

Preparing for Transplant

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Welcome

Welcome to the Fred Hutch Cancer Center Bone Marrow Transplant Program, where we perform around 400 transplants each year. We are devoted to giving you the best possible care and support.

Most people considering transplant have a lot of questions about treatment and its side effects, about what they can expect, and about how they can prepare. We created this manual to help answer some of those questions. As you read it, please write down any thoughts you have.

Feel free to share it with your caregiver, family and friends. They can also read it and our Caregiver Guide by visiting the Fred Hutch patient education page at FredHutch.org/patient-education or scanning the QR code. We hope this manual becomes a valuable resource as you consider a transplant at Fred Hutch.



Fred Hutch brings 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.

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

About us

Fred Hutch

Fred Hutch Cancer Center is an independent, nonprofit organization that serves as UW Medicine's cancer program. This unique relationship creates a powerful team for adults facing cancer. Fred Hutch unites comprehensive cancer care with advanced scientific research to provide the latest cancer treatment options and accelerate discoveries that prevent, treat and defeat cancer and infectious diseases worldwide. Fred Hutch is the only National Cancer Institute-designated cancer center in Washington and has earned a global reputation for discoveries in cancer, infectious disease, and basic research, including important advances in bone marrow transplantation, HIV/AIDS prevention, immunotherapy, and COVID-19 vaccines.

Our Mission

Fred Hutch Cancer Center unites innovative research and compassionate care to prevent and eliminate cancer and infectious disease. We're driven by the urgency of our patients, the hope of our community and our passion for discovery to pursue scientific breakthroughs and healthier lives for every person in every community.

Our Values

Our values are grounded in and expressed through the principles of diversity, equity, and inclusion (DEI). Our mission is directly tied to the humanity, dignity, and inherent value of each employee, patient, community member, and supporter. Our commitment to learning across our differences and similarities make us stronger. Our values include:

- Collaboration
- Compassion
- Determination
- Excellence
- Innovation
- Integrity
- Respect

Our blood and marrow transplants

Blood and marrow transplant (BMT) is often the best therapy for blood cancers. It's also among the greatest success stories in cancer care — and it started right here. Through the Blood and Marrow Transplant Program at Fred Hutch Cancer Center, we've performed more than 17,000 transplants. This makes our program not only the first, but also one of the most respected and successful of its kind in the world. Our depth and breadth of knowledge allows us to treat both common and very rare blood diseases, and help manage any complications that might arise, helping you get better faster. And if you need a donor, we will help you find one. Today, because of advanced research, nearly everyone who needs a donor can be matched with one.

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

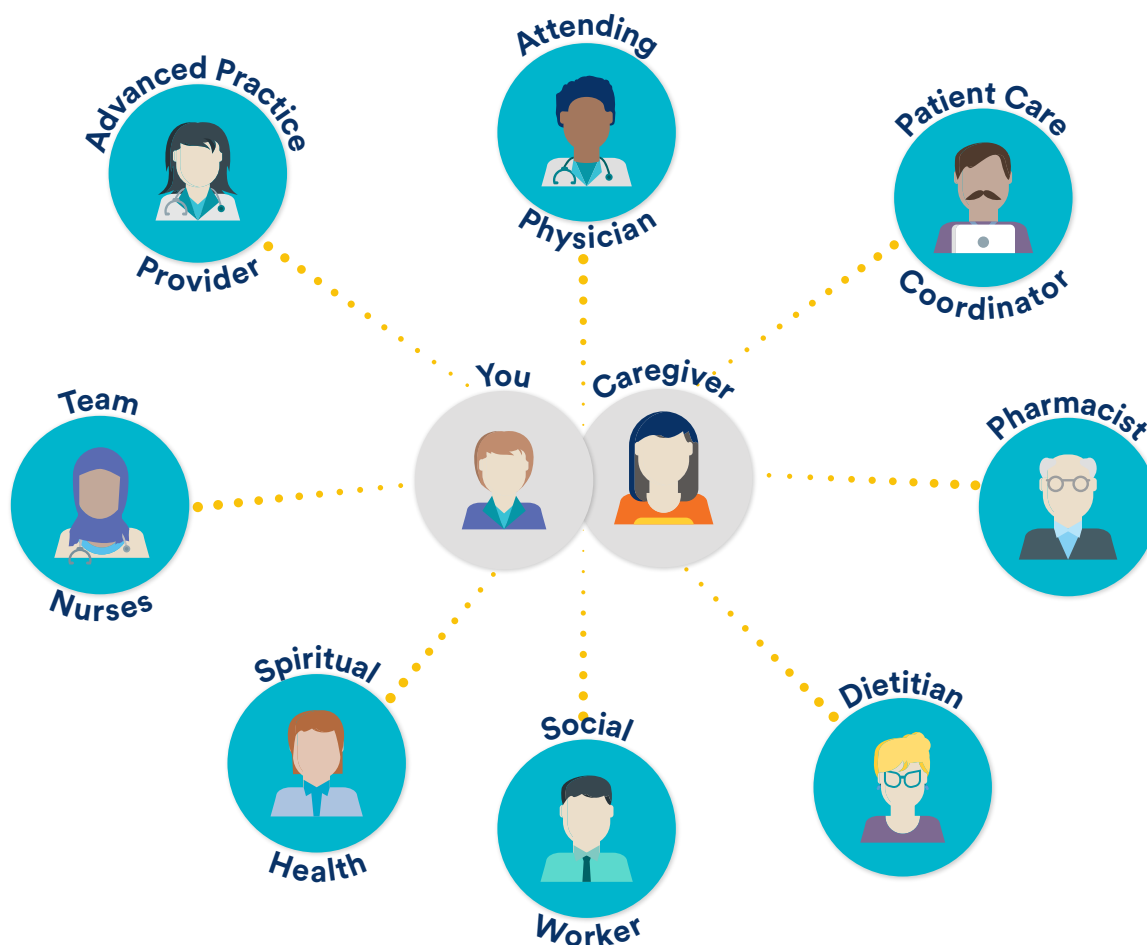
We welcome service animals that fall under titles II and III of the Americans with Disabilities Act. If you bring a service animal, be sure to check in at the front desk on the first floor when you arrive. The front desk staff will ask you some screening questions; if your animal qualifies, they will 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.



Your care team

You, your family, and caregivers are the most important part of your care team. Your team is 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 your team specializes in working with transplant patients and will be well-versed in your individual 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-Montlake 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 obtain 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.
- 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 Assistance Resources
- Housing Options
- Integrative Medicine
- Interpreter Services
- Living Tobacco-Free Services
- Medical Nutrition Therapy
- Oncoreproduction and Fertility
- Pain Clinic
- Patient and Family Resource Center
- Physical Therapy
- Psychiatry
- Retail Stores: Shine and the Gift Shop
- Spiritual Health
- Palliative Care
- 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.

What is a transplant?

This section describes what a transplant is, why it's done, the different types of transplants, and answers other 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 – the cells that form blood cells – are replaced with healthy ones.

Why is a transplant done?

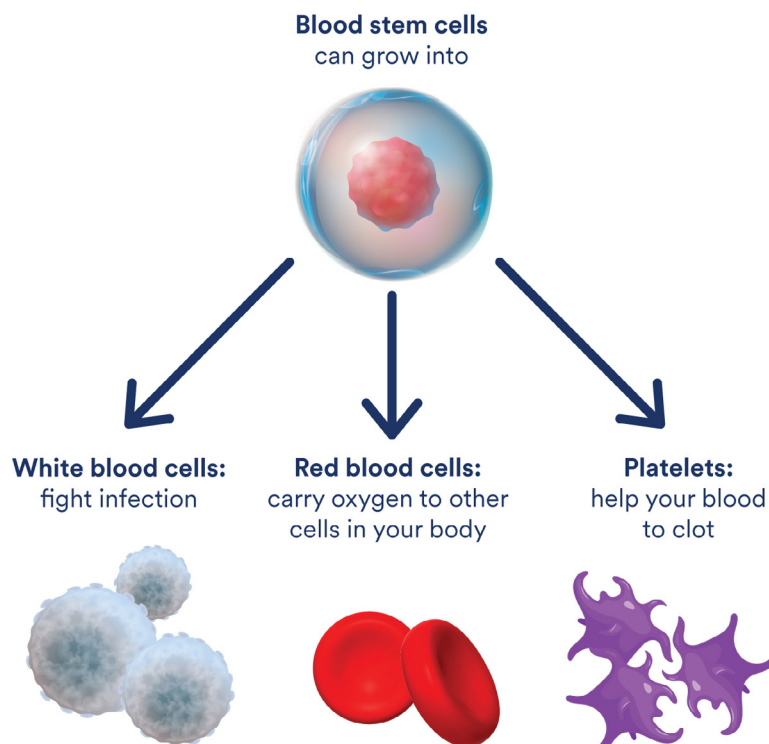
The purpose of a transplant is to cure or treat certain types of blood cancers or disorders using high doses of chemotherapy, radiation, or both. The intense treatment decreases the number of stem cells that make blood cells. After treatment, new stem cells are put into your body through an intravenous (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.

What does the transplant process look like?

In general, there are 7 steps to getting a transplant: planning ahead, preparing for transplant, conditioning, transplant, waiting for engraftment, recovery after engraftment, and long term follow-up. They are each described in the next section of this packet.

What are the different types of transplants?

The 2 main types of transplants are:

- **Autologous (auto) transplant:** Stem cells are collected from your bone marrow or bloodstream, stored in a freezer, and given back to you after you have received chemotherapy with or without radiation.
- **Allogeneic (allo) transplant:** You receive stem cells from another person, either someone in your family or an unrelated donor, or cord blood after you have received chemotherapy with or without radiation. You may receive high dose chemotherapy or low dose chemotherapy depending on your treatment plan.

If someone in your family isn't a "match" for you, we may be able to find a donor in the general population that closely matches your tissue type. We search for donors using the National Marrow Donor Program (Be the Match) which gives us access to about 40 million donors worldwide.

In a cord blood transplant, blood is collected from a baby's umbilical cord and placenta after they are born. This blood is rich in blood-forming cells. We search for cord blood unit matches through the National Marrow Donor Program.

The other types of transplants are:

- **Haplo transplant:** Your donor's cells half match yours and usually come from a parent, child, or sibling.
- **Tandem transplant:** This is when 2 transplants are performed on the same person within about 2 months of each other.

What type of transplant is best for me?

You and your Fred Hutch physician will decide which type of transplant is best for you. The decision is made based on your overall health and the type and stage of disease you have.

How do I decide if I should get a transplant?

Many people feel that having a transplant is a major turning point in their lives. They describe the process as an emotional rollercoaster. Research has shown that hope is a helpful force in surviving and coping with illness. At the same time, you may have feelings of uncertainty even after the decision is made. If there is something you don't understand, please ask the attending during your consult with them. Having a transplant is a big decision and we want to make sure you have all of the information you need.

How long does the transplant process take?

The whole process takes between 2 ½ and 4 months, depending on your disease, treatment plan, and your response to the treatment. Some people spend 2 to 3 weeks in the hospital at Fred Hutch at UW Medical Center-Montlake and then receive care in the Fred Hutch Sloan Clinic for a number of weeks to months. Other patients will receive most of their treatment at our clinic and enter the hospital if needed. Your care team will explain the expected length of treatment to you.

The 7 steps of a transplant

Your experience is unique

The information below is meant to give you a general idea of the transplant experience at Fred Hutch. Keep in mind that your experience is unique. It will differ from others based on your treatment plan and response to treatment.

Transplant is made up of 7 steps:

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

The chart on the next two pages summarizes what happens during each of these steps. The details of each step are described in more detail in the following sections.

To watch a video about the transplant experience at Fred Hutch, visit FredHutch.org/transplant-video.

Step	What to do
Planning ahead	<ul style="list-style-type: none"> • Select a caregiver(s) who can be with you daily throughout your time here. Your caregiver should be someone who understands their roles and responsibilities and is able to fulfill them. • Ask your insurance provider about housing benefits. • Talk with Patient Finance about the costs of transplant; consider fundraising. • If you have children, make decisions about childcare and schooling. • Arrange housing and transportation in Seattle. • Complete advance directives (this can also be done in Seattle). • Confirm your arrival date with Intake. • Discuss dental, nutrition and fertility treatment with Intake. • For an allogeneic transplant: Work with the Intake team and attending physician to select donor.
Preparation	<ul style="list-style-type: none"> • Arrive at Fred Hutch, meet your primary care team: physician, advance practice provider (APP), team nurse, and patient care coordinator. • Meet with other members of your care team from Nutrition Services, Social Work, Oral Medicine, Spiritual Health, Pharmacy, and Psychology/Psychiatry as needed. • Get a medical evaluation. • Attend consent conference; read and sign consent forms and treatment plan. • Attend teaching sessions with your team nurse and classes for patients and caregivers. • Ask questions; talk with staff about any concerns. • Make a plan on how to cope with transplant, such as how you will: get to clinic frequently, if not daily; stay organized; cope with emotional and physical effects. • Get central line placed. • Keep active by walking or doing other exercise that you enjoy. • For an autologous transplant: Stem cells are collected and stored.

Step	What to do
Conditioning	<ul style="list-style-type: none"> • Receive conditioning therapy (chemotherapy with or without radiation) • Take medication to prevent and relieve symptoms • Monitor and report any signs or symptoms of infection • Let staff know how you are doing and what you need • Balance rest and activity
Transplant	<ul style="list-style-type: none"> • Receive infusion of cells through your central line • Celebrate!
Waiting for engraftment	<ul style="list-style-type: none"> • Monitor your counts • Receive transfusions of blood cells or platelets, if needed • Staff will monitor you closely for side effects or complications of treatment and signs of infection; you will be admitted to the hospital or seen in the clinic almost every day • Take advantage of support services such as spiritual health and social workers • Keep as active as possible • Set goals for each day and watch your progress
Recovery after engraftment	<ul style="list-style-type: none"> • Your caregiver helps you with recovery: giving medications, monitoring your symptoms • Start eating regular meals • Gradually increase activity • Take rest periods for recovery • Take things “day by day” and keep track of daily goals to see progress • Get out and take a walk • Prepare to leave Fred Hutch: meet with Long-Term Follow-Up team, attend departure class
Long term recovery	<ul style="list-style-type: none"> • Return to the care of your referring doctor • Report any new symptoms to your doctor right away • Contact the Long-Term Follow-Up staff if you have questions

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, certain medical concerns, and how your treatment will be paid for. This section provides information on each of these topics.

Housing requirement

Our clinic is located in the South Lake Union neighborhood of Seattle. You will need to live within a 30-minute drive to the clinic while you're under our care. See the map at the back of this manual to see which areas this includes.

At Fred Hutch, we have two extended-stay residences for patients and their families: Behnke House and Pete Gross House. Please read our housing guide for detailed information about both options. You can ask Intake for a hard copy of the guide if you don't have one, or you can find it at FredHutch.org/patient-housing.

You are responsible for choosing the most appropriate place to live and arranging the details of your stay with our housing team.

Contact your insurance company to learn if there is a housing and/or travel benefit included in your policy. If you have Washington State Medicaid, see the Fred Hutch housing list and follow the instructions for pre-authorization. If you choose housing that is not on the list, be certain that you are clear about the terms of your lease agreement.

A shuttle runs Monday through Friday between the Fred Hutch Sloan Clinic, Pete Gross House and Behnke House. There is also a shuttle that runs Monday through Friday between the Fred Hutch Sloan Clinic and UW Medical Center-Montlake.

If you would like to learn about other housing options, such as hotels, RV parks, and pet-friendly locations, please contact our Housing team so they can help you.

For more information on Housing services, contact the Housing team at (206) 606-7263 or email them at housing@fredhutch.org.

Transportation

If you are coming from out of town, having a car is optional. Parking in Seattle can be challenging and expensive. And as a patient, you may not be able to drive yourself much of the time due to safety concerns.

Caregiver requirement

Due to the intensity of the treatment, you will need to have a caregiver with you 24 hours a day during treatment and for several weeks after treatment. Your care team will determine how long you will need a caregiver after transplant. This is the same time that you are also expected to live within a 30-minute drive to Fred Hutch.

A caregiver monitors you for symptoms, goes with you to appointments, helps with medications and food preparation, and provides emotional support and physical care. You may find it helpful to have one main caregiver, with help from other family members, friends, or hired caregivers. We recommend bringing your caregiver to appointments even before you start treatment to meet your care team and learn about your treatment plan.

In general, there are 3 levels of support your caregiver will need to provide:

Consistent support: This is when your caregiver is present most of the time and takes breaks less than 3 to 4 hours long. When you're left alone, you should have access to the phone and be able to contact emergency services, operate pumps, get to the restroom, and access food and fluids.

Intermittent support: This is when you do not need a caregiver the majority of hours within a 24-hour period. A caregiver is available 2 to 3 times per day to help you with dressing changes, medications, transportation, and processing information provided during conferences or clinic visits.

Minimal support: This is when you do not require a caregiver, but do benefit from emotional support, such as during a clinic visit or conferences.

You will be required to submit a written plan that details the name(s) of your caregiver(s), dates they will care for you, and their relationship to you. You will not be accepted for transplant at this center if you cannot provide a written caregiver plan. If needed, we are happy to help you explore options for finding a caregiver.

Sample caregiver plan

Dates	Caregiver name	Relationship	Length of time	Comments
Aug 1–28	Jane Smith	Sister	4 weeks	Jane cannot drive at night
Aug 29–Sept 5	John Smith	Brother	1 week	
Sept 6–Oct 1	Mary Smith	Mother	4 weeks	

The role of caregiver

This section explains the role of caring for a person undergoing transplant and the responsibilities that come with it.

Physical and emotional support

Caregivers are responsible for helping with your daily health-related tasks from the time treatment starts until you're discharged from day-to-day care. Caregivers help give medications and intravenous fluids, take care of the central line, and make sure that infection prevention and food safety guidelines are followed. They also monitor you for symptoms and side effects, and help you adjust physically and emotionally.

Fred Hutch offers classes that teach you and your caregiver how to do all of these things, and your nurse will do individual teaching, too. You will receive a Quick Reference for Symptoms that details why, when and who to call when you have symptoms during or after transplant.

Appointments

Caregivers are required to come to all appointments, beginning with your first appointment. During this time, you will learn details about the therapy, what to expect, and the schedule of appointments. It is important for your primary caregiver to hear this information as early as possible. This is also an opportunity for your caregiver to develop a relationship with the care team and learn about the treatment plan.

Hospital stay and discharge

Depending on how you react to transplant, you may be admitted to the hospital. If this is the case, your caregiver is not required to stay; however, many people who are receiving treatment find it helpful to have their caregiver with them. UW Medical Center-Montlake and Fred Hutch Cancer Center Hospital located at UW Medical Center-Montlake are designed for caregivers to stay overnight.

Once discharged from the hospital, you may be weak and fatigued. For more severe side effects, you may need to have special equipment at home such as a walker, shower chair, or raised toilet seat.

Nurses on the Transition Services team will provide you resources for home infusion, medical equipment, and home health care if you need them. They will also provide you hospital discharge education.

Caregiver responsibilities

In addition to what was mentioned above, the checklist below provides an overview of some responsibilities you will have as a caregiver. Your care team will review these responsibilities with you and teach you what you need to know. You can contact your clinical nurse coordinator or Transition Nursing Services with questions.

As a caregiver, you will need to:

- ☐ Be able to reach a nurse 24 hours a day.
- ☐ Be able to contact the home infusion and/or homecare company.
- ☐ Use the emergency call card when needed.
- ☐ Make sure that you and the person you're caring for both have an Emergency Call Card with you at all times. You will need to show this card to medical staff if the person you're caring for needs to go to the emergency room or see any physician.
- ☐ Recognize the most common symptoms of transplant treatment.
- ☐ Understand food safety and food shopping.
- ☐ Understand infection control practices.
- ☐ Understand central line care and how to protect the line during a shower.
- ☐ Understand the transplant medications, when and how to give them, and what to do when running low.
- ☐ Know how to use home equipment such as walkers, diabetes management devices, and other assistive devices.
- ☐ Know how to care for you and the person you're caring for in stressful situations.
- ☐ Know about preventing falls and lifting the person you're caring for safely.
- ☐ Arrange transportation to and from the clinic, track appointments, come to appointments.
- ☐ Provide emotional support.
- ☐ Prepare food and keep the house clean.
- ☐ Communicate with family members and friends.

Caregivers need to care for themselves, too

Being a caregiver is demanding. Because treatment can last several weeks, we encourage your caregiver to ask family members, friends, or professional home health care for help. We strongly encourage all caregivers to read our Caregiver Guide to learn how they care for themselves while caring for you, too. The guide also lists home health care options. View the guide at FredHutch.org/caregiver-guide. You can also ask your care team for a hard copy.

Childcare

If you have young children, you'll need to make decisions about their care—whether they'll come with you or stay at home, and who will care for them either way—before you come to Seattle. Because it can be very difficult for a partner or spouse to care for you and your children at the same time, we recommend asking one person to care for your children and another person to be your caregiver, if possible.

We do not provide day-care or after school care facilities for infants or children. We don't recommend sending children to community day care facilities because of increased exposure to common respiratory viruses.

While there are no age limits for people visiting you in the hospital, it's difficult for infants and young children to be at the hospital for long periods of time since there isn't anything to entertain them.

Medical care before transplant

Fertility preservation

The chemotherapy and radiation treatment used in transplant increases your risk for infertility. This means, if you are currently able to conceive a child, you may not be able to after transplant. **Discuss your fertility and fertility preservation options with your physician before you arrive for treatment. If you choose to freeze your eggs or bank sperm, it must be done before you start your transplant treatment.**

How treatment impacts fertility

- Females often stop having periods and may resume their menstrual cycle after treatment. Some people resume normal menstrual cycles but are still unable to become pregnant due to damage to eggs in the ovary. Others may experience complete menopause.

- Males often stop making sperm completely or have very low sperm counts during and for several months after cancer treatment. Not every person who ejaculates will resume normal sperm production and may be infertile.
- You will need to test your sex hormones, sperm counts, or ovarian function after treatment to see if your fertility is intact.

Fertility preservation options

A fertility specialist (reproductive endocrinologist) can provide more information about your fertility status and the opportunity to store sperm, eggs, or embryos.

- For females, the standard approach is to collect eggs, which can require hormone therapy and a medical procedure. This process can take up to 2 weeks. Eggs can be frozen individually or fertilized with sperm to create embryos before freezing. Eggs and embryos can be safely frozen for many years.
- For males, sperm banking is the standard approach. Sperm can be collected several different ways, but the simplest is to provide a sample of ejaculated semen. Sperm can be safely frozen for many years.

Adoption and other family-building options may be available after cancer treatment.

Fertility and insurance

Fertility services are not always covered by insurance. Work with your reproductive clinic to determine what may or may not be covered and what the costs will be. Ask them about financial assistance resources if you need them. Don't let fear of cost prevent you from asking what services are possible.

Your weight

If you are at a normal weight now, you do not need to try to gain weight before transplant. If you are underweight now, we recommend you try to gain weight. If you wish to take vitamins or supplements, we recommend a one-a-day multivitamin and mineral supplement that is iron free (usually labeled as vitamins for older adults). Dietitians can help guide you on appropriate food choices.

Dental care

Your mouth can be a source of infection after transplant. These infections are usually traced to diseases in your teeth and gums that were there before transplant. It is important to get a complete dental examination, including X-rays, before you come to Seattle for transplant.

If your medical condition allows you to do it safely, you should also get a dental cleaning, review of oral hygiene care, and repair any decayed or broken teeth before you arrive. Braces should be removed, and loose or poorly fitting dentures should be adjusted. If you have any questions, please contact Fred Hutch Oral Medicine at (206) 606-1333.

The cost of transplant and related expenses

Transplant costs

Transplantation is a highly technical and expensive treatment, and the cost varies according to treatment plan and insurance coverage. Fred Hutch requires a guarantee of funds to cover the costs, either by health insurance or by prepayment. Patient Financial Services will evaluate your insurance coverage.

Cost of living in Seattle

It is important that you consider the cost of living in Seattle during transplantation. Many families arrange fund-raising efforts at home before coming to Seattle for a transplant. These funds can help with transportation and living expenses, as well as additional medical expenses not covered by insurance. Please contact your insurance case manager to see if any of these expenses are covered by your insurance plan.

Financial support

Please see the Financial Support and Fundraising section of this packet to learn more about organizations that may help with expenses and to learn about fundraising.

Step 2: Preparation

This section explains how we will help prepare you for treatment when you arrive to Seattle.

Education

Transplant manual

During your arrival appointment at Fred Hutch, you will receive a transplant manual that includes information about the transplant process and other important information. The manual is not meant to be read in one sitting. Instead, it's meant to be a reference throughout your treatment.

Classes

You and your caregiver will take classes online and have individual teaching sessions on topics such as how to manage your care at home and follow food safety guidelines. Online classes are offered on a weekly basis to patients, caregivers, friends, and family members. Class recordings are available at FredHutch.org/patient-education-videos. Scroll down to “Blood and Marrow Transplant.”

Medical evaluation

Physical exam and tests

Before treatment starts, you will have a medical evaluation that includes a physical examination, 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 assess your pre-transplant function, strength, and range of motion. This gives us baseline data to compare with your post-transplant progress.

Donor medical evaluation

If a family member is your donor (providing bone marrow or stem cells for you as part of the treatment), the family member will have a medical evaluation during the beginning of your treatment. Most out-of-town donors make a second trip to Seattle to donate later in the process. If family members are unable to travel to Seattle, there are also processes to collect cells from them through the Be The Match registry. Family members who are not donors and have limited time off from work or school may want to delay their arrival in Seattle until you begin treatment.

Feelings of uncertainty

As you prepare for your transplant, you may experience a sense of urgency to get started with treatment and feel “in limbo” 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.

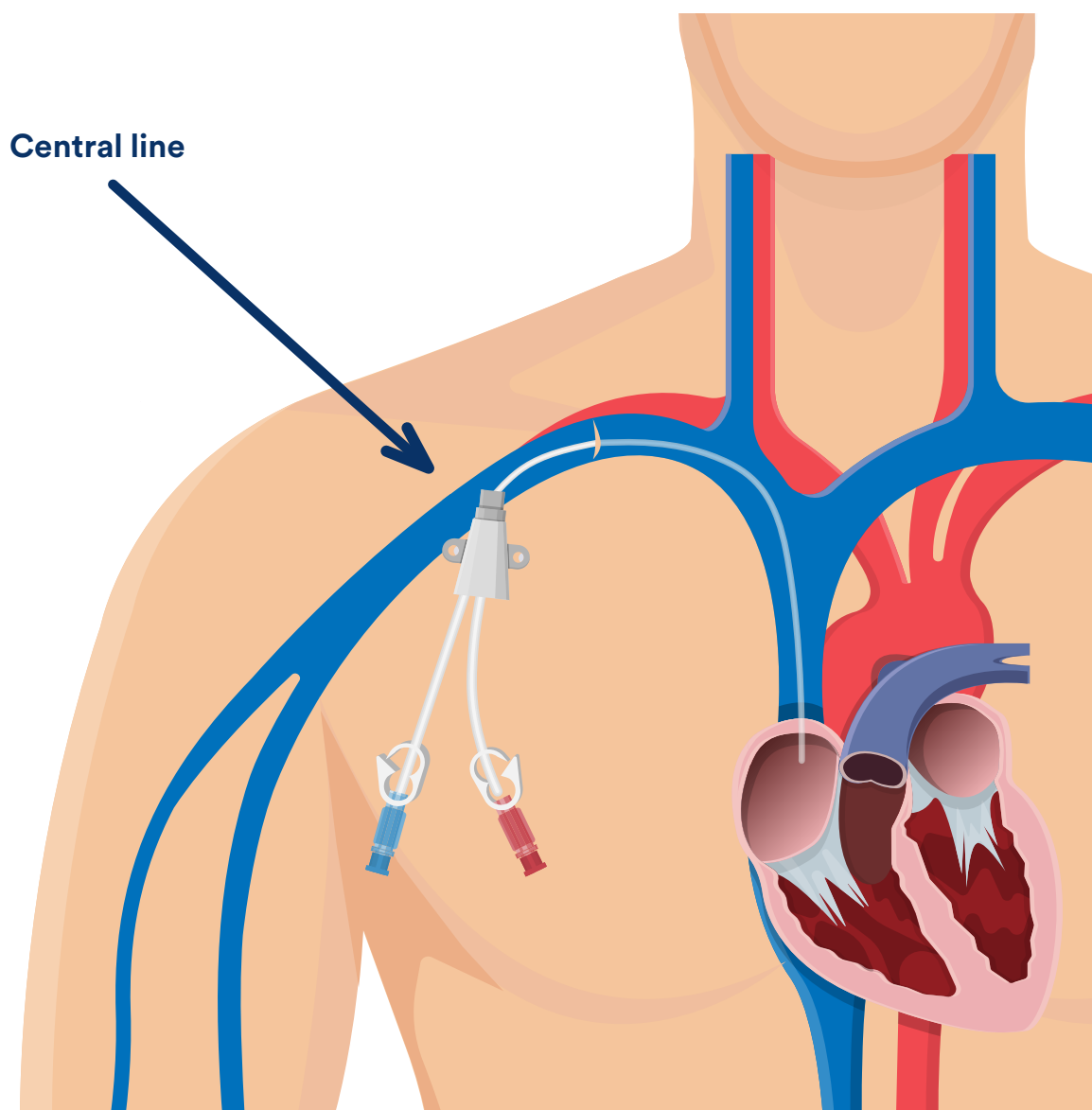
At the conference, you will sign consent forms that summarize the potential risks and benefits of each part of the proposed treatment. It is important that you understand this information and that all of your questions are answered before you sign these forms. You must give your written consent for the 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 undergo a transplant with us. We encourage you to read and ask questions about all studies and protocols before signing them.

Central intravenous (IV) line placement

In preparation for treatment, 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 to numb your neck and chest. You may also be sedated.



Communicating with your family, friends, and staff

Former patients and family members tell us that when faced with life-threatening illness, they have found it helpful to discuss their fears and concerns with family, friends, and staff. Some of the things we have heard are:

- “I thought I was the only one who felt that way until I talked with others.”
- “Talking about my fears helped me put them aside so I could concentrate on curing my illness.”
- “It has brought our family closer together.”

Even though you or your family members may want to talk about the possibility of dying, it can be very hard to do so, even with the people you are closest to. Our social workers, spiritual health clinicians, nurses, physicians, and psychologists can talk with you about your concerns and fears and help you talk with your family. They can also help you identify resources and offer support that can help you throughout your transplant experience.

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 used to prepare you for an autologous or allogeneic transplant. This 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.

Side effects of high dose conditioning, continued

Please ask questions and tell us about changes in your symptoms, because 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.

Step 4: Transplant day

The day you receive stem cells is “transplant day.” The process doesn’t take long, but it is a significant event.

You will receive your treatment in either the hospital or the clinic.

If you are getting an allogeneic transplant:

The bone marrow, cord blood, or peripheral blood stem cells that were collected from your donor are placed in bags that look very much like those used for blood product transfusions. You will receive the cells through your central line.

If you are getting an autologous transplant:

Your own harvested and frozen stem cells are thawed and given to you through your central line. The preservative used during freezing has an odor and taste similar to garlic.

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.

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 a transplant with lower dose conditioning, a rising white count does not necessarily mean engraftment. In this type of a transplant, we measure engraftment through a DNA blood test. 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 an uncommon but real possibility.

Infection risk and other complications

Until the new cells engraft, you are at high risk for infections, bleeding, and fatigue. If you are unable to eat and drink at this time, you may receive intravenous (IV) nutrition until you can eat and drink adequately. Possible complications include:

- **Viral, bacterial, and fungal infections** can be serious problems after a transplant. You will take medications to help prevent certain infections during your treatment.
- **Pneumonia** may occur in the first months after transplant. We will watch for early signs of pneumonia.
- **Sinusoidal obstruction syndrome (SOS)** is when the liver isn't doing its job of removing waste products from your body. This is a possible complication for allogeneic transplants only. If this occurs, it will most likely occur during the first month after transplant. We will give you medication to prevent SOS.

Emotional impact

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. In fact, you may feel like you are on an emotional roller coaster. You may feel like you have lost personal control of your life as you cope with the daily monitoring and medical procedures. All of these are common feelings during transplant and coping with them can be a challenge. It may help to develop a schedule that provides you some structure during this time.

Step 6: Recovery after engraftment

Coping with recovery

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 accomplish.

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.

Monitoring for graft-versus-host disease (GVHD)

GVHD is a complication that may occur after allogeneic transplants. As the new donor stem cells start growing, they may recognize your body as foreign and attack some of your organs. There are 2 forms of GVHD: acute GVHD and chronic GVHD. Symptoms may be mild and treated in the outpatient clinic or can be serious and require hospitalization.

Acute GVHD might develop in your skin, liver, or gastrointestinal tract and symptoms might appear within weeks after your transplant.

Chronic GVHD can begin as early as 3 months after transplant and may continue for months/years after transplant. Chronic GVHD may require long term treatment and monitoring.

Your care team will teach you signs and symptoms of GVHD and give you medications to prevent and treat it (if you develop it).

Preparing to leave Fred Hutch

- **Allogeneic transplant patients:** The average allogeneic transplant patient stays in Seattle for approximately 100 days after stem cells are infused. The estimated time you should plan to stay in Seattle including the pre-transplant evaluation and conditioning is about 4 months. After you are producing adequate numbers of red blood cells, white blood cells, and platelets, and are medically stable, you can make plans to leave Fred Hutch and return home. We will do a complete medical evaluation at this time and you will receive the results and recommendations in a conference with your care team.
- **Autologous transplant patients:** The average autologous transplant patient stays in Seattle 40 days after stem cells are infused. The amount of time in Seattle before transplant will vary depending on the procedure used to collect stem cells.
- **Tandem transplants:** If you are having a tandem transplant, you may be in Seattle as long as 7 to 8 months from start to finish.

Transitional transplant clinic (TTC)

Transitional Transplant Clinic is a clinic for patients with complex conditions such as GVHD that is not well controlled, serious infections, or other conditions that require ongoing management. Your transplant team will evaluate your health condition and give you an estimate of how long you are expected to be in Seattle based on your proposed treatment plan.

Long Term Follow Up class

You will need to attend the Long-Term Follow Up (LTFU) “departure” class which meets online and provides specific instructions on how to care for yourself after leaving Fred Hutch. You can also watch a video of the class online by visiting FredHutch.org/patient-education-videos and scrolling down to “Blood and Marrow Transplant.”

Step 7: Long-term follow-up

It takes time to recover from a transplant. This section includes resources and information about your long-term recovery.

Energy level and return to work

You may not have much energy for weeks to months after returning home. It may take up to a year or longer for your immune system to become normal. Your care team will tell you to continue following infection prevention guidelines during this time. The decision to return to school or work full time depends on your immune function, medical status, and the type of work you will be doing.

Long-term follow up

Fred Hutch's Long-Term Follow-Up (LTFU) department is dedicated to managing the long-term recovery needs of our patients. They are available to you and your referring physician by telephone or email to answer questions and assist you in your recovery. They send requests to you and your physician on a yearly basis to assess any prolonged medical, psychological, or social problems you think may be related to your transplant. We recommend allogeneic transplant patients come back to Seattle 1 year after transplant for a detailed evaluation of your marrow graft and immune system, and to evaluate for GVHD.

Potential chronic problems

Some complications are more likely to arise several months after your transplant. It is important that you report any new symptoms to your referring physician promptly. Some complications include:

Chronic graft-versus-host disease (GVHD) for allogeneic transplant patients

Chronic GVHD occurs in about one half of allogeneic transplant patients. It generally develops 3 to 24 months after transplantation. If you get chronic GVHD, you may experience skin changes, mouth irritation, liver abnormalities, vision changes, gastrointestinal distress, or breathing problems.

There are medications to treat chronic and acute GVHD. If you develop GVHD, your referring physician will work with the Fred Hutch LTFU team to determine

which medications you should take at home. GVHD does not occur in autologous transplant patients.

Infertility

One of the possible side effects of total body irradiation or high-dose chemotherapy is infertility. Infertility is defined as not being able to get pregnant despite having frequent, unprotected sex for at least a year for most couples. Many also experience premature menopause, the symptoms of which can be eased with hormone replacements.

See the fertility preservation section of this packet for information on preserving your fertility before you start the transplant process.

Cataracts

Total body irradiation and steroid therapy can increase the possibility of developing cataracts, a clouding of the eye lens. Cataracts can be surgically removed.

Recurrence of disease

Unfortunately, even with a bone marrow transplant, some patients experience a recurrence of disease. Despite the risk of serious complications and relapse, bone marrow transplantation does offer the hope of cure. Some of our first transplant patients are now decades post-transplant and living normal, productive lives.

Quality of life after transplant

The large majority of long-term survivors after transplant say they are leading meaningful lives. What did it take to re-establish their lives? For some, it included dealing with chronic physical complications. For others, it required an adjustment in relationships with their spouse, family, and friends. Still others changed their work or other priorities. Re-establishing life varies from easy and smooth with few problems to difficult and depressing.

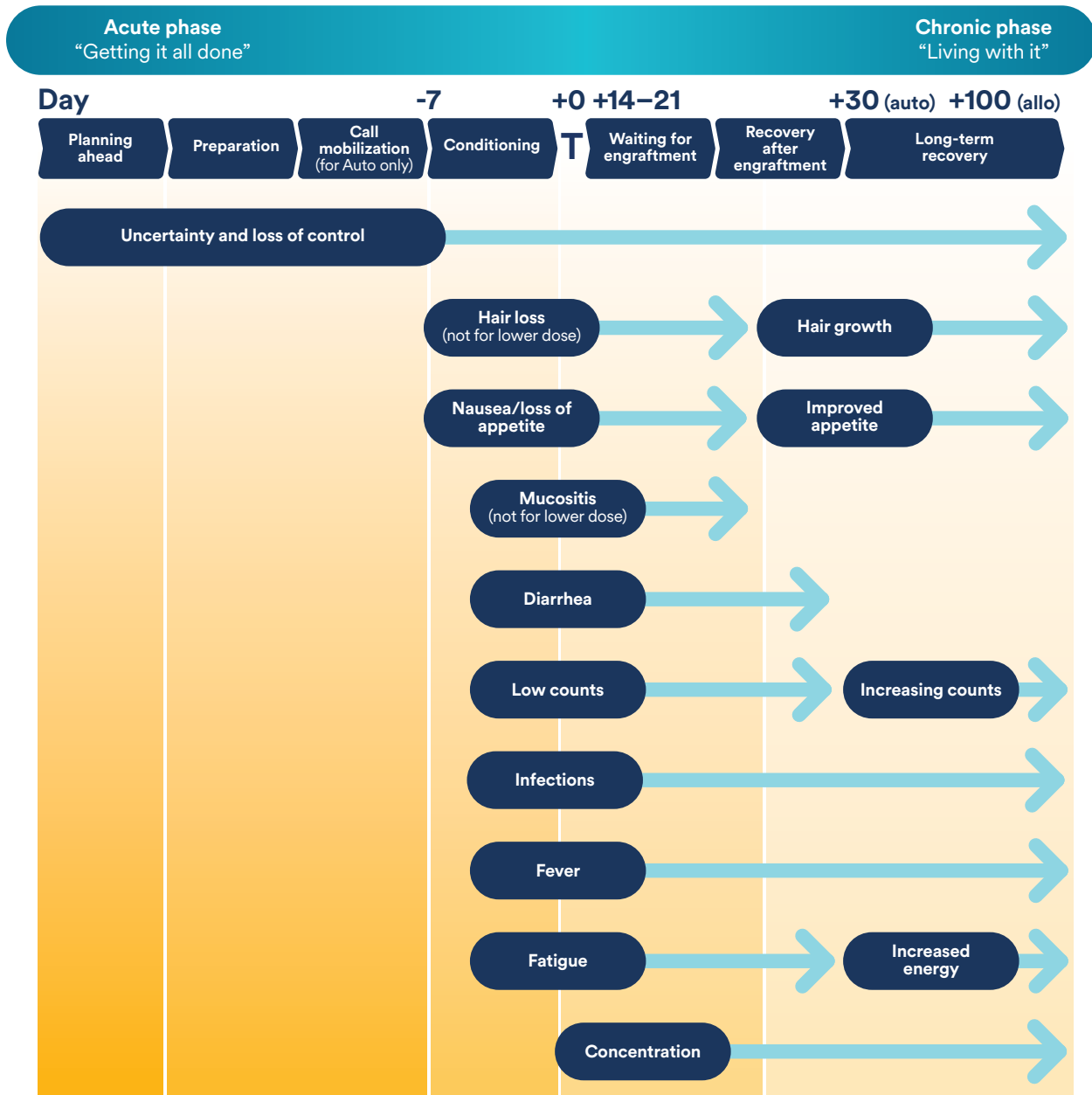
Although the initial re-establishing of life is often a challenge, most survivors report that the quality of their lives is now the same or better than before transplant. They report benefits such as becoming more easygoing, learning how to rise above personal fears, gaining a greater appreciation of life, and discovering a spiritual strength as a result of the transplant experience.

Quality of life after transplant, continued

With these gains, there are also some common problems. Some people report that work or outside activities are less satisfying than before, and one of the more common issues survivors face is diminished sex life and sexual satisfaction. Realistically there are tradeoffs, with some gains and some losses. It is important to continue being open and honest with yourself and your loved ones when you experience problems. There are resources to help you cope with many of them.

Timeframe for recovery

The chart below shows the steps of transplant and side effects you may experience during each step, through your recovery. “T” in the chart stands for transplant day.



Infection prevention

During and after transplant treatment, your immune system will be weak (immunocompromised). This means you may have a higher risk for getting infections. If you get an infection during or after your transplant treatment, it is more serious than when a healthy person gets an infection.

What can I do to prevent infections?

Your care team will give you infection prevention and food and water safety guidelines to follow before, during, and after transplant. It is very important to follow them. Some of the most important steps you can take to prevent infection are to:

- Clean your hands often.
- Wear a mask in the clinic.
- Limit your exposure to others and wear a mask around people outside of your household (after your care team tells you it's OK to see people outside of your household).
- Maintain your personal hygiene.
- Avoid activities with high risk for infection.
- Prevent infection from animals.

To learn more about how to prevent infections before, during, and after transplant, watch these videos:

Allogeneic patients: FredHutch.org/allo-prevent-infection-video
Autologous patients: FredHutch.org/auto-prevent-infection-video

What vaccines do my caregivers and household contacts need?

We recommend anyone you are in close contact with after transplant get the following vaccines. If your caregiver or household contacts have already received the vaccines listed, they do not need to be vaccinated again. Please talk with your care team if you have any questions.

Vaccine for caregiver and household contacts	Recommendations
COVID-19	It is strongly recommended that caregivers and household members should remain up to date with COVID-19 vaccination and boosters as recommended by the Center for Disease Control (CDC).
Hepatitis A	Routine vaccination is recommended for: <ul style="list-style-type: none"> • Children 12 months of age or older, and • Other people at risk for hepatitis A, such as food workers.
Inactivated influenza (the flu shot)	Strongly recommended during each flu season (October to April). All caregiver and household contacts should get the flu vaccine every year.
Intranasal influenza (FluMist®)	The flu shot is preferred over the FluMist® vaccine because FluMist® is a live vaccine that has a low risk of spreading the virus to others the first 7 days after getting the vaccine. If caregivers and household members experience cold and flu symptoms after getting the live FluMist®, they should avoid contact with the transplant patient and visits to Fred Hutch and UW Medicine until symptoms are gone.
Inactivated polio vaccine	Vaccination is not routinely recommended for adults but should be given to children who have not been vaccinated.
Measles, mumps, rubella (MMR)	Vaccination recommended for all people 12 months or older who are not pregnant or immunocompromised. Although MMR is a live vaccine, household transmission does not occur.

Vaccine for caregiver and household contacts	Recommendations
Pertussis, diphtheria, and tetanus	<p>The combined vaccine is recommended without any concerns to the transplant patient. It comes in two different formulas:</p> <ol style="list-style-type: none"> 1. Diphtheria, tetanus, and acellular pertussis (DTaP): for under 7 years of age. 2. Tetanus, diphtheria, and acellular pertussis (Tdap): for adolescents and adults.
Varicella (chicken pox)	<p>Vaccination should be administered to all persons 12 months or older who are not pregnant or immunocompromised and have not had chickenpox. The vaccine is a live vaccine and poses a very small risk of household transmission, usually only if the vaccinated person develops a rash. If the vaccinated person develops a rash, the transplant patient might be placed on an antiviral medication, such as acyclovir, if they are not already taking it.</p>
Shingles	<p>Shingrix (zoster vaccine) is recommended for those 50 years of age or older (2 doses separated by 2-6 months) to help prevent the development of varicella zoster (also known as shingles). Vaccination can decrease the risk of getting shingles, which is important as close contact with household members with active shingles can be a risk for some high-risk cancer patients.</p> <p>The vaccine can be given whether or not they have had herpes zoster before or have gotten a prior dose of Zostavax (a shingles vaccine that is no longer available for use in the United States). It is not necessary to screen, either verbally or by lab test, for evidence of prior varicella virus infection. This is not a live virus vaccine so there is no risk for transmission with vaccination.</p>
Rotavirus	<p>People may receive the vaccine without any concern to the transplant patient. The vaccine is recommended for infants.</p>

Source: Guidelines for Preventing Infectious Complications among Hematopoietic Cell Transplantation Recipients: A Global Perspective. Biology of Blood and Marrow Transplantation, Volume 15, Issue 10, Pages 1143-1238. June 2009. M. Tomblyn, T. Chiller, H. Einsele, R. Gress, K. Sepkowitz, J. Storek, J. Wingard, J. Young, M. Boeckh

Donor information

This section is written for donors and the word “you” throughout it refers to the donor. This section may be shared with anyone who is considering being a donor for an allogeneic or haplo transplant.

Stem cell information

What is a stem cell?

Within the various tissues of the body are immature cells called “stem cells” that contain basic genetic information about the particular cells of that organ or system. There are stem cells for skin, liver, intestines, ova, sperm, heart, brain, and blood.

The blood stem cell is the most primitive blood-forming cell. It is the “parent” cell of the blood supply and has the amazing capacity to mature into a red blood cell, white blood cell, or platelet based on the body’s needs. These stem cells produce an unending supply of blood cells. On average, a small number of stem cells produce an ounce of new blood, about 260 billion new cells, each and every day.

Where are stem cells found?

The majority of blood stem cells are found in marrow cavities of the body’s large bones. Normally, only a small number circulate in the blood stream.

How are stem cells used in cancer treatment?

Doctors have discovered radiation and chemotherapy can destroy the ability of the bone marrow to produce blood cells. Fortunately, bone marrow function can be restored by giving healthy stem cells to the person with cancer after the radiation and chemotherapy treatment. The healthy stem cells are given as a transfusion into the blood stream. The transplanted stem cells migrate back to the marrow space and grow into new blood cells.

How are stem cells collected from the donor?

At Fred Hutch, we collect donor cells through either a bone marrow harvest or through apheresis. Both are described in detail on the next few pages.

Apheresis collection process

Stem cell collection includes 7 steps, all of which are described in detail:

1. Donor evaluation, consent, and screening
2. Orientation and vein check
3. Mobilization of stem cells
4. Stem cell collection by apheresis
5. Stem cell analysis
6. Stem cell transfusion and/or storage
7. Follow-up care

Step 1: Donor evaluation, consent, and screening

- **Evaluation:** This may include a health history, physical examination, electrocardiogram, blood samples, and other diagnostic tests. These are done to ensure that the process of stem cell collection will not put your health at risk, and that infusing your blood cells to the patient will not be harmful in any way. Female donors must not be pregnant and must avoid becoming pregnant during the time of growth factor and stem cell collection.
- **Consent:** The attending physician will discuss the specific stem cell collection plan with you. You will be asked to read and sign consent forms for the collection protocol and blood tests.
- **Screening:** You will answer questions about your life to determine whether you have risk factors that may affect your eligibility as a donor. These questions are very similar to what people are asked when they donate blood. In addition to screening questions, the nurse will also share who the members of your care team are and how to contact the clinic and people on your care team.

Step 2: Orientation and vein check

Before your first stem cell collection, you will be scheduled to visit the Apheresis Unit. An apheresis nurse will explain the procedure, answer your questions, and show you the Apheresis Unit and equipment. The nurse will also go over Pre-Apheresis Instructions and give you a handout to take home. Please read the handout carefully and ask your nurse any questions.

Before your first apheresis appointment, the apheresis team will determine the best way to access your blood stream. In some cases, it is possible to use a large vein in each arm. An intravenous (IV) needle with tubing is placed in each arm. The blood moves from the vein in one arm, through the apheresis machine, and is returned to the vein in the other arm. When the stem cell collection is complete, the needles are removed. This process is repeated each day of apheresis collection. Your cells may need to be collected over more than 1 day to make sure we have enough.

In some cases, a donor's veins are not large enough for this procedure. If this happens, we may need to surgically place a catheter, or tube, into a large vein. The catheter stays in place and is used each day during apheresis. When the stem cell collections are complete, the catheter is removed.

You will be thoroughly prepared and instructed for whichever method is chosen.

Step 3: Mobilization of stem cells

In order to collect stem cells by apheresis, we will stimulate your bone marrow with growth factors to produce larger-than-normal numbers of stem cells and release them into the blood stream. The process is called "mobilization." Read more about growth factors below.

What are growth factors and what do they do?

Growth factors are naturally occurring proteins that stimulate the production of stem cells in the body. With growth factor mobilization, your white blood cell count will increase dramatically. The number of stem cells in the blood stream will also increase, making it possible to collect these cells by apheresis.

When and how are growth factors given?

Growth factors are given by injection. A nurse will give these injections daily over several days before you start stem cell collection. The treatment plan for the transplant patient determines the dose, number of days of growth factor injection, and collection days for the donor. Generally, donors get 4 to 6 days of growth factor injections and have 1 to 3 days of collection. The doses of growth factor continue until the stem cell collections are complete.

What are the side effects of receiving growth factors?

The most common side effects of growth factor therapy are bone pain, muscle pain, or headache. For some people these symptoms are mild, while others may experience more severe discomfort. We can prescribe medications to help manage these symptoms. We will monitor your daily blood counts. Your white blood cell count will likely rise 3 to 5 times your usual count. Other temporary side effects of growth factor therapy may include a rash, mild fever, and flu-like symptoms such as loss of appetite and generalized fatigue. Nausea is an uncommon side effect but can occur.

What do I need to do during mobilization?

Your care team will explain your specific mobilization plan and responsibilities. Mostly, you will be responsible for:

- Getting a daily blood draw
- Getting daily injections of growth factor until the stem cell collection is complete or you are told to stop
- Reporting any side effects that you experience to your care team so they can help you manage them right away

Step 4: Stem cell collection with apheresis

Apheresis is a procedure where blood is sent through a machine that separates parts of your blood using a centrifuge (equipment that spins at a high speed). A certain type of blood cell is collected, exchanged or treated, and the rest of your blood is returned into your bloodstream during the procedure.

We follow strict guidelines to make sure you are safe:

- You are closely monitored by an apheresis nurse.
- Your blood never leaves the sterile tubing circuit. Supplies are used for 1 collection and then discarded.
- There is only a small volume (a little more than 1 cup) of your blood in the cell separator at any time; your blood is returned to you at the same rate it is being removed.
- You will receive an anticoagulant (blood thinner) during the procedure. Depending on the type of anticoagulant used, your blood may remain anticoagulated (thinned) for up to 6 hours after the procedure.

Step 5: Stem cell analysis

After your collection is complete, the product is sent to the lab where they will analyze the types and numbers of different blood cells collected and test them for bacterial contamination.

Step 6: Stem cell transfusion or storage

Your stem cells may be given to the transplant patient right away, held overnight for next day infusion, or frozen for use later.

Step 7: Follow-up care

You will return to the clinic the day after your collections for a follow-up. We encourage you to tell your personal physician that you have donated cells and get a complete blood count to confirm that everything has returned to normal. We want to make sure you are in good health.

Common questions about apheresis

Where are apheresis procedures done?

The Apheresis Unit is located on the 5th floor of Sloan Clinic 1.

What activities can be done during the procedure?

You may bring your caregiver, a friend, or family member to your appointment. Typically, up to 2 visitors may stay in your room during apheresis. During times of COVID-19, however, only 1 person may stay. Check with your care team for current visitor guidelines.

We recommend bringing a book, tablet, laptop, or other form of entertainment to help pass the time; each bay in the Apheresis Unit also has a TV. You can also sleep, eat, and drink. Keep in mind, if we are using IVs in your arms for your procedure, your movement will be limited and some of these activities may not be possible.

How long does each procedure take?

This varies from one donor to another, but will generally take 2 to 6 hours.

What are the side effects during apheresis?

You may experience the following side effects:

- Minor bruising from the IV catheters
- New bleeding where the central line was put in due to the blood thinner given during apheresis

Other common side effects can be easily managed during your procedure by slowing the flow of blood through the machine or giving you calcium. These side effects include:

- Temporary numbness or tingling in your fingers, face, mouth, or lips
- A sour taste in your mouth
- Muscle cramping in your jaw, fingers, legs, or toes (less common)
- Anxiety, nausea, vomiting, or fainting (less common)
- Severe muscle cramping (rare)

You also may feel tired or have sore muscles from lying in one position during the procedure.

What will I feel like when the procedure is over?

Some people feel tired after apheresis, and others feel no different than before the procedure. We recommend you rest after the procedure and avoid strenuous physical activity.

How many apheresis collections will I need?

Generally, apheresis collections continue daily for a set number of days or until the desired amount of stem cells is collected and stored. The number of donor collections varies according to the protocol; the average is 1 to 2 collections.

What do I need to do to achieve a successful stem cell collection?

- Follow your pre-collection care plan by getting growth factor injections, blood draws, and caring for your intravenous catheter if you have one. These are the most important steps you can take for a successful stem cell collection.
- Make your stem cell collection top priority for the few days it will take. Pamper yourself and don't put unnecessary expectations on yourself during this time.

- Starting 2 to 3 days before collection, eat calcium-rich foods like dairy products or dark green vegetables. Ask your care team for the [calcium handout](#) if you need food suggestions. You may take calcium supplements to help lessen potential side effects like facial tingling, shivering or muscle cramps from the blood thinner used during collection.
- Being well-hydrated decreases the length of time the procedure lasts and helps lessen potential side effects. Drink plenty of fluids 2 to 3 days before collection to remain well-hydrated unless your care team tells you specifically to limit your fluid intake.
- Arrive on time for your apheresis appointment and plan for the procedure to take about 6 hours.
- During the procedure, immediately report any unusual sensations you experience to a nurse.

Who do I contact with questions?

If you have other questions about the collection of stem cells or bone marrow harvest, please ask any member of the Fred Hutch healthcare team. We are committed to providing you with the best possible care. For additional general information on bone marrow harvest and donation, please visit the National Marrow Donor Program at bethematch.org.

Bone marrow harvest collection process

During a bone marrow harvest, bone marrow is taken from the backside of your pelvic bones, from an area called the “iliac crest.” The procedure is done in an operating room. Bone marrow collection includes the below 6 steps which are explained on the following pages:

1. Donor evaluation and consent
2. Donor screening for anesthesia
3. Bone marrow harvest procedure
4. Bone marrow cell analysis, transfusion, and/or storage
5. Follow-up care
6. Long term recovery

Step 1: Donor evaluation and consent

- **Evaluation:** This may include an extensive health history, physical examination, electrocardiogram, blood samples, and other diagnostic tests. These are done to ensure that the process of bone marrow harvest will not put your health at risk, and that infusing your blood cells to the patient will not be harmful in any way.
- **Consent:** The attending physician will discuss the specific bone marrow harvest procedure with you. You will be asked to read and sign consent forms for the collection protocol and blood tests.

Step 2: Donor screening for anesthesia

The Pre-Surgery Clinic at UW Medical Center-Montlake will call you before your procedure to discuss anesthesia options. Most bone marrow harvests are done with general anesthesia, but spinal anesthesia is an option. For general anesthesia, you will be completely asleep (unconscious). For spinal anesthesia, you will be given medication to keep you calm and sleepy and won't feel any pain at and below the harvest site.

Step 3: Bone marrow procedure

You will be given instructions for how to prepare for the procedure and when to arrive for it. The harvest takes place at UW Medical Center-Montlake's surgery pavilion and is considered a day or “outpatient” surgery procedure. You may have someone come with you to the hospital. The bone marrow is harvested by using large-bore needles and syringes to pull the bone marrow from the pelvis. The entry sites are limited to 2 or 3 skin puncture sites on each side, while the bones are punctured multiple times.

You will be admitted and discharged the same day you donate your bone marrow, unless your surgeon would like to monitor you overnight in the hospital. Make arrangements to have a caregiver take you home from the hospital (this person cannot be a cab or rideshare driver).

You will not be able to be discharged unless you have someone with you. You must also have someone stay with you for the first 24 hours after your procedure. You will be scheduled for a follow-up appointment at Fred Hutch the day after your procedure, so please do not plan to leave Seattle immediately after your donation.

Step 4: Bone marrow cell analysis, transfusion, and storage

The amount of marrow taken is based on the body weight of you and the transplant patient. For an average adult transplant patient with an adult donor, about a quart of marrow is taken from your iliac crest. In rare cases, additional marrow will be taken from the front of your hip. Your body will replace the bone marrow that was removed within 4 to 6 weeks.

The collected bone marrow is screened and filtered, collected in a large bag, and taken to the patient receiving the transplant. On occasion, the red blood cells or plasma need to be reduced in the bone marrow, which delays delivery to the patient.

Step 5: Follow-up care

After your procedure, the site will be bandaged. The bandages can be removed during your Fred Hutch clinic follow-up appointment the next day. You will receive supplies and instructions for home care when you are discharged from Fred Hutch.

Step 6: Long-term recovery

In general, you will need at least a week to return to your normal routine, including work or school. During this time, you may feel pain, swelling, and tenderness around the area where your procedure was performed.

You may find that light exercise, such as walking, can help ease your symptoms. Please follow the physical activity guidelines you receive when you leave the hospital. Your team will call you within 3 weeks of your return home to follow up on your recovery. To help your recovery and speed the production of blood cells, you will be prescribed iron supplements. Please take all the supplements you receive. If symptoms don't go away, or if you are concerned about your recovery, please follow up with your team.

Common questions about bone marrow harvest

What are the side effects of a bone marrow harvest?

Anemia, a low red blood cell count, is the most common side effect of the procedure. Anemia can make the donor feel tired and short of breath.

How long does the procedure last?

The bone marrow harvest procedure takes about 1 hour. Your total time at the hospital will depend on your pre-surgery preparation, the type of anesthesia, and recovery time after the surgery.

If I'm from out of town, how long should I plan to be in Seattle for the bone marrow harvest?

You should plan on being in Seattle for about 5 to 6 days. This includes time for additional blood tests and an updated physical examination before your procedure, and a follow-up visit the day after your procedure. Typically, you are asked to arrive back in Seattle 24 to 48 hours before your procedure.

Who do I contact with questions?

If you have other questions about the collection of stem cells or bone marrow harvest, please ask any member of the Fred Hutch healthcare team. We are committed to providing you with the best possible care. For additional general information on bone marrow harvest and donation, please visit the National Marrow Donor Program at bethematch.org.

Financial support and fundraising

Even with good health insurance, transplants can be expensive, and paying them can be overwhelming. In this section, we provide a list of organizations that offer support or may be able to help you find support. Please note that inclusion on this list does not mean endorsement by Fred Hutch.

Organizations that offer financial or travel support

Organization	Contact Information
Angel Flight West	angelflightwest.org
Corporate Angel Network (CAN)	corpangelnetwork.org
Fred Hutch Travel Desk	(206) 667-3434 phone
Help Hope Live	helphopelive.org (800) 642-8399 phone
Leukemia & Lymphoma Society (LLS)	lls.org to find your local chapter
Mercy Medical Angels	mercymedical.org
Social Security Supplemental Income Disability	ssa.gov (apply for disability)

Organizations that offer information on fundraising

Organization	Contact Information
GoFundMe	Gofundme.com
Be the Match website	bethematch.org/patients-and-families/before-transplant/paying-for-transplant/fundraising/
Be the Match Patient Support Center	1 (888) 999-6743 phone Monday through Friday, 8 a.m.–5 p.m. Central Time patientinfo@nmdp.org
The Bone Marrow Foundation	bonemarrow.org
HelpHOPELive	helphopelive.org

Resources

Packing list

Many people wonder what they should bring with them to Seattle. We recommend packing the following items, in addition to other personal belongings you'd like with you.

Medical items

- ☐ Insurance cards and other important paperwork, such as passport or driver's license. You will need a form of photo identification.
- ☐ Please bring a list of your current medications. (Medical and dental information will be requested by your Intake team ahead of your arrival, including diagnostic films, diagnostic slides, reports, notes.)
- ☐ Living will and durable power of attorney for health care if you have them. If not, you can do this when you get here.

Personal items

- ☐ Large bag or backpack to carry materials to and from the clinic
- ☐ Something to help pass the time between appointments such as books, magazines, an electronic device, or handwork. Please bring headphones if you are listening to something on your electronic device.
- ☐ Water bottle

Clothes

Seattle has a moderate climate, with heavy rainfall from October through June. If you visit Seattle during these months, you should bring a raincoat, sweater, and umbrella. During other months, we suggest bringing layers, as it is often cooler in the mornings and evenings, but warm during the day.

- ☐ Comfortable loose fitting/oversized shirts, shorts, and sweatpants that are washable. Dress in layers, as temperatures vary in the clinic and in Seattle.
- ☐ Front buttoning pajamas
- ☐ Head cover ups, scarves, hats, or wig

- ☐ Female patients may find sports bras helpful because of the central intravenous line connection
- ☐ Comfortable socks, shoes, and slippers that have backs on them (no mules or slides)
- ☐ Athletic, tennis, or walking shoes

Items for your house

- ☐ Paper towels and spray bottle for bleach
- ☐ Night light to reduce falls
- ☐ Meat thermometer for monitoring food temperature for food safety
- ☐ Cuff weights and heart rate monitor (if you have them)

Glossary of terms

Allogeneic transplant (allograft): A transplant in which bone marrow, peripheral blood stem cells, or cord blood stem cells come from a donor, such as a family member or unrelated person

Absolute neutrophil count (ANC): A laboratory procedure that determines the number of neutrophils (a type of white blood cell) in a blood sample

Anticoagulant: An agent that decreases the ability of the blood to clot

Apheresis: A procedure used to collect certain types of blood cells. Blood from a donor is passed through a continuous-flow blood processor; the type of cell being collected is removed from the blood and the remaining blood components are returned to the donor

Attending physician: A doctor who leads the healthcare team and supervises the medical care provided to the patient

Autologous transplant (autograft): A transplant in which the bone marrow or peripheral blood stem cells are taken from the patient, frozen, and later returned to the patient

Bacterial contamination: The presence of bacteria which makes a solution, surface, or body organ impure, for example, bacterial contamination of the blood

Biotechnology: Engineering of procedures and agents used to alter or influence living organisms and processes

Blood draw: The removal of a small sample of blood from a vein

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

Bone marrow aspiration: Obtaining a sample of bone marrow using a needle and syringe; this is done to obtain a sample for laboratory study

Bone marrow harvest: Collecting marrow from the hip bones with a needle and syringe for use in transplant; marrow is harvested in the operating room

Bone marrow transplant: The process of treating disease with chemotherapy, radiation therapy, or both, and then giving stem cells (directly from bone marrow, peripheral blood, or cord blood) to restore the production of blood cells

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

Caregiver: A responsible family member or friend who is able to provide physical care, observational care, and emotional support for a patient in the home setting

Catheter: A rubber or plastic tube that is inserted into the body to drain fluids or deliver fluids or medication

CD 34 + cells: Lymphocytes (white blood cells) which have a specific antigen marker which allows them to be detected in a sample of cells; the number of CD 34 + cells are counted after stem cell collection to determine if adequate numbers of stem cells are present

Cell separator: A mechanical device used to collect blood cells and separate the various blood components, such as red cells and white cells

Central intravenous catheter/line: A small, flexible tube inserted into a large vein near the heart; this serves as a route for medications, fluids, and to obtain blood samples

Central line placement: The process of inserting a catheter into a large vein; this is a minor surgical procedure performed in the operating room under either local or general anesthesia

Centrifuge: A device which spins around a central axis to increase gravity, which separates materials of different densities; apheresis machines use a centrifuge to separate and collect blood cells

Chemotherapy: Medications used to destroy or slow the growth of abnormal cells, usually cancer cells

Collection: The process of accumulating or keeping together, such as collecting stem cells

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

Complication: An undesired symptom or medical problem that is a consequence of therapy, or another disease

Conditioning: The treatment given to the patient before transplant, intended to kill cancer cells and prepare bone marrow to receive stem cells; this consists of chemotherapy and/or radiation therapy

Cord blood: Stems cells collected from the umbilical cord and placenta when a baby is born and then frozen for future use

Counts: Refers to monitoring the ANC (absolute neutrophil count) when watching for engraftment

Donor: A person who gives stem cells to be infused into the patient following chemotherapy and/or radiation. A donor may be the patient, family member, or unrelated person

Erythrocytes: Red blood cells carry oxygen on hemoglobin from the lungs throughout the body.

Engraftment: The process by which the normal growth and production of blood cells and the bone marrow resumes

Exit site: The place on the chest where the central intravenous catheter emerges from the skin

Graft-versus-host disease (GVHD): A process whereby the transplanted cells (the graft) attack certain organs in the recipient (the patient/ host)

Growth factors: Substances naturally occurring in the body that control the production and function of blood cells; these may be given after transplant to speed up engraftment, or given to donors to increase the number of stem cells in the blood stream that will be collected for transplant

Glycoprotein: A protein that has carbohydrates attached to it

Hormone: Produced by certain organs of the body; stimulates and regulates body functions

Immune system: A complex network of organs, cells, and specialized substances distributed throughout the body which defend it from foreign invaders that cause infection or disease

Immunosuppression: A decrease in the ability of the immune system to fight infection that can be caused by chemotherapy, radiation, or GVHD therapy

Informed consent: How a patient learns about and understands the purpose, potential risks, and benefits of a research protocol and then agrees to participate; patient may decline to participate

Infusion: Administration of medications or fluids into a vein over a period of time

Infusion pump: A device used to infuse medications or fluids through a catheter into a vein over a specific amount of time

Intravenous (IV): A route of administration for fluids or medications that are given into a vein

Leukocytes: White blood cells that play a major role in the body's immune system

Mixed chimerism: A transplant that uses stem cells from the patient and a donor

Mobilization: Stimulating the bone marrow to produce and release large numbers of stem cells into the bloodstream

Mucositis: Reddening and soreness of the tongue, lips, mouth, throat, and gastrointestinal tract as a result of chemotherapy or radiation therapy

Neutropenia: Low neutrophil (type of white blood cell) count; a person with neutropenia is at high risk for developing an infection

Neutrophil: A type of white blood cell that provides defense against infection

Non-myeloablative transplant: A transplant in which stem cells are received from a family or unrelated donor and conditioning is done with moderate dose chemotherapy and/or radiation

Oncology: An area of medical science that studies tumors and cancers

Peripheral blood stem cells (PBSCs): Cells made in the bone marrow that are circulating in the blood stream and have the ability to develop into white blood cells, red blood cells, or platelets

Peripheral blood stem cell transplant: Stem cells circulating in the bloodstream are collected and later given back to a patient after chemotherapy or radiation therapy is given

Platelets: Tiny disc-shaped blood cells that help the blood to clot and help prevent bleeding

Pneumonia: A disease in which the lungs are inflamed or infected

Protocol: The plan for a specific treatment; may be a scientific study such as a research protocol

Protocol consent forms: A document that outlines the treatment plan/research study that the patient signs to indicate understanding and consent

Radiation therapy: A cancer treatment that uses radiant energy waves to damage/kill cancer cells

Red blood cell: A type of blood cell (also called erythrocyte) that carries oxygen in the body

Rejection: A process by which transplanted cells are attacked by the patient's immune system

Side effect: An additional and usually undesirable effect from a drug or other treatment

Sinusoidal obstruction syndrome (SOS): A disease caused by obstruction of blood flow through the small blood vessels in the liver, resulting in damage to the liver

Standard treatment: A treatment or other intervention currently being used that has been proven effective on the basis of past clinical studies

Stem cell: An immature cell which is the “parent” cell of the blood cell and has the capacity to mature into a red blood cell, white blood cell, or platelet

Syngeneic transplant: An identical twin donates stem cells to the other twin for transplant

Tissue typing: Tests that determine how closely the tissues of a donor and the patient match

Total body irradiation: Radiation treatment of the entire body, used to destroy malignant cells and bone marrow cells in preparation for transplant

Total parenteral nutrition (TPN): Nutritional support given intravenously; also called hyperalimentation

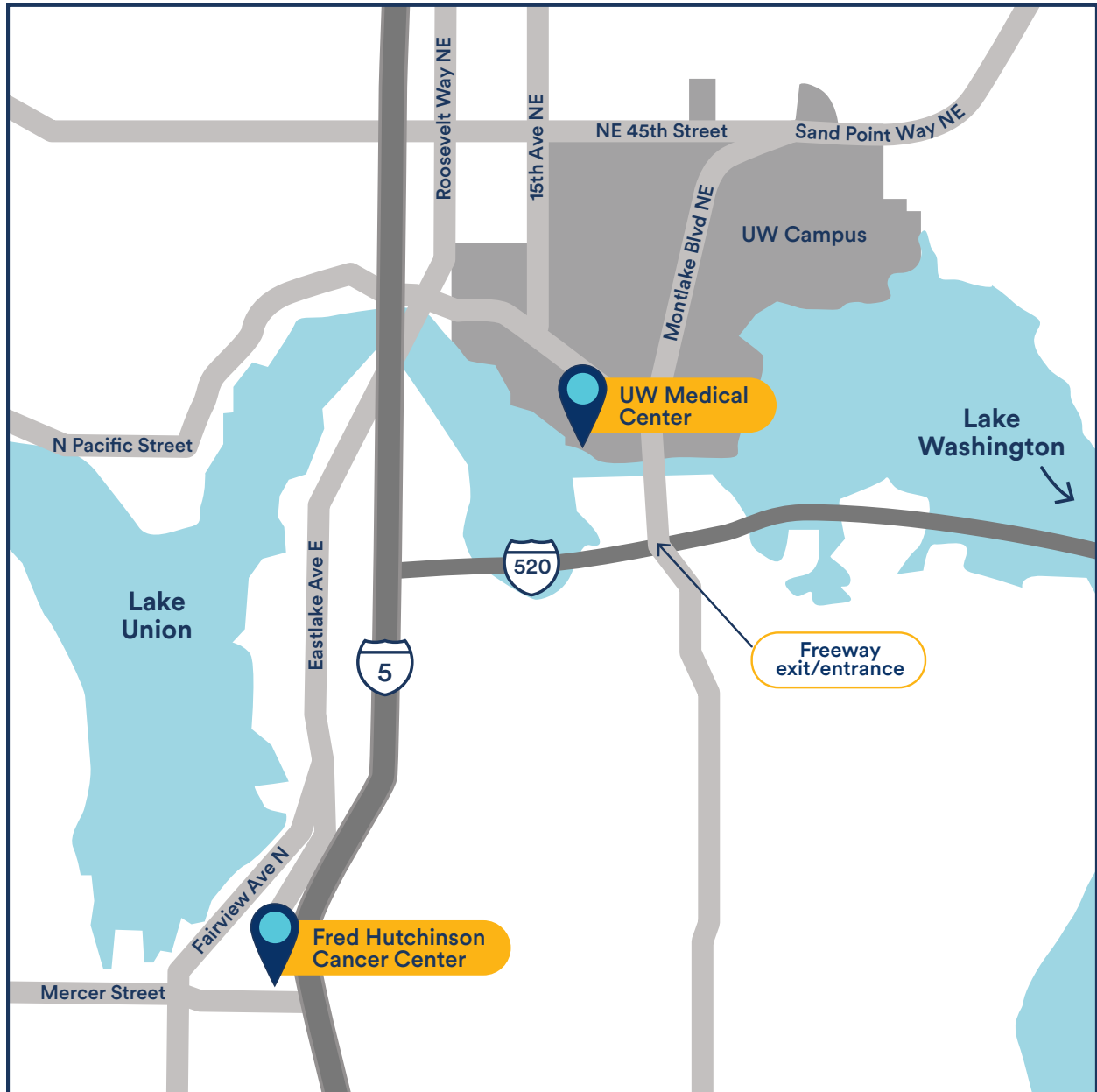
Venous access: A method used to gain entrance into a vein

Viable: Capable of living

White blood cells: A group of blood cells, the leukocytes, which helps fight infection

Fred Hutch map, directions, and parking

Map of Fred Hutch and UW Medical Center-Montlake



Directions to Fred Hutch Sloan Clinic

1354 Aloha St.
Seattle, WA 98109
(206) 606-7222

From I-5 north or southbound:

- Take exit 167, Mercer St./Seattle Center, and move to the far-right lane.
- Turn right at the end of the ramp onto Fairview Ave. N.
- Veer **right** at the light, staying on Fairview Ave. N. (do not turn right onto Valley St.) and travel one block to Aloha St.
- Turn **right** on Aloha St. and travel two blocks to the Fred Hutch building.
- Enter the Fred Hutch clinic parking garage between Yale Ave. N. and Eastlake Ave. E.

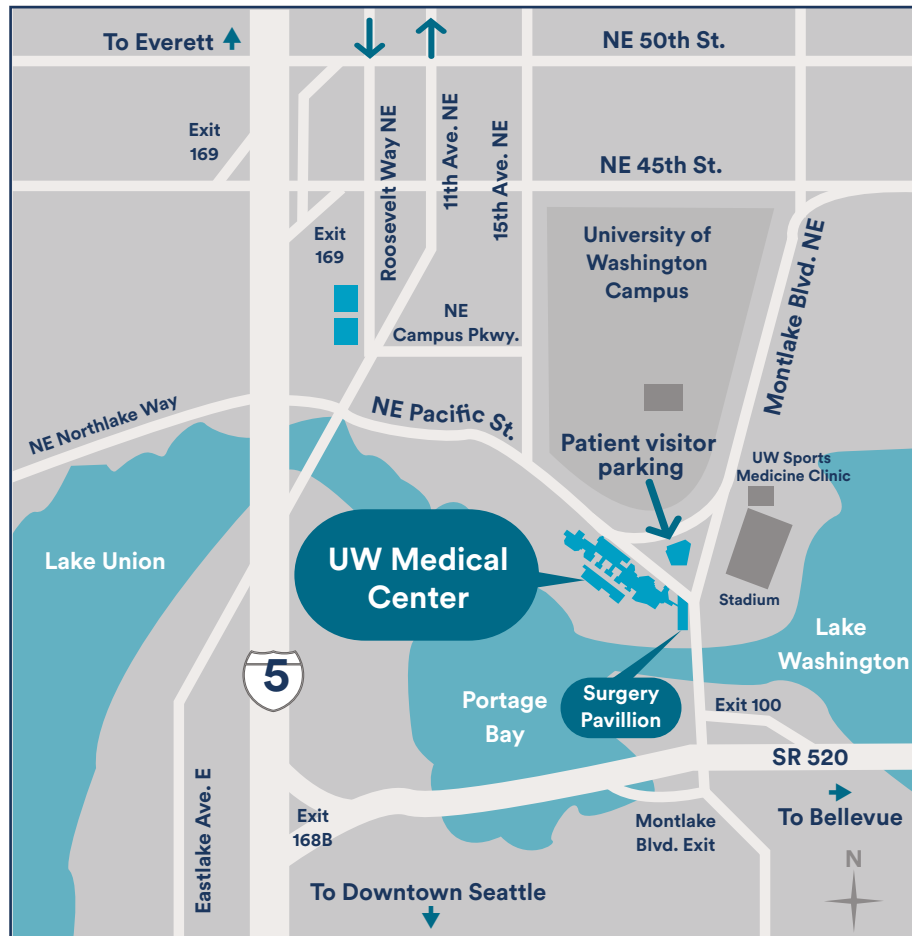


Parking at the clinic

Patients may park in Fred Hutch Sloan Clinic's underground parking garage for no more than \$4 per day, with in-out privileges. There is limited paid street parking. Paid parking hours are typically 8 a.m. to 6 p.m. It is extended until 8 p.m. in some areas. Parking in the clinic garage is free on weekends and holidays.

For other transportation options and current street closures, visit FredHutch.org/patient-transportation.

UW Medical Center-Montlake Map, Directions, and Parking



UW Medical Center-Montlake address

1959 NE Pacific St, Seattle, WA 98195, (206) 598-3000

Directions to UW Medical Center-Montlake from Fred Hutch Sloan Clinic:

- Travel north on Fairview Ave. N. or Eastlake Ave. E. (street becomes Eastlake Ave. E.)
- Cross the University Bridge
- Turn right at N.E. Campus Pkwy.
- Turn right at Brooklyn Ave. N.E.
- Turn left at N.E. Pacific St.

Parking information for UW Medical Center-Montlake is on the next page.

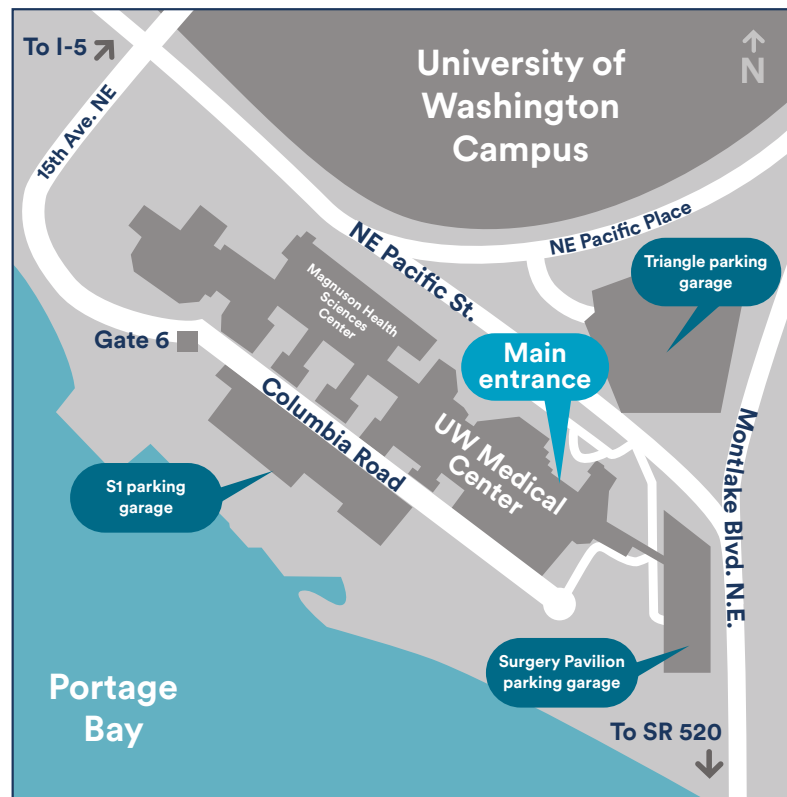
Parking at UW Medical Center-Montlake

All UW Medical Center-Montlake garages and the Fred Hutch garage offer same-day reciprocal parking. Simply bring your receipt from a participating garage to your next appointment at the other location and any remaining paid time will be honored. Patients have in-out privileges. Keep your parking receipt and present it to the attendant. UW Medical Center-Montlake offers valet parking

on weekdays from 8 a.m. to 5 p.m. The valet booth is on the drive to the main hospital entrance. There is limited metered street parking near all buildings.

At UW Medical Center-Montlake, parking is available in 3 places at the hospital (see map above).

- Triangle Parking Garage — Access from N.E. Pacific Place off of Pacific Street, across the street from the UW Medical Center-Montlake via a pedestrian tunnel under N.E. Pacific. (Garage height restriction is 6' 8".)
- Surgery Pavilion Parking Garage — On Pacific Street, turn left at turning lane toward the Surgical Pavilion. Veer left into the Pavilion Parking Garage. Take garage elevator up to third floor. (Garage height restriction is 6' 8".)
- S-1 Parking Garage — On foot, once you get to the main entrance of UW Medical Center 8SE, follow signs for the "Cascade Elevators." Take elevators to 8th floor (8SE). Turn right from elevators and check in at the 8SE reception desk (parking can be validated here).



Live within a 30-minute drive from Fred Hutch Sloan Clinic



Important phone numbers

	Contact Information	Reason to call
Fred Hutch intake office	(206) 606-1024 or 1 (800) 804-8824 phone (206) 606-1025 fax	If you are interested in becoming a patient at Fred Hutch.
Fred Hutch Housing Services	(206) 606-7263 phone housing@fredhutch.org	If you have questions about Fred Hutch housing options or other temporary housing options in Seattle.
Oral Medicine	(206) 606-1333 phone	If you would like more information on dental health.
Transition Services	(206) 606-2125 phone	If you have questions about transplant education, anything caregiver related, or about home care planning.

