the first time. The dressing will need ongoing care as long as you have the central line in place. This care is described in the next few pages.

Parts of your central line



Ongoing central line care

You will need to care for your central line daily to prevent infection. Care involves cleaning your central line, flushing your lumens (lines), protecting your central line from water, and changing your dressing. The chart below gives an overview of this care.

Central line care	How often
Clean central line • Use alcohol wipes • Change tape tabs, if using	Daily
Flush lumens	Daily or with each use
Protect line from water: • Put Parafilm® on end caps • Put AquaGuard® or Press'n Seal® over dressing	When bathing/showering
Change dressing	Every 7 days for Tegaderm® CHG or other clear dressing. Every 1–2 days for gauze and tape dressing

Supplies to care for your central line

Below are the supplies used to care for your central line. There are several ways to get them. You can:

- Buy the supplies with an asterisk (*) next to them at the Fred Hutch Pharmacy.
- Buy all of the items online.
- Buy Press'n Seal at the grocery store.
- Buy alcohol wipes, plastic tape, and gloves at most drug stores.

If you have any questions about which supplies you should buy, please ask your nurse.

Supplies

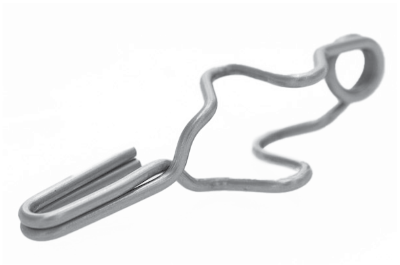

Parafilm*


AquaGuard* or Press'n Seal; you do not need both


Alcohol prep pads*


Plastic tape* —do not use paper, cloth, scotch, or masking tape


Clean medical gloves*


Cannula "Bulldog" clamp (Fred Hutch will provide this)


2 lanyards (Fred Hutch will provide these)


Cloth pouches (Fred Hutch will provide these)

Important notes on central line care

Keep your line safe

- Keep your bulldog clamp with you at all times. The bulldog clamp is a safety clamp. If the central line leaks, gets cut, or breaks, clamp the central line close to your chest and call the clinic immediately.
- Secure your central line to prevent accidental removal of the line by either:
  - Placing central line ends in a clean cloth pouch and securing the pouch with a bulldog clamp to clothing or a lanyard. Pouches are for one-day use and should be washed daily; **or**
  - Placing plastic tape tabs between clamp and cap on the central line and changing them daily. Use the plastic tape tabs and bulldog clamp to secure the central line to clothing or a lanyard.
- Always place central line clamp on the thick reinforced area of the line.

Protect your line from water

- Always cover your central line dressing with a plastic covering such as AquaGuard or Press'n Seal to prevent water from entering the dressing and exit site. The uncovered dressing and exit site should never come in contact with water.
- Always securely wrap your central line end caps with Parafilm to prevent water from entering the cap top or into the connection to the central line. If you notice moisture under the Parafilm, ask to have your end caps changed in the clinic.

Clean your line

- Clean your lumens once a day with alcohol wipes after your bath or shower. If using plastic tape tabs to secure your line, replace tape tabs each day.
- Your care team will tell you how often to change your dressing and if you will change it yourself or have it changed in the clinic.
- If your dressing starts to come off, gets wet, or if there is moisture underneath it, it needs to be changed. Ask to have your dressing changed in the clinic. You may change it yourself if you have been taught how to do this and have the correct supplies at home.

Do not

- Do not remove the end caps off your central line.
- Do not let end caps, central line, or dressing go under your bath water.
- Do not go into swimming pools and hot tubs.
- Do not store central line supplies in a moist (humid) area, such as the bathroom or kitchen.
- **Do not use scissors near your central line.**

Antibiotic infusions

If you are receiving antibiotics, your care team will instruct you to alternate your infusions of antibiotics between the lines of your catheter.

To watch videos on how to clean, flush, and protect your central line from water, visit FredHutch.org/patient-education-videos.

Cleaning your central line

It is important to clean your central line daily. This helps prevent infection. See instructions below for how to do this.

Supplies

- 4 or more alcohol wipes (use 2 per lumen)
- Plastic tape, if using

Instructions

1. If using tape tabs, remove plastic tape tabs. If not using tape tabs, go to step 2.
2. Use 2 alcohol wipes, 1 to hold the line and 1 to clean it. Start where the line exits the dressing and wipe towards the end cap. Using the same alcohol wipes, clean the clamps.
3. If using plastic tape tabs, replace them. Fold about ½ inch of tape over at each end to make the tab easier to remove.
4. Repeat this for each lumen.

Flushing your central line

When to flush your central line

- Flush each lumen with saline at least once each day.
- If you have a blood draw or infusion at the clinic, the central line will be flushed there. You do not need to flush it again at home.
- If you are doing an infusion at home:
  - o Flush the central line at the beginning of the infusion with saline.
  - o Flush the central line at the end of the infusion with saline.

How to flush your central line

Gather your supplies and then follow steps 1 through 9.

Supplies

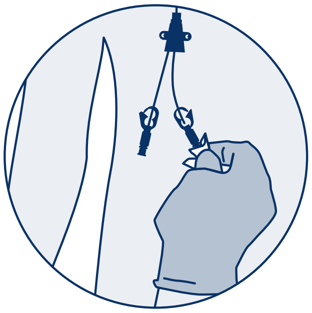
- 2, 10ml saline syringes*
- 2 alcohol wipes
- 1 pair of gloves

*You need a prescription for saline syringes.

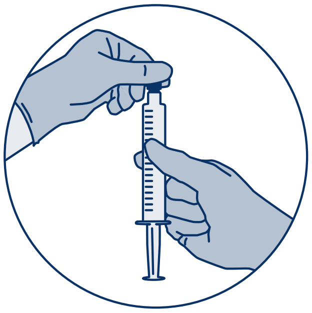
Instructions

1. **Wash your hands.**

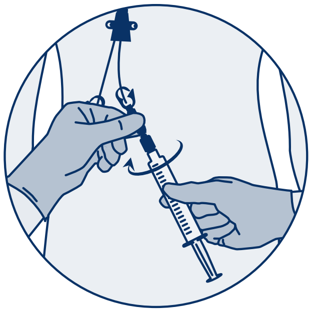
2. **Place all supplies on a clean surface.** Remove syringes from their packages by peeling the plastic downward.



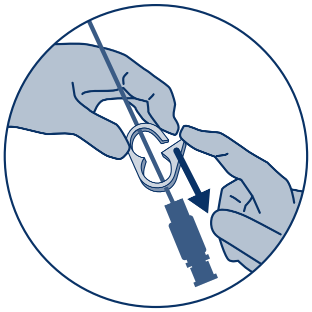
3. Put on gloves. Vigorously scrub the central line end cap with an alcohol wipe for 15 seconds (count one one-thousand, two one thousand, etc.) using a twisting motion as if you were juicing an orange. **Take special care to clean the tip of the cap.** Allow the cap to dry completely (at least 5 seconds).



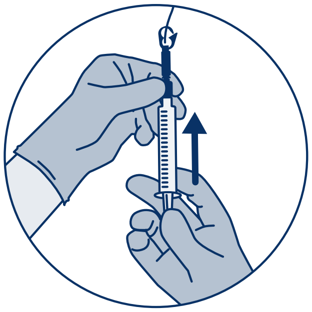
4. Hold the saline syringe with the cap on, pointed towards the ceiling, and remove the cap off the syringe. Carefully remove the air bubble by gently pulling down and then pushing up on the plunger. **Do not touch the end of the syringe because it is sterile. If you touch it, throw it out.**



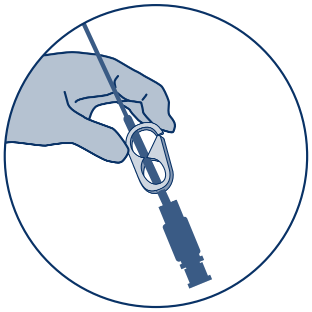
5. **Do not touch the tip of the end cap or the end of the saline syringe with your hand**. Insert the saline syringe into the center of the end cap by pushing in and turning clockwise. Suggestion: A flushing routine that starts with the same color lumen is helpful for remembering which lumen has been flushed.



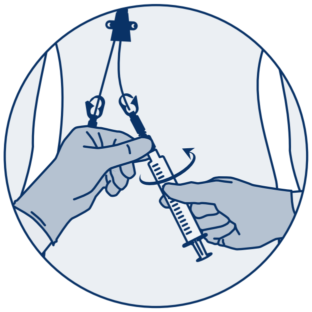
6. Unclamp the central line.



7. Flush the line by pushing the plunger on the saline syringe with **alternating pressure and release** (starting and stopping to create turbulence) to inject the fluid into the central line. This keeps clots from forming in the central line. Leave ½ ml of saline in the syringe.



Clamp the central line (leaving ½ ml of saline in the syringe) while keeping your thumb on the end of the plunger of the syringe.



8. Remove the syringe. **Hold the end cap,** not the central line, when disconnecting from your line. Throw syringe away in regular garbage can.

9. Repeat steps for each lumen.

Protecting your central line when bathing or showering

It is important to protect your central line from water. You will do this by covering your central line end caps with Parafilm and covering your dressing with AquaGuard or Press'n Seal. Repeat the instructions below for each end cap.

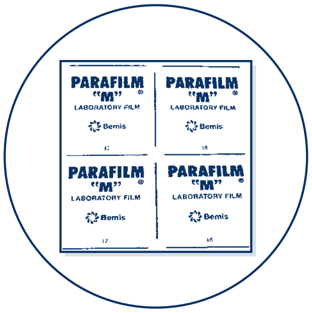
Supplies

Gather your supplies and then follow steps 1 through 9.

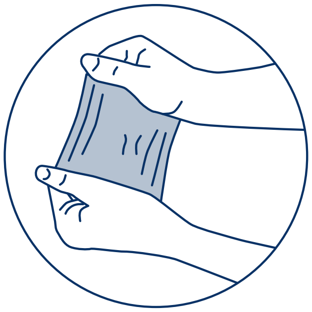
- Parafilm
- AquaGuard or Press'n Seal
- Clean cloth pouch or tape tabs
- Alcohol wipes
- Bulldog clamp
- Lanyard

Instructions

1. **Wash your hands.**

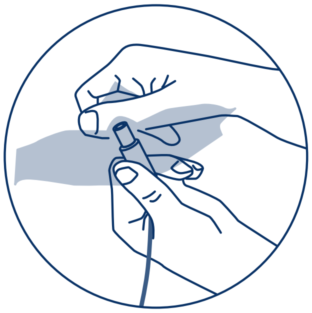


2. Place Parafilm on central line end cap and tubing connection. Use 4 squares for each side of your central line.



2a. Peel Parafilm from adhesive cover backing.

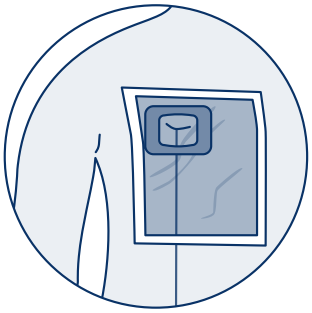
2b. Stretch the Parafilm. This makes it stick to itself.



2c. Place it over the end cap of the central line.

2d. Fold Parafilm over the top of the end cap (like you would seal the top of an envelope). Make sure it covers the connection point between the end cap and the central line. This will make it waterproof.

3. Wrap only around the thicker part of the end of the central line. The Parafilm will fit closely around the end cap and will stick to itself. Make a tab on the end so it will be easier to remove. Use the heat of your hand and grip onto the wrapped end cap to mold the Parafilm around the central line.



4. Cover the entire dressing with a square of AquaGuard or Press'n Seal. If you are using Press'n Seal, it may be helpful to use a piece large enough to drape over your shoulder. The central line lumens should hang out of the bottom edge of AquaGuard or Press'n Seal. Reinforce the edges with medical tape if it does not stay secure.

5. **If you take a bath, the central line should be kept above the water level at all times. If you shower, the dressing should be kept out of the direct stream of water.**
6. After bathing, dry the AquaGuard or Press'n Seal with a towel, then remove and throw it away.
7. Dry the Parafilm with a towel, then remove it from the central line end caps — **do not use scissors**. After removing, check end cap connections to make sure they are secure.
8. If there is moisture underneath the dressing or if it has come loose, the dressing should be changed.
9. Clean both sides of your line once a day with alcohol wipes and replace plastic tape tabs, if using. Secure your central line one of the below ways to prevent accidental removal of the line:
   - Place central line in a clean cloth pouch and secure the pouch with a bulldog clamp to clothing or a lanyard. Pouches are for one-day use and should be washed daily; OR
   - Place plastic tape tabs between clamp and cap on the central line and change daily. Use the plastic tape tabs and bulldog clamp to secure the central line to clothing or a lanyard.

Changing your dressing

In most cases, your dressing will be changed in the clinic. You may be taught how to change your dressing at home. If so, please follow the instructions on the next few pages. While you have your central line, please:

- Look at your dressing and exit site every day. Report any redness, drainage, or pain to your care team.
- Talk to your nurse if your skin is sensitive to the dressing.

If you have a Tegaderm CHG dressing:

- It should be changed every 7 days.
- The dressing should also be changed if:
    - The exit site cannot be seen because of drainage or moisture
    - The gel pad stays depressed when pressed with finger (this means there is too much moisture in the pad)
    - The dressing starts to come off

If you have a gauze and tape dressing:

- It should be changed every 24 to 48 hours.

How to change your Tegaderm CHG dressing

Supplies

- 1 ChloraPrep® applicator (also called chlorhexidine)
- 7 alcohol pads (4 pads are for cleaning the line — use 2 per lumen — and 3 pads are for removing the dressing)
- 2 pairs of clean gloves
- 2 Cavilon No-Sting Barrier Film® pads or swabs
- 1 transparent dressing (Tegaderm® CHG)
- 1 syringe with saline
- 1 sterile gauze pad
- Plastic tape (if using for tape tabs)
- Adhesive remover (optional)

Instructions

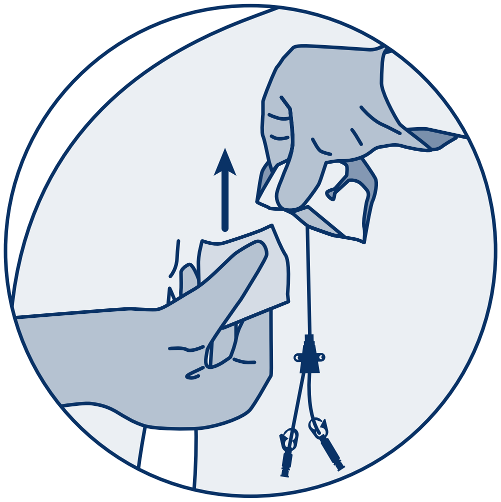
1. Wash your hands with soap and water and put your supplies on a clean work surface.

2. Put on clean gloves.

3. If present, remove plastic tape near central line end caps.

4. Remove existing dressing.

If you have a Tegaderm CHG dressing:



Remove the old dressing by starting at bottom corner, lifting up and folding back upon itself, pulling “low and slow” or rolling with fingers. When gel pad is reached, use an alcohol pad or adhesive remover if needed to loosen gel pad from central line and skin while continuing to slowly pull back on dressing, grasping both the gel pad and dressing. **Do not use scissors. Remove dressing and throw away.**

If you have a gauze and tape dressing and are switching to Tegaderm CHG: Remove the old gauze and tape dressing and throw away. **Do not use scissors.**

5. Tell your nurse if there is any of the following at the central line site:

- Bleeding or drainage
- Redness or swelling
- Pain or discomfort

6. Remove gloves.

7. Wash your hands again.

8. Put on pair of clean gloves.

9. Wet the sterile gauze pad with the sterile saline syringe. Using the gauze pad, cleanse the area around the central line exit site. If there is crust, clean it from the central line exit site using an alcohol wipe, if necessary. If there is a scab, you do not need to remove it.

10. Activate the ChloraPrep applicator by squeezing the wings. Scrub around the central line exit site with the ChloraPrep applicator using a back-and-forth motion for 30 seconds. Allow to dry completely for 1-2 minutes.
    Make sure the chlorhexidine you used to clean the central line exit and area around the exit site (in the ChloraPrep One-Step Swab) is completely dry before you apply the Cavilon No-Sting Barrier Film.

The squiggle shows the back-and-forth motion referred to in step 10.

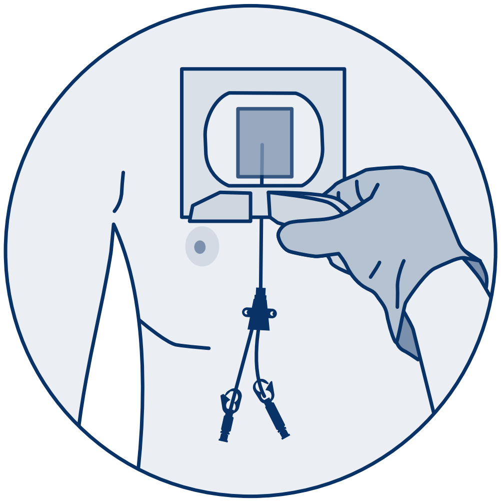
- **Cleaning steps if you have chlorhexidine allergy:** Use a povidone-iodine swab to clean the exit site in a circular motion, starting at the central line exit site and moving outward away from the exit site. Repeat with the other two povidine-iodine swabs, for a total of 3 cleanings at the exit site. Allow to air dry and **do not wipe off.** If you are sensitive to povidone-iodine, you may remove the iodine with a sterile gauze pad soaked with sterile saline syringe.

- **Cleaning steps if you have chlorhexidine AND povidone-iodine allergies:** Use a 70% alcohol swab to clean the exit site in circular motion, starting at the central line exit site and moving outward away from the exit site. Repeat with the other two alcohol swabs, for a total of 3 cleanings at the exit site. Allow to air dry and **do not wipe off.**

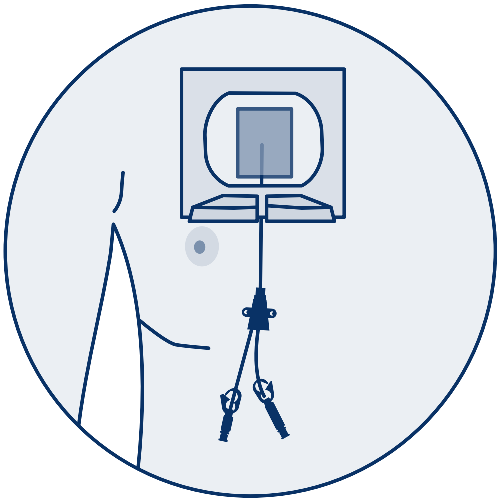
11. Open 2 alcohol wipes for each lumen. Use one to hold the line near the exit site and one to wipe it, start at the exit site and wipe towards the end of the line. Take special care to thoroughly scrub around the connection between the line and the central line end caps. Repeat for each lumen.

12. After cleansing has dried completely, apply Cavilon No-Sting Barrier Film to the area that will be under the clear dressing. Avoid the exit site and the area that will be under the chlorhexidine gel pad. Allow to dry completely for 1-2 minutes.

13. Apply new dressing.



- Apply Tegaderm CHG transparent dressing by peeling the liner from the dressing, exposing the adhesive surface.
- Center the dressing and gel pad over the central line exit site and press gently to make it stick. Make sure the central line comes out of the dressing edge at a notch.
- Slowly remove the paper frame from the dressing while smoothing down the dressing edge.
- Smooth the entire dressing from the center towards the edge using firm pressure to enhance adhesion. If your gloves stick to the dressing, you may remove them.



- Remove tape “wings” from frame, lift central line, and apply wing across opening of dressing underneath the central line, creating a little hole where the central line comes through. This helps keep the central line secure.
- Paint border (outside edges) of transparent dressing with Cavilon No-Sting Barrier Film to create a seal between the transparent dressing and the skin.

How to change your gauze and tape dressing

Supplies

- 2 packages 2x2 gauze or 2 packages 2x2 split gauze
- 4 alcohol pads for cleaning line (use 2 per lumen)
- 1, 10 ml saline syringe
- 1 sterile gauze pad
- Skin Prep
- Paper tape

- 1 ChloraPrep One-Step applicator, also called chlorhexidine
- 2 pairs of clean gloves
- Plastic tape (if using to make tape tabs)

Instructions

1. Wash your hands with soap and water and put supplies on a clean work surface.

2. Put on clean gloves.

3. If present, remove plastic tape near central line end caps.

4. Remove existing dressing and throw away. **Do not use scissors.**

5. Tell your nurse if there is any of the following at the central line site:

   - Bleeding or drainage
   - Redness or swelling
   - Pain or discomfort

6. Remove gloves.

7. Wash your hands again.

8. Put on pair of clean gloves.

9. If crust is present, clean it from the central line exit site using an alcohol wipe if necessary. If there is a scab, you do not need to remove it.

10. Activate the ChloraPrep applicator by squeezing the wings. Scrub around the central line exit site with ChloraPrep applicator using a back-and-forth motion for 30 seconds. Allow to dry completely for 1 to 2 minutes.

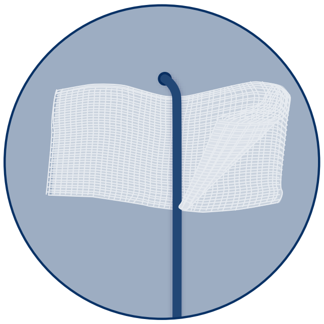
The squiggle shows the back-and-forth motion referred to in step 10.

Make sure the chlorhexidine you used to clean the central line exit and area around the exit site (in the ChloraPrep One-Step Swab) is completely dry before you apply the Cavilon No-Sting Barrier Film.

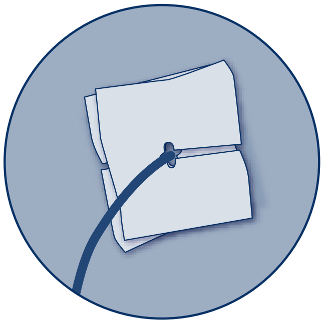
- **Cleaning steps if you have chlorhexidine allergy:** Use a povidone-iodine swab to clean the exit site in a circular motion, starting at the central line exit site and moving outward away from the exit site. Repeat with the other two povidine-iodine swabs, for a total of 3 cleanings at the exit site. Allow to air dry and **do not wipe off.** If you are sensitive to povidone-iodine, you may remove the iodine with a sterile gauze pad soaked with sterile saline syringe.
- **Cleaning steps if you have chlorhexidine AND povidone-iodine allergies:** Use a 70% alcohol swab to clean the exit site in circular motion, starting at the central line exit site and moving outward away from the exit site. Repeat with the other two povidine-iodine swabs, for a total of 3 cleanings at the exit site. Allow to air dry and **do not wipe off.**

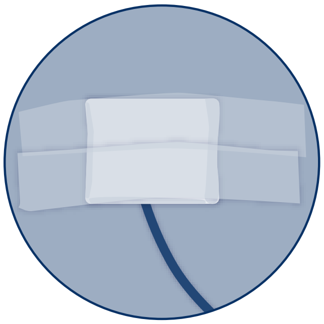
11. Open two alcohol wipes for each lumen. Use one to hold the line near the exit site and one to wipe it, start at the exit site and wipe towards the end of the line. Take special care to thoroughly scrub around the connection between the line and the central line end caps. Repeat for each lumen.
12. After cleansing has dried completely, apply Cavilon No-Sting Barrier Film to the area that will be under the transparent dressing. Avoid the exit site and the area that will be under the chlorhexidine gel pad. Allow to dry completely for 1-2 minutes.
13. Apply dressing.

- **If using folded gauze:** Touching only the corner, remove one of the 2x2 gauze pieces, fold in half and place under the central line.



- **If using split gauze:** Touching only the corners, place the 2 split gauze with the slits positioned horizontally (in opposite directions) around the central line as close as possible to where it exits the skin.





- Place the second 2x2 over the line and gauze.
- Secure gauze to skin with paper tape.

14. Secure the central line **one** of the below ways to prevent accidental removal of the line:

- Place central line in a clean cloth pouch and secure the pouch with a bulldog clamp to clothing or a lanyard. Pouches are for one-day use and should be washed daily; OR
- Place plastic tape tabs between clamp and cap on the central line and change daily. Use the plastic tape tabs and bulldog clamp to secure the central line to clothing or a lanyard.

Troubleshooting your central line

Problem	Solutions
Line does not flush.	1. Check to see if central line is clamped or kinked. 2. Call the Fred Hutch clinic or after-hours number for instructions.
Fluid is leaking from the central line. Central line may have been accidentally cut if the dressing was removed with scissors.	1. Immediately place a bulldog clamp on the central line as close to the chest as possible. 2. Wash hands and put on gloves. 3. Check the central line to find the break. It can be as small as a pinhole. 4. Clean the break with an alcohol wipe. 5. Wrap a sterile 2x2 gauze or an alcohol wipe around the break in the central line and tape it in place. 6. Call the Fred Hutch clinic or after-hours numbers for instructions.
Central line end cap comes off.	1. Immediately clamp central line — **do not replace cap.** 2. Wash hands and put on gloves. 3. Scrub central line end with alcohol for 15 seconds and let dry 5 seconds. 4. Place sterile saline syringe on end of central line — **do not flush.** 5. Call the Fred Hutch clinic or after-hours numbers for instructions.
Swelling around the exit site or fluid leaking from exit site. Swelling of the exit site, or bloody drainage or fluid leaking from the exit site can be a sign that the central line is out of place.	1. Stop any fluids running into the central line. 2. Place an ice pack on the swollen area; do not apply directly to bare skin. 3. Call the Fred Hutch clinic or after-hours numbers for instructions.
Swelling of the neck and face. Swelling of the neck and face can be a sign that the central line is out of place or that the vein is blocked.	1. Stop any fluids running into the central line. 2. Call the Fred Hutch clinic or after-hours numbers for instructions.

Problem	Solutions
Air in the central line, you *are not* short of breath. This could be caused by air being accidentally injected into the central line or the end cap falling off when the line is not clamped.	1. Check the clamp to make sure that it is closed. 2. Wash hands and put on gloves. 3. Open 2 saline syringes. 4. Scrub the end of the central line cap with alcohol wipe for 15 seconds and let dry 5 seconds. 5. Attach one of the saline syringes. 6. Unclamp the line. **7. Pull back** on the syringe until blood appears. 8. Clamp the line and discard the syringe. 9. Scrub the end of the central line cap with alcohol for 15 seconds and let dry for 5 seconds. 10. Flush the central line as usual, making sure to close the clamp at the end of the flush. 11. Call clinic if central line end cap is off. **12. If you become short of breath, call 911.**
Air in the central line and you suddenly become short of breath, dizzy, or confused.	1. Lie down on your left side so that your right hip is lifted above the level of the heart while checking the clamps on the central line to be sure they are closed. 2. Call 911 for emergency assistance. 3. Tell medics to take you to UW Medical Center-Montlake emergency room.

Day-to-day care: The first year and beyond

In addition to the information in this manual, you will receive information from your care team that will help you manage your care when you leave the clinic.

Take pride in your journey through an intensive medical treatment but remember that full strength and fitness will take several more months, or sometimes years, to achieve. Recovery is usually a gradual process. Continue your programs of rest, exercise, and good nutrition.

Transition to home

The Long-Term Follow-Up (LTFU) Program offers telephone consultation services to you and your primary care provider when you return home. Call your local provider for everyday concerns. Call your oncologist for treatment related issues. If you or your provider are concerned about transplant-related side effects or complications, call LTFU. If you leave a voicemail, please spell your name and describe your question. Your question will be reviewed and an experienced transplant nurse will return your call within 24 to 48 hours.

Contact information for LTFU:

- Phone number: (206) 667-4415
- Toll-Free Fax: (800) 376-8197
- Fax: (206) 667-5619
- Email: LTFU@fredhutch.org

Recommendations for self-care after transplant

It's important to take care of yourself after transplant. Please know that there is a real possibility that you may be readmitted to a hospital during your first year after transplant. The next page offers recommendations for self-care after transplant.

Visits with your home provider

These include physical exams, labs, and tests, such as blood counts and kidney and liver function tests. We recommend:

Time after leaving the transplant clinic	How often to see your home provider
Within the 1st month	Weekly
Within the 2nd and 3rd months	Every other week
After the 3rd month	Every 3–4 weeks
You may see your home provider more often than this if you are experiencing complications.	

Visits with Long Term Follow Up

You will be invited to schedule your 1-year evaluation with Long Term Follow Up when you are 6 months out from transplant. This week-long evaluation looks for your original disease, measures how well your new immune system is maturing, and looks for graft versus host disease. Please call LTFU early to schedule this visit as our appointments fill up well in advance. If you have graft versus host disease, you may be asked to return to see LTFU anywhere from every 3 months to yearly so we can help your home providers manage the treatment.

Guidelines for long term follow-up can be found on our website at:

For patients: FredHutch.org/ltfu-patient-info

For physicians: FredHutch.org/ltfu-physician-info

Skin care

Protect yourself from the sun

Sun can increase your risk of skin cancer. Take the following steps to protect yourself from harmful UVA and UVB rays.

- Protect your lips with SPF 30 lip balm.
- Use sunscreen SPF 30 or greater. Reapply it every hour while outdoors.
- Wear clothing with SPF in the fabric, such as Columbia®, Solumbra®, and ExOfficio®.
- Avoid long (over 1 hour) exposure to the sun.
- Apply sunblock or wear SPF clothing even on cloudy days. Cloudy days can still expose you to harmful rays.

How to treat dry skin

- If dry skin is a problem, you do not need to bathe daily.
- To help moisturize your skin, avoid long showers and excessive scrubbing. Try to use warm water instead of hot water.
- Try natural soap for sensitive skin.
- Apply a thick layer of moisturizer immediately after bathing. Then wrap yourself in a wet towel covered by a warm blanket to help the moisture absorb into your skin.

Nail care

- **Do not get manicures and pedicures if your immune system is still recovering and you are on antibiotics.**
- Avoid fake/acrylic/gel nails and cutting your cuticles.
- You can get a manicure or pedicure only if you meet all 3 of these requirements:
    - Your ANC (absolute neutrophil count) is greater than 1,500,
    - You do not need transfusions, and
    - You are off high dose steroids (greater than 1mg/kg).

  Make sure a clean tub or fresh liner is used in the tub to soak your hands or feet, and equipment is sterilized after each person.

Daily mouth care

Careful flossing and brushing is important to maintain dental health and prevent infections. Continue to use saline rinses if your mouth is dry, if you have too much mucous, or if you are being treated for oral fungus. Rinse your mouth using ¾ teaspoon table salt in 1 quart of warm water.

Dental visits

Six months after you return home, get a dental exam to monitor for tooth decay and overall oral care. Your dentist should also monitor for oral cancer every 6 months. Wait at least 6 months after transplant to have a routine dental cleaning and 12 months for elective dental work. You may need to take additional safety steps for cleanings and dental work if you are still immunosuppressed, including taking an antibiotic based on recommendations from the American Heart Association. Please contact LTFU before your dentist visit to review your risk factors.

Dry mouth

A dry mouth increases the risk of tooth decay. Fluoride and excellent oral hygiene can minimize or prevent decay. See a dentist if you have extreme problems. We recommend using fluoride brush-on gels or custom fluoride trays at home. Follow guidelines provided by the Oral Medicine department. Saline rinses or other non-prescription products, such as Biotene®, can help relieve dryness.

Mouth changes

Contact your provider for any changes such as ulcers, clear blisters on the soft area of the roof of your mouth or the inside of your lower lip, stinging, burning, dryness, pain, difficulty eating or swallowing, or loose teeth.

Common changes

“The new normal is not a bad normal, just different. Perspective is everything.”
—BMT Survivor

Memory and concentration changes

Many people experience problems with memory and concentration during or after cancer treatment. These are called cognitive problems. A common term used to describe cognitive problems is “chemo brain” or “brain fog.”

Cognitive changes are receiving more research attention. Cancer causes biochemical changes that are now suspected of contributing to cognitive changes, even before any treatment. High-dose chemotherapy and radiation affect cognitive function. Studies show varying incidences of “chemo brain” among transplant patients. However, research indicates that the decrease in memory, ability to multi-task, and attention that characterize post-treatment cognitive changes go away for a majority of people after about a year.

People can return to their pre-transplant cognitive functioning anywhere from 1 to 5 years after transplant. Some people will continue to have memory or fine motor difficulties. If you are still having difficulties with cognitive changes after 1 year, ask your provider for a referral for neuropsychological testing so you know what your challenges are and what you can do about them.

Review the **Memory and concentration** symptom sheet in this manual. In the meantime, help your memory by keeping a notebook where you put the things you want to remember. Make sticky notes about what you do not want to forget, like taking a medication before you go to bed. Put the sticky note by something you always remember, like brushing your teeth. Keep a basket by the door for the things you need to take with you like keys or glasses.

Sleep

Most people have difficulty with sleep at some point during and after transplant. It can be hard to get on a regular cycle of sleep and worry tends to increase as people lie in bed awake. Medication should be a short-term solution, not a lifetime aid. See the "Sleep Problems and Healthy Sleep Habits" handout for tips on how to create healthy sleep habits.

Depression and other feelings

"People are entitled to their feelings. And they're entitled to them at every stage of treatment and survivorship. We know from the science of emotion that the most harmful way, the most damaging way, to manage emotions is to try to dictate them."
—Dr. Karen Syrjala (in *Surviving Survivor Stereotypes* by Curtis Pesmen)

You may continue to experience significant distress after your transplant. Sometimes, this can lead to feelings of sadness or depression and worry, anger, and fatigue. Distress can also lead to changes in sleep and eating patterns. Even post-traumatic stress can happen. We recommend making time and saving energy to participate in activities that you enjoy, so life is not entirely about your health. Spend time with friends and family.

If these symptoms continue for more than a couple of weeks, it is important to discuss them with your care team. Some people find that talking to a therapist after transplant is very helpful. Talking with a therapist can help you reclaim your life and make sense of what you have gone through.

Fatigue, weight, and exercise

"Some problems such as fatigue can begin during therapy and may continue indefinitely, though the duration and severity differs greatly between individuals."
—Rabiya Tuma, PhD, *Treatment Aftershocks*

Fatigue, weight, and exercise, continued

Many people report increased fatigue after transplant. Exercise is an effective way to decrease this fatigue over time and also helps with bone strength, sleep problems, and memory and concentration changes. We recommend daily moderate exercise, such as walking. Increase the distance and pace as your strength and stamina increase.

It is also important to rebuild muscle by gradually increasing weight training through a steady program. Couple this with stretching, yoga, and/or gentle fitness classes.

See if a YMCA near you has a low-cost cancer survivorship program, or ask for a physical therapy referral to get an exercise plan from someone who has experience with exercise after cancer treatment. The best exercise is the kind that you do regularly.

Follow the advice of your dietitian. Eat healthy foods.

If you exercise at a moderate level and have rebuilt muscle, but your fatigue continues, or if your fatigue increases, talk to your provider about other possible causes of fatigue.

Osteoporosis for transplant recipients

Osteoporosis (bone loss) may happen in some patients. It is related to radiation, steroids, inactivity, and low hormone levels. Weight bearing exercise is recommended to help prevent or stabilize osteoporosis. You may need calcium and vitamin D supplements, or bone-rebuilding medications. You can discuss this with your local provider.

Immune system recovery

Adequate immune function takes about 1 year after transplant to recover, perhaps longer if you are still on immunosuppression to treat GVHD. During this time, you are still at risk for infections. Tell your provider right away if you have signs of infection, such as fever, chills, coughing, difficulty breathing, severe diarrhea, or vomiting.

Cytomegalovirus (CMV) monitoring

You may need weekly CMV monitoring after treatment. At discharge, you will receive information on CMV monitoring to take to your local provider.

Exposure to others

Avoid crowds, especially during cold and flu season. Avoid people with a contagious infection. Please contact your provider if you are exposed to chicken pox or shingles.

Hand washing

Continue to be as careful about hand washing as you have been throughout the transplant process. Wash your hands frequently with soap and water or an alcohol-based hand sanitizer with 60–85% alcohol. Ask family and friends to wash their hands or use hand sanitizer when they come into your home. Wear disposable gloves if you must change a diaper. Wash hands after throwing away gloves.

Taking your temperature

Take your temperature if you are feeling ill, have shaking chills, or suspect that you have a fever. Note the time and what was happening when you got the temperature. For instance, did you just get out of the shower? Notify your provider promptly for:

- Temperature taken by mouth between 38–38.2°C (100.4–100.8°F) for one hour or more, or a temperature that is 38.3°C (100.9°F) or above.
- Temperature taken under the arm (axillary) between 37.5–37.7 (99.5–99.9°F) for one hour or more, or a temperature that is 37.8°C (100°F) or above.

Rash

Notify your provider promptly if any rash develops.

Animals and plants

Avoid contact with urine, poop, and vomit of all animals, and do not sleep with pets. Do not bring new pets into the home during the first year. Household pets may remain in the home. Established plants may return to the home around day 30, or when you are discharged from active treatment in the outpatient clinic. Gardening is not recommended until at least 1 year after transplant and off immunosuppression.

Sexual activity

Limiting your number of sexual partners is advised. Use condoms for protection against sexually transmitted infections (STIs). Follow normal cleanliness routines. Use birth control as necessary to prevent pregnancy, as you may not be sterile. Discuss this with your care team. If dryness is a problem, try using a sexual lubricant. Do not use medications for erectile dysfunction (inability to have an erection) without getting a cardiac (heart) evaluation.

Swimming

You can swim and use hot tubs when you are 6 months out from transplant and off immunosuppression. If you are still on immunosuppression, wait until you are 1-year out from transplant. After that, be cautious. Swimming may expose you to microorganisms that cause infections. Think about the benefits of swimming versus the infection risks. If you like to swim or do water aerobics, do it in a well-maintained pool with enough chlorine. Do not put your face under the water. Never swim with a central line in place.

Travel

Take extra medications with you when you travel and consider where you could receive treatment if you became ill. Move around during flight or travel time to prevent blood clots that could lead to a major lung problem.

Many patients travel home within the first 6 months after transplant. As with any activity involving risk, weigh the specifics of your situation. To minimize risks when traveling:

- Take a copy of critical medical records with you.
- Seek medical care promptly for new symptoms.
- Avoid crowds. If you cannot avoid them, wear a mask, and take other steps to prevent infection, like washing your hands frequently.
- If you fly, ask to be moved if you are seated near someone with respiratory symptoms. Carry hand sanitizer and wipes.

Other reminders

- **Avoid** exposure to dirt and aerosolized material.
- **Reduce** sun exposure as much as possible; use sunscreen (SPF greater than 30).
- **Use** a hat, long-sleeve shirts, and long pants if outside for long periods of time.
- **Avoid** construction sites.
- **Avoid** contact with people who:
  - Have cold and flu symptoms like coughing and sneezing.
  - Show symptoms of other types of infections, such as vomiting or skin rashes.

Immunizations

Typically, you should get the following immunizations starting at 1 year after transplant. The seasonal flu and COVID-19 vaccines may be given earlier, starting at 3 months after transplant. You will get more information on immunizations from the Long Term Follow-Up program:

- Tetanus
- Diphtheria
- Pertussis
- Meningococcal
- Inactivated polio
- Influenza
- Pneumonia
- Haemophilus influenzae type B
- Hepatitis B
- Hepatitis A
- Human papilloma virus (HPV), ages 9-45
- COVID-19
- Shingrix or Varivax

If a household member receives the Varicella (chickenpox) vaccine, you should be taking acyclovir. If a household member develops a rash or skin lesions, avoid them until their skin clears.

Chronic Graft-versus-Host Disease (GVHD)

One form of GVHD that may occur around day 80 or later is called chronic graft-versus-host disease. About 33% of people (33 out of 100) who get allogeneic transplants are diagnosed with chronic GVHD. You are more likely to develop chronic GVHD if you:

- Had acute GVHD
- Had a donor that was not related to you or was not fully matched to you
- Are assigned male at birth and had a donor assigned female at birth
- Received peripheral blood stem cells from your donor (rather than bone marow or umbilical cord blood)

Chronic GVHD can affect any organ. Fifteen percent of patients (15 out of 100) develop severe chronic GVHD that goes on for many years and may lead to disability. The range of medical issues caused by GVHD can be mild to severe.

Having GVHD may not be all bad. Patients with GVHD have a lower risk of the cancer returning after transplant than patients who do not develop GVHD.

Symptoms of Chronic GVHD

Report any of the following changes to your physician:

- **Skin:** Rash, thickness, lighter or darker color changes, tightness, texture changes, shining, itching
- **Hair:** Thinning or coarse
- **Nails:** Texture changes, brittleness, ridges
- **Eyes:** Dryness, grittiness, irritation, burning, blurring, discharge, tears, sensitivity to light or wind
- **Mouth:** Dryness, pain, sensitivity to spicy foods or toothpaste, sores, white lacy changes on gums and cheeks that do not brush off with a toothbrush
- **Vagina:** Dryness, irritation, tightening
- **Penis:** Irritation, rash, sores
- **Digestive system:** Nausea, vomiting, diarrhea, loss of appetite, unexplained weight loss
- **Lungs:** Chronic dry cough, wheezing, shortness of breath
- **Liver:** Jaundice and elevated liver test numbers. Make sure your physician is watching for possible changes in your liver and kidney function test results.
- **Joints:** Unable to fully extend fingers, wrists, elbows, ankles or knees; joint pain or stiffness
- **Energy level:** Increased fatigue
- **Temperature sensitivity:** Sensitive to cold, unable to sweat

Treatment of Chronic GVHD

Most people with chronic GVHD take immunosuppressants for 2 to 3 years after the first symptoms appear. Immunosuppressants are medicines used to decrease the activity of GVHD in your body. About 10% of people (10 out of 100) require treatment for 7 years or longer. Eventually, your body will accept the graft and GVHD will go away on its own. After the chronic GVHD goes away, some symptoms may remain due to the damage the GVHD caused to your body.

The immunosuppressants most commonly used for chronic GVHD are prednisone, cyclosporine, tacrolimus, ruxolitinib, ibrutinib, belumosudil, mycophenolate mofetil, sirolimus, and others. All immunosuppressive drugs have some side effects. The most common side effects for the treatment of GVHD are listed below.

Immunosuppressant	Side effect
Prednisone	Osteoporosis, deterioration of joints that can require joint replacement, increased risk of infections, diabetes, cataracts and emotional variance, changes in body habitus (weight gain, moon face)
Cyclosporine (Neoral®)	Kidney function issues, wasting of magnesium, tremors, headaches, seizures, nausea, increased blood pressure
Tacrolimus (Prograf®)	Similar to cyclosporine
Ruxolitinib (Jakafi®)	Decreased platelet count, decreased white blood cells, anemia
Ibrutinib (Imbruvica®)	Fatigue, bruising, bleeding, heart rhythm changes
Belumosudil (Rezurock®)	Nausea, diarrhea, cough, bleeding, abdominal pain, edema (swelling caused by too much fluid; usually shows up in legs and feet)
Mycophenolate mofetil (MMF or CellCept®)	Nausea, vomiting, diarrhea, bleeding, decreasing white blood cells count, anemia
Rapamycin, Sirolimus (Rapamune®)	Decreased white cells or platelets, increased triglyceride level, edema (swelling caused by too much fluid; usually shows up in legs and feet), and others

Even though they have side effects, it is very important for your long-term health to continue taking your medication until your physician says it is OK to stop. Damage from untreated or undertreated chronic GVHD to the eyes, lungs and skin cannot be reversed and it is worse than the side effects of the medications used to treat it.

Medications

To maintain your general health, take your medications as prescribed.

Medication	What it does and how long to take it
Bactrim® (sulfamethoxazole-trimethoprim):	• Used to prevent pneumocystis pneumonia and certain types of bacterial infections (streptococcus pneumonia and haemophilus influenza) • Taken for at least 6 months after transplant, longer if you continue taking immunosuppression medications.
Acyclovir or valacyclovir	• Antiviral medications used to prevent varicella zoster (shingles). • Taken for at least one year after transplant, longer if you continue taking immunosuppression medications.
Hormones	• Used for people in premature menopause caused by conditioning therapy • You and your physician will discuss how long to take these.
Immunosuppression	• Used to treat GVHD • Record the dates of when you stop or restart immunosuppressive medications, such as prednisone, cyclosporine, MMF, tacrolimus, and sirolimus. • You may need to get your blood levels checked when taking these medications.

Secondary cancers

Long-term survivors have an increased risk of getting a different cancer after transplant. The risk starts to increase 5 years after transplant. The most common sites of secondary cancers after transplant are skin, mouth, thyroid, and breast. To monitor for these cancers, these routine screenings are recommended:

- Complete skin examination
- Oral (mouth) exams
- Breast exams and mammograms
- Prostate exam
- Colonoscopy (according to age and history)
- Others as needed

We also recommend getting your original disease restaged on a regular basis. We will include a calendar for restaging and screenings or monitoring in the discharge summary we send to your oncologist.

Reconnecting with life and survivorship

“This has been five years that I wouldn’t wish on my worst enemy, but strangely enough, wouldn’t trade for the world.”
—BMT Survivor

It is normal to feel vulnerable after returning home. Try not to panic every time someone sneezes. It’s important for you to see your friends and return to normal activities, too. Just use common sense: “when in doubt, don’t.” Some patients find it hard to plan for the future. Make a specific detailed plan for something you want to do. This helps you to feel like you are moving toward something, not just marking time while you recover.

Helpful hints

- It is healthy to find something hopeful about your situation. It doesn’t mean that you forget the difficult times, it’s just that the difficult times are not the whole story.
- You are your own best friend. Take care of yourself. Get enough rest, exercise, and good nutrition. Be patient with yourself and others.
- Watch for changes in your body, hair, nails, eyes, skin, mouth, and joints. Tell your provider about any changes.

- Try to take one day at a time; focus on your goals for today, particularly after you first return home. Make sure you include something you enjoy in each day.
- It is normal to feel alone at times; it's true that no one else has been down your road and really knows what it is like for you. Make it a goal to connect with people and do activities you enjoy so that you start to feel like part of your community, even if at first you don't feel like it.
- Remember that your caregiver and family have also been through a major challenge. Check in with them weekly to let each person describe what they are experiencing. You don't need to fix each other's concerns; just use this as a time to listen and reflect upon what each person is feeling. Ask if there is anything that would make things better.
- Do not be afraid to ask for professional guidance; you deserve it. Almost everyone receives some kind of help.
- Check with your employer to see if you have access to an Employee Assistance Program.

Relationships

It may be difficult to resume relationships as they were before your transplant because your experience has changed your perspective on life. Your illness may have affected the feelings and perspectives of the people around you. It may have changed the roles of you and other people in your life. People report that these changes can be very positive, but they also can take some time to sort out.

Make sure each person in your family has a chance to describe their fears and concerns. Even if it is hard, try to give each person time to describe what is going on in their lives and thoughts.

Caregivers may be used to taking care of you and home tasks and need to re-adjust to not having to do as much as they were. This can take time. You can help them along by discussing a weekly plan of who will do what. As you are ready for more responsibility, make this clear to your caregiver. With friends, it might help to discuss what is different in your life and how much the friendship means to you. Sometimes you may have to reach out to friends rather than waiting for them to come to you.

Returning to work

There is no exact timeline for returning to work. You need to be ready both physically and emotionally. Much of the timing for returning to work depends on the type of work you do and how long your employer is willing to hold your job. Talk with your transplant team about infection prevention before you return to work outside your home.

- It is very important to keep in touch with your employer (Human Resources and your manager) during and after your treatment.
- Likely you will not be able to return to full time work right away. Increasing either your hours or number of days slowly over time will likely make your return go more smoothly.
- Your employer is required to provide you with accommodations including flexible hours/ location, change in job duties, and time off for medical appointments (see Americans with Disabilities Act at ada.gov) until you are able to work at full capacity.
- If you need resources to improve your fatigue, physical strength, or anxiety surrounding work, ask your medical team for a referral.
- If you wish to change jobs or careers for whatever reason, that is possible too. You can choose whether or not you wish to tell a possible employer about whether you had a stem cell transplant.
- Do not be afraid to ask a member of your medical team to speak directly with your employer; they may be able to help you get the changes you need.
- If you need more information on what your legal rights are, a good resource is triagecancer.org. There are many organizations that assist cancer and transplant survivors with employment issues. For more information on your employment rights, see the resources section at the end of this chapter.

You may be eligible for disability benefits because of your recovering immune system. This will be the case for at least 1 year. If you are currently receiving disability benefits, you may be able to return to work part-time and still receive your disability benefits for a total of 9 months. Your social worker or social security administration benefits counselor should be able to help you with this.

Returning to school

There is no exact timeline for returning to school. It may depend on the type of program you are enrolled in and whether there is an opportunity to start your program online. Talk with your transplant team about infection prevention before you return to school outside the home.

- Increasing your number of classes or days in school slowly over time will likely make you more successful.
- You may benefit from meeting with your school team before returning to school in person.
- Please speak with your medical team if you have questions about your readiness to return to school, including the need for neuropsychology testing, physical therapy, or occupational therapy referral.
- If you need documentation to excuse school absences, enroll in individualized education plan, or 504 plan, please speak with your medical team.
- If you are having any difficulties communicating or coordinating the return-to-school process, do not be afraid to ask a member of your treatment team to speak directly with your school.
- If you need more information on the return-to-school process, a good resource is bit.ly/LLS-returning-to-school.

Financial concerns

Many people report insurance and financial concerns. We recommend looking into social security and private disability insurance. Look online and at the Resources at the end of this chapter for more information on financial concerns. Many patient assistance programs offer help with ongoing costs of care and medication.

Sexuality

"Nobody wants to talk about it. It becomes a self-propelling problem, in that, the longer time goes by, people then also become kind of less connected with that part of themselves."
—Sharon Bober, PhD

Most people notice a drop in sexual desire during the first year. Make time for intimacy so that you begin to re-awaken those feelings. You may have a low energy level or feel unattractive due to the changes in your body.

Partners often hesitate to make sexual advances out of concern for your health. Vaginal changes and erection problems can occur. Medications can be the cause of some of these changes. Problems may disappear over time or after you stop taking the medications.

Hormones can change after transplant. It often takes a full year for testosterone levels to return to normal, affecting both erections and desire. It's important for both partners to talk about their feelings and to be patient with one another. Begin to set aside "date" time to be romantic, include touching in your intimate time together. Start trying sexual activity even if your desire is not back to its previous level.

If dryness or irritation is a problem, a silicone-based lubricant can be helpful. Water-based lubricants are also safe but won't last as long. If sensitivity is a problem, ask to see a sexuality-after-cancer specialist or look online at transplant websites on sexuality to learn more about what can be done for these problems. Medications used for erectile problems can be helpful, but do not use them until after you've had a cardiac (heart) evaluation.

Survivor syndrome

"Little studied, survivor guilt brings with it a host of issues that can cause depression, anger and self-blame that may even compromise health."
—Kathy Latour, *Getting Through Survivor Guil*t

You may have feelings of guilt because you are alive when others did not survive. You may also have a strong sense of grief and loss. Even though you are glad to be alive, it is normal to feel that you have lost things that you will never again be able to regain. Talking with a therapist can help put this in perspective. If you aren't sure what you want to do, or feel like you want a change, give yourself time to recover while you discover what you want most. Some people re-evaluate what they want to do for the rest of their lives.

Survivorship Clinic

Cancer and its treatment can result in some potentially long-lasting or late-onset effects. Our Survivorship Clinic addresses various challenges cancer survivors may face after therapy ends. These include pain, fatigue, fear of recurrence, living with uncertainty, neuropathy, lymphedema, bone loss, sexual dysfunction, cardiovascular disease, memory issues, and future cancer risk. At the Survivorship Clinic, our medical staff will talk with you about how to assess and manage late complications or issues you may be experiencing and develop a plan to support your future health.

As part of your appointment in the Survivorship Clinic, you will receive an individualized Treatment Summary and Survivorship Care Plan. This includes an evaluation and information on the prevention of the late effects of your cancer and cancer treatment, recommendations, and resources for dealing with long-term effects, and suggestions for healthy lifestyle behaviors.

Copies of the treatment summary, survivorship care plan, and any recommendations made during the appointment are shared with your health care team, including your oncologist and primary care provider. The clinic does not provide testing for recurrence of your cancer; this care will be provided by your oncologist. To schedule an appointment in the Survivorship Clinic, please call (206) 606-1024. You can also visit the Survivorship Clinic website at: FredHutch.org/adult-survivorship-clinic

Sample letter for returning home

This is an example of a letter or email you can share with family and friends to tell them how you're doing after transplant and how they can support you.

> To my family and friends:
>
> I am recovering from a bone marrow transplant. I am able to return home; however, my recovery from this procedure can take months. The following is a list of some of the ways you can help with my recovery.
>
> ### My risk for infection continues
>
> It will take at least ____ months for my immune system to recover. It's possible that it could take even longer, depending on what medications I will need or what complications I might experience. I am at a higher risk for infection and will need to pick activities that will minimize my risk of infection. Family and friends need to be up to date with their vaccinations, including COVID-19 and the flu. Please see the vaccination recommendations in the "Preparing for Transplant" booklet at FredHutch.org/preparing-for-transplant.

Washing your hands and wearing a mask

Washing your hands and wearing a mask are the most effective ways to prevent infection from spreading. I was taught to wash my hands frequently. My family, friends, and visitors will be asked to do the same when in my company. Please don't be offended if I remind you to wash your hands or wear a mask.

Time to eat

I have to follow a special diet while my immune system recovers. If you wish to help by providing meals, I would be happy to give you a list of what I can and cannot eat.

Fatigue

I will have good days and bad days. I would like to see you; however, short visits will be better for me. Some days I might not be up to visitors, long conversations, or involved activities. Exercise can help with fatigue so please offer to walk with me.

Memory and concentration

The treatment and medications I take can affect my memory and ability to concentrate.

My caregiver

______________ had a lot of responsibility while we were in Seattle. Now that we are home,______________ will still have caregiver responsibilities along with all the usual home and work routines. If you would like to help, please see the list of suggestions below:

- Drive me to and from appointments.
- Run errands for my caregiver or visit with me so my caregiver can have a break.
- Take my children out for an activity.
- Help with household chores and/or yard work.
- Remember my caregiver with a phone call or offer to do something fun.
- Join me for a walk.
- Walk the dog.

And please remember, all of your help and phone calls are appreciated as I move forward with my "post-transplant" life! Your support is an important part of this transition.

Thank you so much for your support,
[your name]

Resources

Organizations

Below is a list of organizations that may be helpful to you. Inclusion on this list does not imply endorsement by Fred Hutch.

Organization	Website	Phone
General information		
American Cancer Society	cancer.org	1 (800) 227-2345
Be The Match	bethematch.org	
Blood and Marrow Transplant Information Network	BMTinfonet.org	(847) 433-3313 1 (888) 597-7674
Cancer Hope Network	cancerhopenetwork.org	1 (800) 552-4366
Cancer Lifeline	cancerlifeline.org	(206) 297-2500 1 (800) 225-5505
Cancer Pathways (formerly Gilda's Club)	cancerpathways.org	(206) 709-1400
Caregiver Action Network	caregiveraction.org	(202) 454-3970
Leukemia and Lymphoma Society	Lls.org	1 (800) 955-4572
National Bone Marrow Transplant Link	nbmtlink.org	

Organization	Website	Phone
National Cancer Institute	cancer.gov, and these webpages on that site: - Facing Forward- Life After Cancer Treatment cancer.gov/cancertopics/coping/life-after-treatment - When Someone You Love is Being Treated for Cancer cancer.gov/cancertopics/coping/when-someone-you-love-is-treated - Taking Time: Support for People with Cancer cancer.gov/publications/patient-education/taking-time - Eating Hints: Before, During and After Cancer cancer.gov/cancertopics/coping/eatinghints - Chemotherapy and You: Support for People with Cancer cancer.gov/cancertopics/coping/chemotherapy-and-you - Radiation Therapy and You: Support for People with Cancer cancer.gov/cancertopics/coping/radiation-therapy-and-you	1 (800) 422-6237
Stupid Cancer	stupidcancer.org	1 (877) 735-4673
Treatment/diagnostic information		
National Library of Medicine-Medline	nlm.nih.gov/medlineplus/druginformation.html	1 (888) 346-3656
Appearance		
Beauty and Cancer Program (UW Medicine)		(206) 598-3604

Organization	Website	Phone
Look Good Feel Better	Lookgoodfeelbetter.org	1 (800) 395-5665
Fitness/exercise		
Team Survivor Northwest	teamsurvivornw.org	(206) 732-8350
Insurance and employment rights		
America's Health Insurance Plans	ahip.org	(202) 778-3200
Cancer Advocacy Now	canceradvocacy.org/cancer-advocacy-now	
Employment Rights Cancer and the Americans with Disabilities Act	eeoc.gov/laws/guidance/cancer-workplace-and-ada	
The Job Accommodation Network	askjan.org	
Fair Employment for Cancer Patients and Survivors	canceradvocacy.org/resources/employment-rights/how-employment-discrimination-laws-protect-cancer-survivors	
American Cancer Society Health Insurance	cancer.org/treatment/finding-and-paying-for-treatment/understanding-health-insurance.html	
Fertility		
Livestrong Fertility	livestrong.org/what-we-do/program/fertility	1 (855) 220-7777
Resolve-The National Infertility Association	resolve.org	(703) 556-7172
Save My Fertility	savemyfertility.org	(312) 503-2504
Travelers with disabilities and medical conditions		
Transportation Security Administration	tsa.gov/travel/special-procedures	
Skin cancer		
Skin Cancer	skincancer.org	

Organization	Website	Phone
U.S. Food and Drug Administration	fda.gov (search for sun safety)	
Survivorship		
The National Coalition for Cancer Survivorship	canceradvocacy.org	1 (877) 622-7937
Patient Access Network Foundation (help with post-transplant medication costs)	panfoundation.org	
Patients Cancer Survivors Network	csn.cancer.org	
Center for International Blood & Marrow Transplant Research	cibmtr.org	
National Marrow Donor Program Post-Transplant Care	bethematchclinical.org/post-transplant-care	

Medical care for family members

Fred Hutch provides medical services to patients only. All other family members who need medical treatment while in Seattle have the following options. You may want to contact your insurance provider to find out which, if any, are covered under your health care plan.

- Go to your local doctor.
- Visit a walk-in, urgent care clinic in Seattle. These clinics are open 7 days a week for walk-ins and appointments. There are several options in Seattle including the following UW clinics.
  - **Urgent care.** You can wait in person, visit uwmedicine.org/services/urgent-care to get a place in line, or call to make an appointment. If you sign up online, you'll receive a text message when it's time for you to go to the clinic. For appointments at Seattle urgent care clinics, call:
    - Ballard (206) 789-7777
    - Ravenna (206) 525-7777
  - **Virtual clinic.** Call the UW Medicine Virtual Clinic 24/7 at (855) 520-5250.
  - **Appointment-only clinic.** Belltown: (206) 443-0400. This clinic does not offer urgent care.

Directions and map to UW Medical Center-Montlake

To UW Medical Center-Montlake from Fred Hutch South Lake Union

1. Travel north on Eastlake Ave. E.
2. Cross the University Bridge.
3. Turn right at N.E. Campus Pkwy.
4. Turn right at Brooklyn Ave. N.E.
5. Turn left at N.E. Pacific St.

Parking at UW Medical Center-Montlake

Parking lot is across the street from the Medical Center on NE Pacific Place off of Pacific Street. After you park, you can access the hospital by walking through a pedestrian tunnel. Note: Garage height restriction is 6′8″.

Address

Fred Hutch Hospital and UW Medical Center - Montlake

1959 N.E. Pacific St.
Seattle, WA 98195
(206) 598-3000

Fred Hutch clinic, Fred Hutch Hospital, and UW Medical Center-Montlake (Surgery Pavilion and Triangle) parking garage offer same day reciprocal parking. Simply bring your receipt from a participating garage to your next appointment and it will be honored.

Map and parking for Fred Hutch – South Lake Union

Building 1

Main entrance (where the Transplant Clinic is located) and car turnaround for drop off and pick up are located at:

1354 Aloha St.
Seattle, WA 98109

Parking is located in the alley off of Aloha (see map).

Building 2

Patient entrance and parking are located at:

820 Yale Ave.
Seattle, WA 98109

Parking in both buildings is $4 with validation.