Patient Guide

Resource for immunotherapy and cell transplant therapy patients



Introduction

We know bone marrow transplants, stem cell transplants and CAR T-cell therapy can be challenging physically, emotionally and financially. We will do our best to identify and find the resources and supports you need for your care at OHSU. Please read through this patient guide and ask your care team if you have any questions.

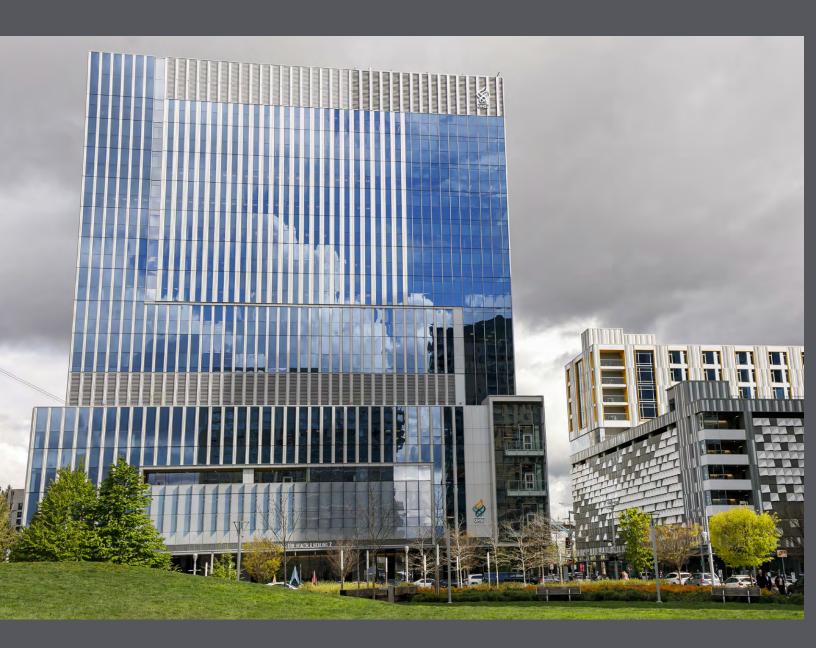


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Introduction to CHH2 and Getting Around OHSU

Clinic and treatment locations

We have oncology clinics at the Center for Health and Healing (CHH), Building 2 on floors 9, 10, 11 and 12. The treatment floors are on 11 and 12. At the end of each appointment, we will give you directions to the next one.

Ve have oncology clinics at the

www.ohsu.edu/visit

Plan a transit trip at

www.trimet.org

Parking at your appointments

Center for Health and Healing (CHH)

We recommend parking in the garage under CHH, Buildings 1 and 2. There is free valet parking, and it is easy to get to both buildings.

Rood Family Pavilion

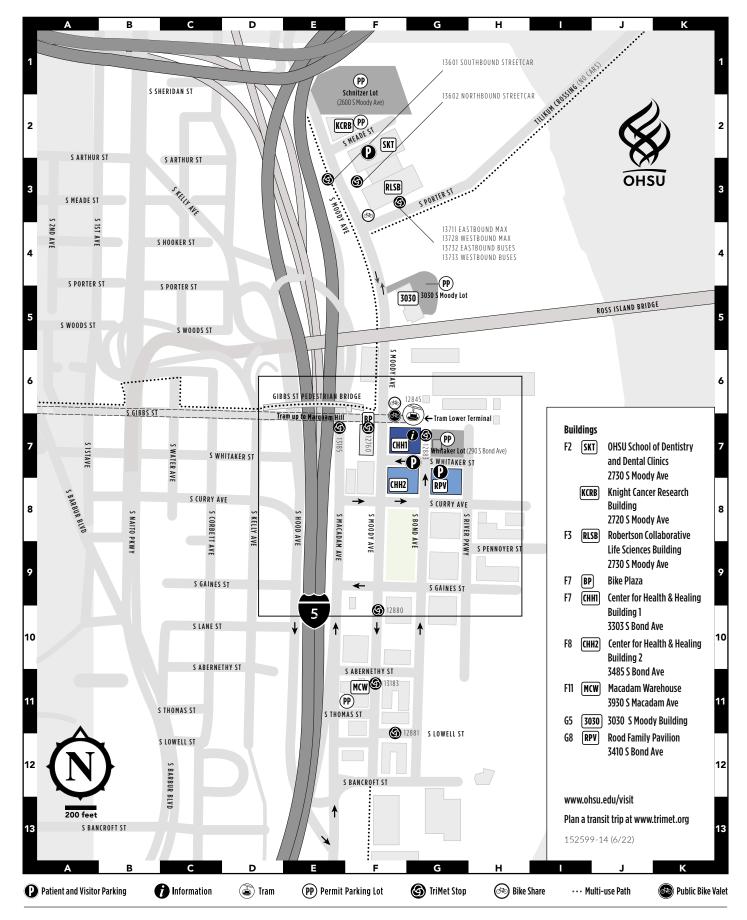
You may also park at the Rood Family Pavilion. This building is next to CHH2, one block east. Use SW Whitaker Street to drive to the underground parking garage and to Rood Pavilion parking.

Get map and information on directions and parking for the South Waterfront campus at www.ohsu.edu/visit/south-waterfront-campus.



Center for Health & Healing, Building 2

3485 S Bond Ave., Portland, OR 97239



SOUTH WATERFRONT CAMPUS



Floors to remember

In order to navigate your visit to CHH2, there are several floors you will need to remember:

CENTER FOR HEALTH AND HEALING BUILDING 2

Floor 1 Main Lobby Receptionist

Weekday hours are 5:30 a.m.-6:30 p.m.; and weekend hours on Saturday and Sunday are 6:30 a.m.-6 p.m.

Floor 1 Pharmacy

Monday through Friday hours are 8 a.m. – 6 p.m.; Saturday and Sunday hours are 8 a.m.- 4:30 p.m.

Floor 1 Lab

Monday through Friday hours are 5:30 a.m.- 6:30 p.m.; and Saturday and Sunday hours are 6:30 a.m. – 6 p.m.

Floor 10 Knight Cancer Institute: Clinics

Monday through Friday hours are 8 a.m.- 5 p.m.; no Saturday and Sunday hours available

Floor 11 Knight Cancer Institute:

Treatment Center

Monday through Friday hours are 7 a.m.- 7 p.m.; and Saturday and Sunday hours are 8 a.m.-6 p.m.

If you need to change your appointment

Please contact us right away if you need to cancel or reschedule your appointment. Also, please call us if you will be late.

If you feel sick, please call the clinic. We will have you talk with the nurse coordinator. If your caregiver becomes sick, please call the clinic for advice on how to stay safe. The clinic number connects you to the on-call physician when the clinic is closed.

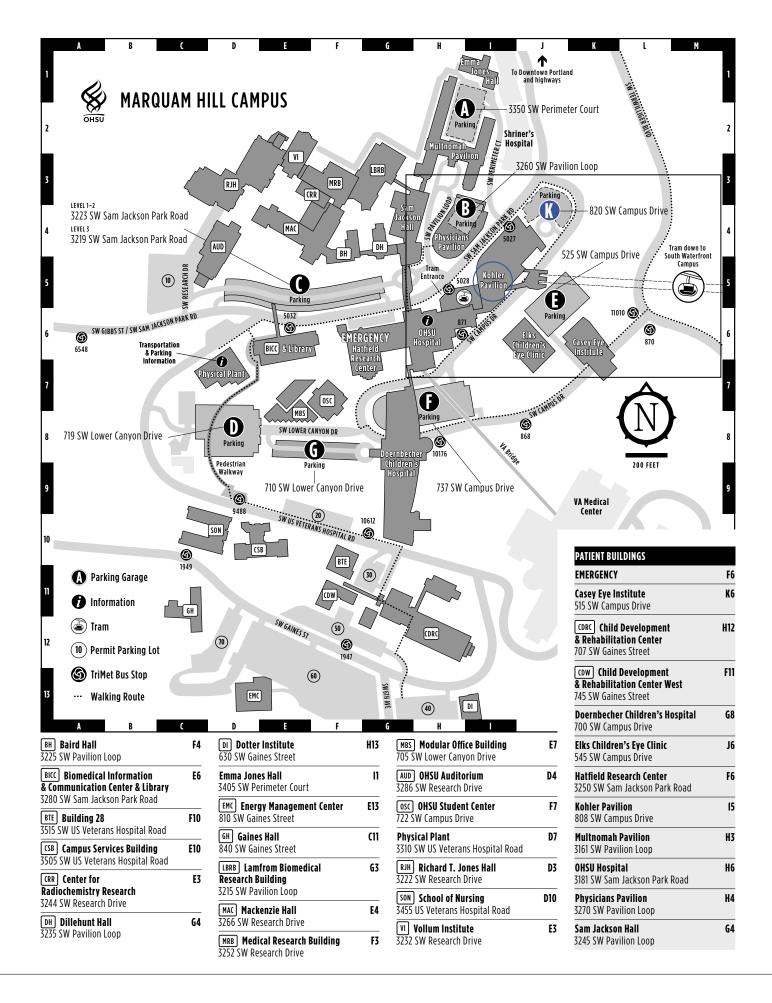
For the Center for Hematologic Malignancies and Clinic in CHH2 at OHSU

For the clinic, call 503-494-5058.

Reminder, if your caregiver becomes sick, please call the clinic on how to stay safe.

For urgent issues after hours, weekends (Saturday or Sunday) and holidays, call the OHSU Operator at **503-494-8311** and ask to have the Medical Oncologist On-Call paged.

For any life threatening emergencies, call 911.



Getting to OHSU

Portland Aerial Tram

One way to get around is by taking the Portland Aerial Tram.

The Portland Aerial Tram goes between the lower OHSU campus called South Waterfront and the upper campus called Marquam Hill.

Patients may ride the tram free to their appointments. Ask your clinic for a tram pass. You can also get one at the information desk in CHH Building 1 or 2.

Members of the public can ride the tram by purchasing a ticket. For more information visit, www.gobytram.com.

For parking on the Marquam Hill campus

The main patient parking garage is part of the Peter O. Kohler Pavilion on Marquam Hill (). This is near the intersection of SW Sam Jackson Park Road and Campus Drive.

From the parking garage, take the elevator to the 9th floor. To get to the 13th or 14th floor of Kohler Pavilion, take the elevators. These are near the tram stop.

Here is some help getting around campus.

We know finding your way around OHSU can be a challenge at first. Please reach out to your care team or any OHSU staff member with questions. You can also visit www.ohsu.edu/visit before you arrive to help you find your way.



Places to go on the South Waterfront campus

- Vesta's breakfast and lunch offerings. CHH2, 1st floor.
 Open weekdays 7 a.m.-2 p.m.
- Daily Café at the Tram. CHH1, 1st floor. Open weekdays 7 a.m.-5 p.m.
- **Skybridge to CHH1.** CHH2, 3rd floor. Open every day. Vending machine snacks available.

Places to go on the Marquam Hill campus

- Starbucks Coffee on the 9th floor of OHSU Doernbecher Children's Hospital, in the Doernbecher lobby. Take the elevators with a picture of a kangaroo.
- **Summit Coffee** on the 9th floor of OHSU Hospital, near Kohler Pavilion and the tram stop.
- Food and snacks at the OHSU Hospital cafe on the 3rd floor, health food store on the 9th floor, and other locations.
- OHSU Gift Shop on the 9th floor of OHSU Hospital.
- **Skybridge** to the Veterans Administration (VA) Hospital on the 9th floor of OHSU Hospital. The VA has a store that is open weekdays, 7:30 a.m.-5 p.m..

Support Services



Support for your body, mind and spirit

Many things go into being well, or in good health. Each of these things is important, and they are all connected. During cancer treatment, your mental, spiritual, social and emotional health are as important as your physical health.

Social work services

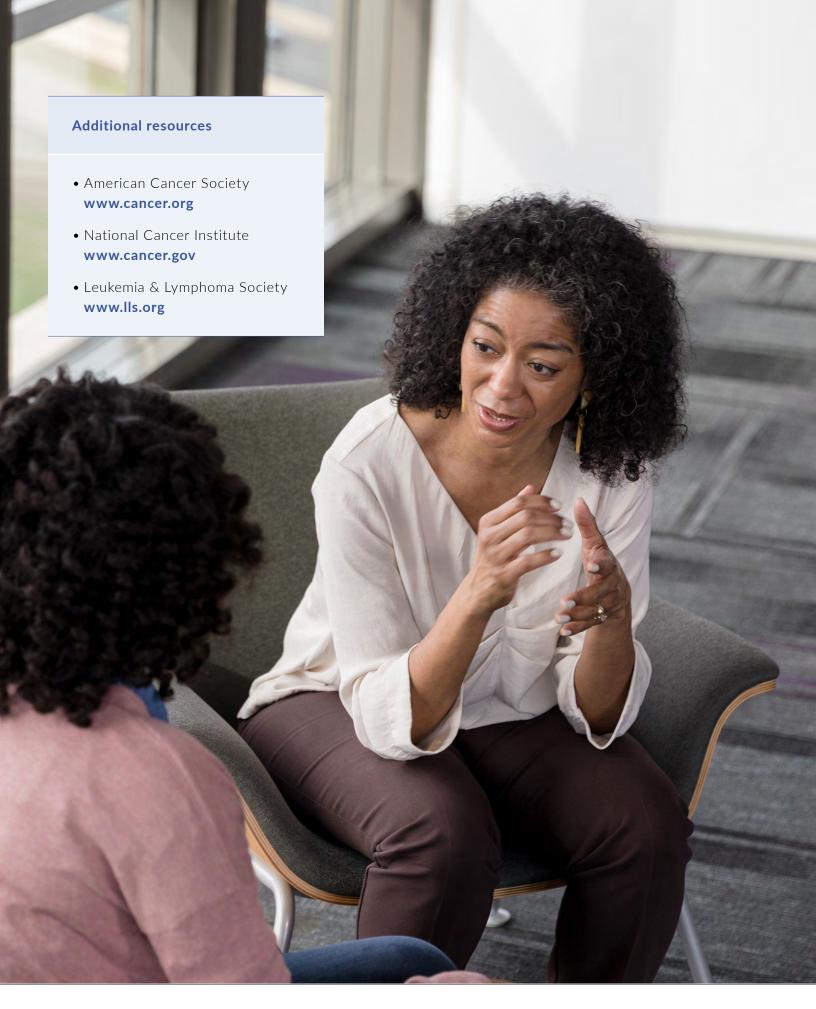
Social workers can support you during and after your cancer treatment. They can help you find information, help and services for yourself and your family. These include:

- Support around adjustment to your diagnosis
- Help with communication between you and your medical team
- Information and referrals for community-based services
- Grief and loss support
- Support to you, your caregivers and family
- Help mediating family conflict related to illness
- Help with transportation and lodging or housing
- Help with navigating OHSU
- Help with advance directives and end-of-life issues
- Help with palliative care
- Information and referrals for financial and insurance concerns

Our Palliative Care Clinic

- Palliative care is specialized medical care that focuses on providing patients with relief from the symptoms and stress of a serious illness.
- The goal of palliative care is to improve quality of life for both the patient and the family.
- Palliative care is provided by a specially-trained team of doctors, nurses, and other specialists who work together with a patient's other doctors to provide an extra layer of support.
- Palliative care is appropriate at any age and at any stage in a serious illness, and it can be provided along with curative treatment.

Please speak with your oncology doctor, nurse, or social worker, and they can determine if a referral to the palliative care clinic would be appropriate to help support you during your journey.



Adjusting to cancer

You will probably feel many emotions when you learn you have cancer. For example, you might:

- Feel shocked and overwhelmed
- Feel pressured to do something right away
- Think "this can't be happening to me"
- Feel like you are in a bad dream
- Have trouble thinking or paying attention

WHAT CAN I DO?

- Talk about your feelings
- Tell other people what you are going through
- Figure out what you do have control over



You might feel afraid of the following things. These are all common when you learn you have cancer.

- Dying
- Losing your independence
- The treatment not working, or cancer coming back later
- Side effects from treatment
- Changes in your life, routine and relationship

You may also feel anxious or depressed. For example, you might notice:

- A fast heartbeat or racing thoughts
- Feeling "on edge" nervous or restless feelings
- Trouble sleeping
- Less interest in doing things, even activities you enjoy
- Trouble dealing with your daily routine
- Sadness or depression
- Thoughts about hurting yourself

Feelings of anxiety and depression are normal and can happen because you are feeling more stress.

Uncertainty and not knowing what will happen or changes in your regular routine can make this worse.

WHAT CAN I DO?

- Talk with a social worker about how to handle your thoughts and cope with daily activities.
- Talk with your doctor about taking medication.

Cancer can affect how other people act around you. They might:

- Not know what to say or do
- Say or do things that are not appropriate or helpful
- Share their own feelings about your cancer this might be hard for you to cope with

Cancer can also change your relationships with other people. You might notice that:

- Family and friends act in new ways or do new things
- People act differently around you
 - Some friends seem to go away
- Some friends get closer or do more

WHAT CAN I DO ABOUT RELATIONSHIP CHANGES?

- Talk about how you feel.
- Tell friends and family what would help and what you need.
- Ask a friend or family member to talk with other people, if you do not feel comfortable doing it.

Having cancer can change things at work. You might notice:

- Changes in the way other people treat you some people might avoid you.
- Difficulty doing your job or staying the whole day
- You have to work less, or cannot work
- Your employer might give you support, or they might not

WHAT CAN I DO ABOUT CHANGES AT WORK?

- Talk with your family, friends and social worker about any changes at work
- Talk with the human resources department at work. You can ask about:
 - Family Medical Leave This is time off the law gives you when you or a family member is sick.
 - **Sick leave** Another type of time off when you are sick.
 - **Disability** This is insurance that pays if you cannot work because of a health problem.

Your health insurance and other benefits

Your doctor will probably need to fill out papers with information on your health. You can bring the papers to your appointments.

You may get a credit on your taxes for the money you spend on cancer treatment. This is sometimes called a "deduction" or "write-off." It means the government does not ask you to pay taxes on the money.

Keep all the receipts for your cancer treatment. This includes supplies, medications, the cost of traveling to your appointments, and more. You may want to talk with an accountant who does taxes.





Financial counseling

A financial counselor can help you understand the cost of treatment and find ways to pay. You can talk with a financial counselor here at OHSU.

They can:

- Help you learn what your health insurance will pay for treatment.
- Help you find ways to pay, if you do not have insurance.
- Find ways to pay other than insurance.

If you need financial counseling, please call us at **503-494-6842** or email **oncfc@ohsu.edu**.

Giving someone financial power of attorney

You can choose someone to handle bills and money for you if you cannot do it. The legal term for this is "power of attorney." A lawyer, or attorney, helps you write instructions for what the person can do. It is important to have this completed as soon as possible, preferably before starting treatment.

You are in charge of what the person can do with your power of attorney. They can do as much or as little as you decide.

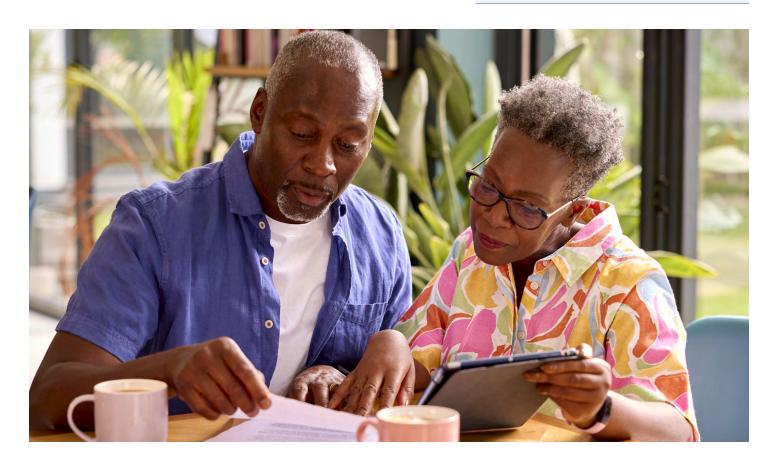
This can include:

- Paying your personal bills
- Paying medical bills
- Paying your taxes
- Managing property, such as your home or farm
- Managing your bank account or investment
- Talk with your social worker if you need free or low-cost legal resources.

Advance Directive

An advance directive is a document that says what your health care choices are if you are not able to talk for yourself. It also says who can make choices if you are too sick to do this. It is important because we want to know what is important to you and give you the treatment you want. It is important for us to know your values and we want to honor your wishes.

If you already have an advance directive, please bring us a copy. If not, consider making (or completing) one. We can keep a copy with your records.





Rehabilitation

Physical therapy, speech therapy and occupational therapy can all help you deal with cancer and treatment.

A rehabilitation therapist can help you with:

- Being very tired (fatigue)
- Problems moving around or keeping your balance
- Numbness and tingling in your hands, feet and sometimes other places (peripheral neuropathy)
- Muscle pain and weakness
- Confusion and difficulty thinking (chemo brain)
- Swelling around your arms (lymphedema)

Acupuncture

Check with your provider for when this is safe to pursue after your transplant or CAR T-cell therapy.

Acupuncture is a treatment that uses tiny needles to help energy move around your body. The person who does it puts needles in specific places to help certain problems. You can have acupuncture at any time during treatment, or after treatment. It can help with cancer symptoms and the side effects from treatment.

Acupuncture can help with these side effects of cancer treatment:

- Nausea and vomiting
- Constipation, diarrhea and other digestion problems
- Sleep problems and tiredness (fatigue)
- Anxiety and depression

- Hot flashes and dry mouth
- Numbness and tingling in your hands and feet (peripheral neuropathy)
- Pain

About changing emotions

You can go through many emotions because of the medications you take, changes in your hormone levels and the stress of treatment.

Common emotions are:

- Depression
- Anxiety
- Anger
- Fear of the future (apprehension)
- Feeling stressed

You can always talk with your doctor, nurse, social worker or someone else on our team about this. Talking with family and friends can help. Our team can help, because we see people go through these emotions so often.

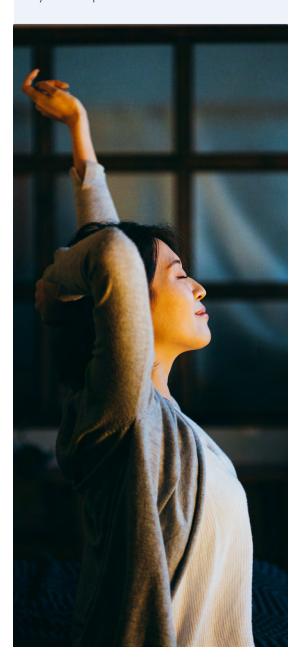
What are you most likely to need support for?

Tiredness and changing emotions are the most common problems during cancer treatment. You will probably have both of these side effects at times. Expect your emotions to go from happy or OK, to sad or angry, sometimes quickly. Also expect to be more tired than usual.



Sleep problems

Cancer and treatment can cause problems sleeping. Try to create a relaxing bedtime routine. You can also talk with your doctor about medication that may help you sleep.



About changes to your body

Cancer and treatment can change the way you look and feel about yourself.

The changes may include:

- Fatigue and physical changes or weakness
- · Losing your hair
- Gaining or losing weight
- Swelling in certain areas
- Looking pale

Below are some things you can do to help you manage changes in your body

- Be aware of how you feel about the changes.
- Talk about your feelings with family, friends or your health care team.
- Think of ways to cope when people react to your looks.
- Consider wearing wigs, hats, scarves and caps to keep your head warm if you lose hair.

Sex and Intimacy

You may be less interested in sex or physical touch during cancer treatment. This is common for many people.

The reasons include:

- Stress
- Changes in your body and body image
- Treatment you may not feel well
- Not being sure sexual activity is safe
- Pain or discomfort

Chemotherapy drugs can be dangerous for your partner. They can also harm the fetus if you get pregnant.

We recommend:

- Using condoms, birth control or dental dams as a physical barrier for sex while you are receiving chemotherapy.
 These types of birth control keep chemotherapy drugs out of your partner's body.
- Using a physical barrier method for 1 to 3 months after you stop treatment.

Your doctor might want you to use birth control for 6 to 24 months after treatment ends. This can help prevent pregnancy. Getting pregnant soon after receiving chemotherapy can harm the fetus. Ask your doctor what is right for you. Let them know if you have questions or concerns about birth control.

You need to be healthy enough to have sex during cancer and treatment. This means your platelet count should be more than 50,000. Your ANC should be more than 1,000. Use lubricant that dissolves in water (water based). Do not use any lubricant that has perfume or coloring in it.

If you are concerned about sex and intimacy, you can:

- Talk with someone on your health care team about how treatment has impacted your sexual wellness.
- Talk with your partner about how you feel.
- Visit www.cancer.gov/aboutcancer/coping/self-image for information from the National Cancer Institute.

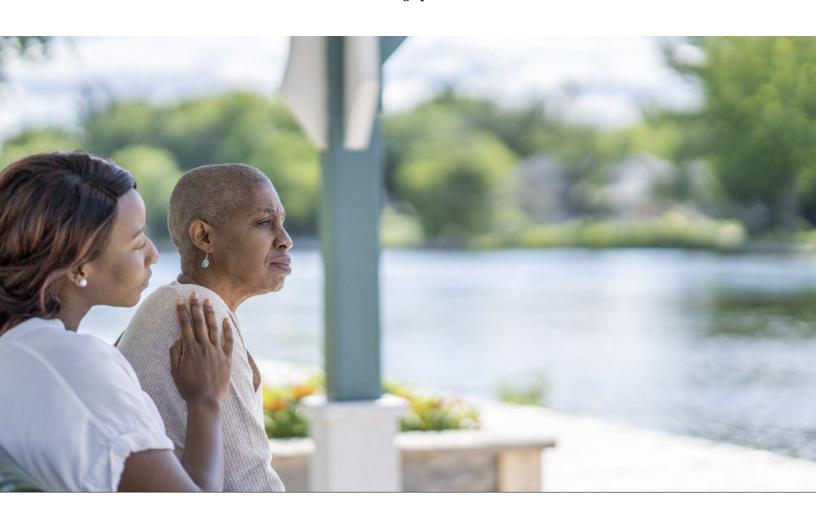


Some ways to cope with cancer and treatment

Some ways to support yourself during cancer and treatment include:

- Doing relaxation exercises or activities that help your mind and body, such as yoga or meditation.
- Getting support from family and friends
- Talking with a counselor
- Exercising, as much as it feels good
- Eating well
- Doing spiritual activities, such as praying or reading spiritual books.

- Taking good care of your body, mind and spirit
- Setting limits
- Asking for help
- Taking leave, using the Family Medical Leave Act (FMLA) to get time off from work.
- Knowing the laws about privacy and information for patients and family members (HIPAA).





Finding transportation during treatment

- Your insurance company may pay some or all of the cost of travel to OHSU, your appointments or other places you need to go for care. The American Cancer Society has a transportation program called Road to Recovery. Call 1-800-227-2345 for more information or to schedule.
- Ride Connection is another option. Contact them at 503-226-0700 to get started.

Places to stay if you need treatment at OHSU

OHSU has a program to help you find a place to stay. We have RV parking on campus and a guest house that some families can use. We can also help you find places to stay in the Portland area.

Call our clinic team at 503-494-5058 to learn more.

Introduction to Cellular Therapy

Please call us at **503-494-5058** if your caregiver gets sick. We will talk with you about how to stay safe and get the help you need.

What type of cellular therapy will I have?

Your doctor will talk with you about the type of treatment that is best for you.

You may receive:

- Your own stem cells (auto transplant)
- Stem cells from a healthy donor (allo transplant)
- Manipulated T cells from your own body or a healthy donor

Please talk with your nurse coordinator or doctor if you have questions.

Your treatment team

Your treatment team may include:

- Doctors
- Nurse practitioners and physician assistants
- Nurse coordinator
- Social worker
- Financial counselor
- Nurses and nursing assistants
- Chemotherapy clinic staff
- Dietician



Evaluations and preparation

Tests and procedures

Before the start of treatment, you may need some or all of the following:

- Dental examination
- Heart and lung tests
- X-rays and other scans
- · Blood and urine tests
- Bone marrow biopsy, lumbar puncture, or both
- Social work evaluation

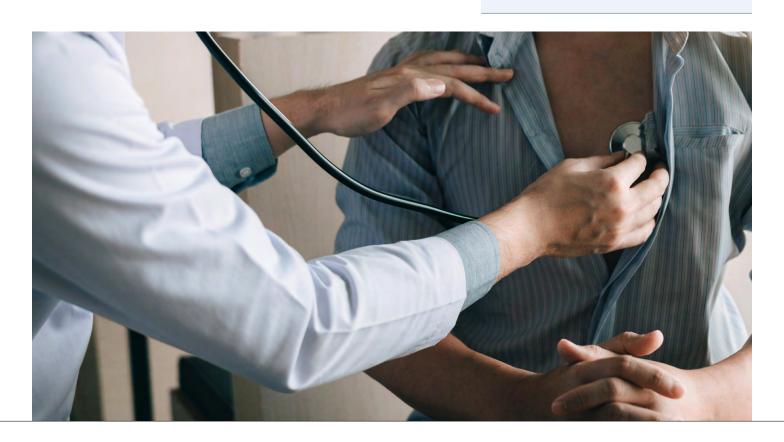
Ways you need to prepare for treatment

You need to prepare for treatment physically by being as healthy as possible and eating well. It is also important to prepare emotionally by understanding your treatment and getting support.

You can prepare financially for costs and payment by talking with a financial counselor and your insurance company. If you will be moving to Portland for treatment, you should make arrangements for your home and pets while you will be gone.

To understand where you are on the therapy process, there are certain terms we use:

- The days before you get your stem cell transplant or CAR T-cells are called "minus days." This means the days prior to your infusion of cells.
- The day you get your stem cell transplant is called **Day 0** (zero).
 Your health care team calls the days afterward "plus days."
- The day you get your infusion of CAR T-cells is called either Day 0 (zero) or Day +1, depending on your treatment. Check with your provider to understand which of these will be used on the day of infusion.



Please call us at **503-494-5058** if your caregiver gets sick. We will talk with you about how to stay safe and get the help you need.



Staying clean and active

It is important to take a shower and brush your teeth each day. Be active, such as walking, if your medical team tells you this is OK. It is important to try and drink at least 2 liters of fluids, unless otherwise advised by your provider or care team, each day to stay hydrated in preparation for and throughout your transplant or CAR T-cell therapy.

Monitored labs: there are several labs we monitor on a regular basis that you should be aware of.

| FOR BLOOD COUNTS | FOR ELECTROLYTES |
|---|--|
| WBCs | Potassium |
| RBCs | Magnesium |
| Platelets | Phosphorus |
| Please note: Transfusions may be required depending on your RBC and platelet levels. | Calcium |
| | An IV or oral replacement electrolyte may be given to maintain safe levels |

Your caregiver

You need someone to take care of you 24 hours a day, 7 days a week after your transplant. Your caregiver will need to help you with rides, meals, medication and more. They also help you stay safe at home and give you emotional support.

Depending on the type of transplant you have, you may need a caregiver for a different amount of time.

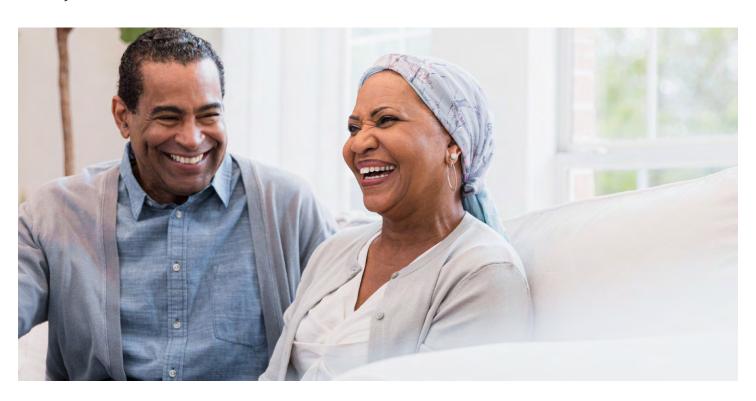
- For 3–4 weeks if you get your own stem cells (auto transplant) or have CAR T-cell therapy
- For about 3 months if you get stem cells from a healthy donor (allo transplant)

What your caregiver does

Your caregiver will:

- Help you get around your home, if needed
- Give emotional support
- Watch out for problems
- Give you rides

- · Cook and make food
- Help with your medications
- Help you clean your living space



Please call us at **503-494-5058** if your caregiver gets sick. We will talk with you about how to stay safe and get the help you need.

Collection of your stem cells (auto transplant) or T-cells (CAR T-cell therapy)

You will either get an IV placed, or a central line placed to collect your cells. If you need a central line, please:

- Do not eat or drink after midnight the night before your appointment.
- Have a driver take you to and from your appointment.

Your central line

You will also get a central line when you get your stem cells or CAR T-cells infused. We will put a small tube in your chest or arm before your infusion. We will use this line to infuse your cells, draw labs, give you medications and fluids as you need them.

We will show you how to take care of your central line. You will have it as long as your doctor says you need it.

- If you get your own stem cells (auto transplant) or CAR T-cells, 2–8 weeks
- If you get stem cells from a donor (allo transplant), about 3 months

Chemotherapy before transplant or CAR T-cell therapy

You will have chemotherapy before your transplant or CAR T-cell therapy. This chemotherapy clears away old cells to make room for new cells. This chemotherapy can be completed in either the clinic or hospital setting, your doctor will decide what is best for you.

You may notice different side effects from this chemotherapy than you have had before. Talk with your health care team about any side effects you experience."

If your caregiver gets sick

You need a caregiver 24 hours a day, 7 days a week. So, please call us at **503-494-5058** if your caregiver gets sick or cannot take care of you. We can help you manage how to stay safe.

Nutrition for Transplant and CAR T-Cell Therapy

For more information

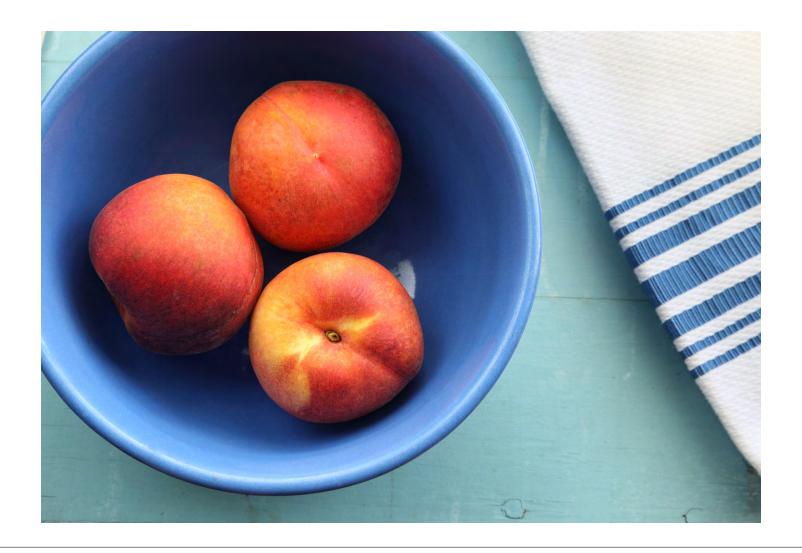
- www.foodsafety.gov
- www.cdc.gov/foodsafety
- www.cdc.gov/healthywater

People with weakened immune systems due to conditioning therapy and transplant are at risk of food borne infections. The goal is to avoid specific foods that are more likely to contain infection-causing organisms while allowing maximum healthy food choices. It is very important to eat well and make sure your food is safe when you are being treated for cancer.

Eating spoiled food or the wrong foods can make you sick, and eating well is important for your health. Look for the word "pasteurized" on milk and other foods and drinks. This means the food was treated to kill bacteria.

When you shop for food, watch out for:

- Food that is older than the date on the package
- · Food and drink containers that are leaking



To minimize risk of foodborne illness:

CLEAN

Wash hands in warm water with soap for 20 seconds before handling food and before eating

Wash cutting boards, dishes, utensils, and counter tops between preparing each food item.

Use paper towels or bleach wipes if able. If using dish cloths or sponges, wash them frequently.

Wash fresh fruits and vegetables thoroughly under running water.

Clean lids of canned goods before you open them.

| AVOID | |
|--|--|
| Avoid food from bulk bins (unless used as ingredients for baking or cooking) | No probiotics and probiotic containing foods such as kombucha, kefir, etc. |
| No raw or unroasted nuts | No matcha tea made from powder or leaves (bottled is okay) |
| No raw sprouts | Avoid the following yogurts: Nancy's yogurt, Dan Active yogurt and Activia |
| No raw or rare meat, fish, or poultry; no cold smoked fish | No home canned foods |
| No food with fresh eggs (salad dressing, egg nog) | No well water |
| No runny egg yolks | No unpasteurized juice or cider |
| No unpasteurized dairy products | No raw honey |

SEPARATE

Separate raw meats, poultry, fish, and eggs from other foods in your grocery cart and refrigerator. Ask the grocery clerk to bag these items separately.

Use one cutting board for fruit and vegetables and one for meat, poultry, and fish. Clean thoroughly after each use/between dish and recipe preparations.

Don't put cooked food or produce on a plate or surface that held raw meat, fish, or poultry.

Never reuse marinades that were used on raw meat, fish, or poultry.

Do not use the same utensils in multiple containers of food to cook with or serve.

CHILL

Chill foods quickly after grocery shopping and after meals are finished. All perishable items (foods that go bad quickly) should be put in the refrigerator within 1-2 hours.

Never thaw food at room temperature (on the counter top). Thaw in the refrigerator, under cold water, or in the microwave.

Clean foods out of your refrigerator frequently.

Eat leftovers within 2 days.

Use food by expiration date on product.

How much and how often to eat

Do not start a special diet, try to lose weight or worry about fat in your diet. You need to eat enough calories to keep your weight the same.

If you are having a hard time eating enough food, try eating small meals 5 or 6 times a day instead of large meals three times a day.

When eating and drinking at home:

- Avoid rich or spicy foods
- Be sure to cook your food completely do not eat food that is uncooked or partly cooked
- · Put food in the refrigerator soon after cooking
- Avoid drinks with caffeine, or have only a small amount
- No alcohol
- Get 2 liters of fluids each day, unless otherwise advised by your provider or care team. Try to include sports drinks, milkshakes or smoothies with whey protein powder or nutritional supplements for calories and protein.

When eating out at restaurants

Depending on your treatment, there are different timelines for when you can have fast food, restaurant food and salad bars or buffets.

If you have an auto transplant or CAR T-cell therapy, you will need to wait 30 days for fast food and restaurant food and wait 60 days for salad bars and buffets.

If you have an allo transplant, you will need to wait 45 days for fast food and restaurant food and 100 days for salad bars and buffets.

Center for Hematologic Malignancies and Clinic in CHH2 at OHSU

For the clinic, call 503-494-5058.

The clinic is open Monday through Friday between 8 a.m. and 5 p.m. Reminder, if your caregiver becomes sick, please call the clinic on how to stay safe.

For urgent issues after hours, weekends and holidays, call the OHSU operator at 503-494-8311 and ask to have the medical oncologist on call paged.

For any life threatening emergencies, call 911.

About medical marijuana

There is little research on the risks and benefits of medical marijuana. If you have questions, talk with your doctor about using marijuana.

You may not bring any type of marijuana to the hospital, even if your doctor says it is OK to use at home.

Staying in the Hospital

Not every patient will need to be hospitalized for their treatment. Your provider and care team will let you know if you will be treated in the clinic or in the hospital.

Leave the following items with your caregiver for access after your hospital stay, especially if you are relocating to the Portland area after treatment:

- Personal medications
- Money, credit cards
- Contact lenses and dental floss

What to bring to the hospital:

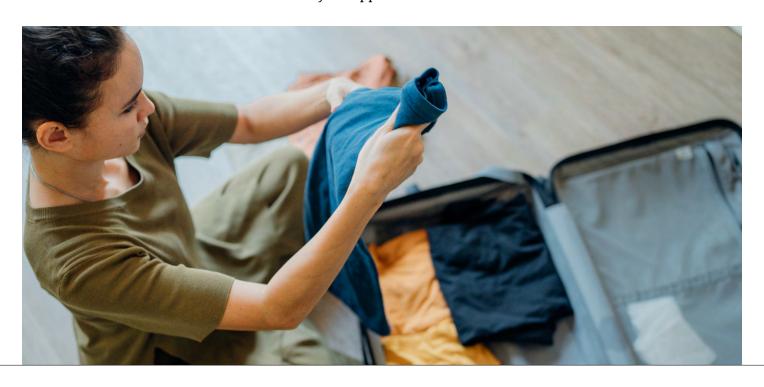
| ☐ Comfortable clothes |
|---|
| ☐ Shoes or slippers with non-slip soles |
| ☐ Your glasses, if you wear them |
| Personal items you would like, such as photos, music, games, books and laptop or tablet |
| Foods you would like to have in the hospital — Made at home or bought at the store (no restaurant food, please) |
| ☐ Plus, your transplant or CAR T-Cell book |

Important information for visitors and caregivers:

Typically, you may have visitors in the hospital. No children under 12, please.

One person over 18 may stay overnight in your room. We have a bathroom and shower for visitors. There is also a sleep room available. Since there is only one, it's possible your caregiver may need to wait if someone else is using it.

However, sometimes circumstances result in temporary restrictions for visitors. Please always double check the rules for visitors with your care team before coming into your appointments.



Staying clean and active

It is important to take a shower and brush your teeth each day. Be active if your medical team tells you this is OK, such as walking in the halls. It is important to try and drink at least 2 liters of fluids each day to stay hydrated.

Leaving the hospital

Before you leave the hospital, you should:

- Drink at least 2 liters of fluids each day, unless otherwise advised by your provider or care team.
- Have no fevers or infections for at least 24 hours.
- Be able to get dressed, use the bathroom and do other regular daily activities, with help from your caregiver.
- Be able to think and understand things clearly.
- Know how to take your medications and care for your central line. This is especially important before you go home.

The daily routine in the hospital

Your health care team will wash their hands when they come into your room, before they touch you. It is OK to ask them to wash their hands if you do not see them do it. Sometimes your health care team will need to wear masks and gloves. If this is necessary your team will discuss this with you.

Nurse checks: In addition, your nurses will meet to discuss your care plan at the beginning of each shift. You can choose to be a part of this discussion as well. Your medical team will meet with you each day to discuss your progress as well.

Your nurse will also check your heart rate, breathing, temperature and blood pressure many times each day and night. They will take a blood sample at midnight. They will also record your weight, how much you eat and how often you use the restroom.

Your nurse will take care of your central line, if you have one. The nurse will also check often to see if you are confused or have difficulty thinking.

Monitored labs: there are several labs we monitor each day that you should be aware of.

| FOR BLOOD COUNTS | FOR ELECTROLYTES |
|---|--|
| WBCs | Potassium |
| RBCs | Magnesium |
| Platelets | Phosphorus |
| Please note: Transfusions may be required depending on your RBC and platelet levels. | Calcium |
| | An IV or oral replacement electrolyte may be given to maintain safe levels |

Your Care in the Clinic

Center for Hematologic Malignancies and Clinic in CHH2 at OHSU

For the clinic, call 503-494-5058.

The clinic is open Monday through Friday between 8 a.m. and 5 p.m. Reminder, if your caregiver becomes sick, please call the clinic on how to stay safe.

For urgent issues after hours, weekends and holidays, call the OHSU operator at 503-494-8311 and ask to have the medical oncologist on call paged.

For any life threatening emergencies, call 911.

Getting care in the clinic

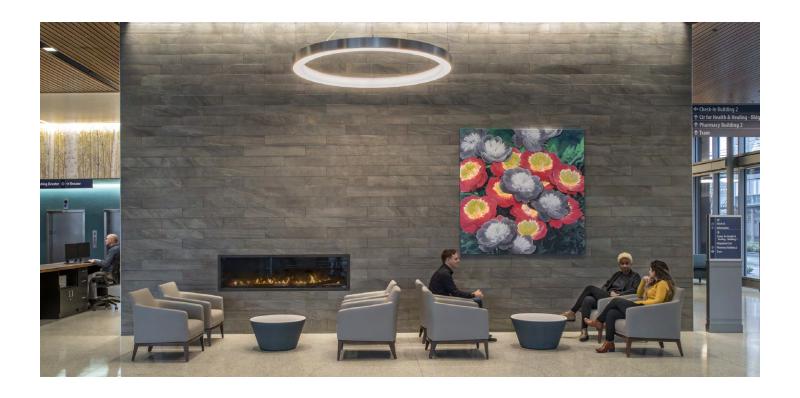
Your clinic visits may include lab draw, visit with provider, and an infusion appointment for any infusion or treatment needs. The length of the day can depend on your blood test results and how you are feeling that day.

YOUR CLINIC APPOINTMENTS

CAR T-cell therapy follow up is every day for the first 7 days after infusion. Then every other day for the next 7 days, and every 3 days until day 30.

Auto transplant therapy will have follow up appointments in the clinic 2–3 times a week for approximately 2–3 weeks after you discharge from the hospital.

Allo transplant therapy will have follow up appointments in the clinic 2–3 times per week for approximately 3 months after you discharge from the hospital.





WHAT TO BRING TO YOUR CLINIC VISITS

- Please bring all your medications to your first clinic visit.
 - Also bring the list of medications you were taking when you left the hospital.
 - If you have questions about any medications, please bring the bottles with you.
- Bring your daily medications with you, such as insulin or blood pressure medications.
- Be sure you bring your caregiver if you will see your APP or doctor.
- You will want to bring a cooler or bag with snacks and drinks for your stay.
- Bring something to keep you busy, such as books, music, work or games.

Central lines

We will change the bandage on your central line each week. We can also teach your caregiver how to take care of the line, if needed.

Please make sure the line is covered when you take a shower, so it does not get wet. If your dressing does get wet, call the triage line and we can arrange for a clinic appointment to have the dressing changed.

Life at Home

If relocating to the Portland area, this refers to your temporary housing.



Here are some tips to help you avoid infections after your transplant or CAR T-cell therapy:

- Give your home a good "spring cleaning."
- Use pump soap, not bar soap, to wash your hands
- Use wipes to clean sinks and toilets, and throw the wipes away after use.
- While at home, your caregiver or someone else should do any activities that involve contact with body fluids or dirt.
- Transplant patients, please be sure to stay away from house plants. Move them to another room or a section of your home away from you.

Personal care and life with pets

- Your pets do not need extra shots, but do have someone give them a bath before you come home from the hospital. Do not let your pets lick your face. Have a caregiver clean the litter box and pick up after your pets.
- Avoid lizards, birds, snakes, turtles, rabbits, guinea pigs, etc.
- Stay out of the sun, and use sunscreen (SPF 30 or more) when you go outside.
- Avoid any skin products that can cause irritation.
- You may go back to being active when you feel well enough, but please talk with your health care team first.

Additional ways to avoid infection

- Avoid crowds and public places.
- Wear your mask when you leave the house.
- Avoid areas with construction or remodeling.
- Shower every day and dry off with a clean towel.
- Wash your hands often.

Please call us at **503-494-5058** if your caregiver gets sick. We will talk with you about how to stay safe and get the help you need.

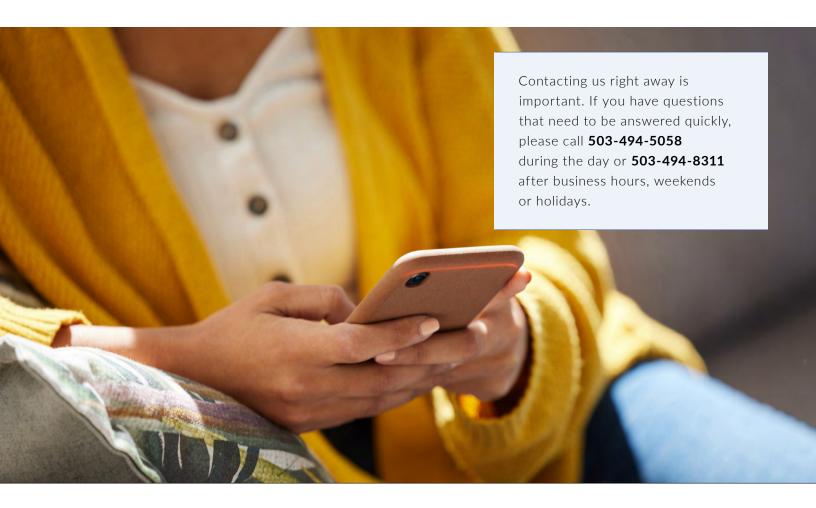
About caregivers and visitors

No one who is sick or does not feel well should visit you. They can call, email, text, do a video visit or send a card.

Contacting us

- We will give you a card with contact information for our clinic team.
- You can also call **503-494-5058** with questions.
- The clinic is open Monday through Friday, 8 a.m. 5 p.m.

Contacting us after business hours, please call **503-494-8311** if you need help or have questions after we are closed. There is always a team member available to help you, so please don't hesitate to call with questions or concerns, and ask for the medical oncologist on call.



Managing Symptoms and Side Effects

Center for Hematologic Malignancies and Clinic in CHH2 at OHSU

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For urgent issues after hours, weekends and holidays, call the OHSU operator at 503-494-8311 and ask to have the medical oncologist on call paged.

For any life threatening emergencies, call 911.

How to contact us

We want you to be comfortable and confident about your care at OHSU.

If you feel sick, please call the clinic. We will have you talk with a nurse.

If your caregiver becomes sick, please call the clinic for advice on how to stay safe. The clinic number connects you to the oncall physician when the clinic is closed.

For the Center for Hematologic Malignancies and Clinic in CHH2 at OHSU:

- For the clinic, call 503-494-5058. The clinic is open Monday through Friday between 8 a.m. and 5 p.m.
 Reminder, if your caregiver becomes sick, please call the clinic on how to stay safe.
- For urgent issues after hours, weekends and holidays, call the OHSU operator at 503-494-8311 and ask to have the medical oncologist on call paged.
- For any life threatening emergencies, call 911.

When to call us

You or your caregiver should call if you have:

- A fever of 100.4 degrees F or 38 degrees C or higher, chills, or "the shakes"
- Blood in your pee (urine) or poop (stool)
- Breathing problems, such as wheezing, cough or congestion
- Diarrhea Call if you have a bowel movement more than 3 times in 24 hours, especially if you had a donor transplant
- A skin rash, especially if you had a donor transplant
- Trouble drinking at least 2 liters of fluids each day, unless otherwise advised by your provider or care team
- · Confusion or a feeling of being disoriented

For any of these signs, we will let you know if you should come to the clinic or emergency department.



When to call 911

Please call 911 if you or the person you take care of has the problems below.

- Bleeding you cannot stop, or constant bleeding
- Fainting or passing out
- Choking or being unable to breathe
- Chest pain
- Any signs of a stroke.

These include:

- Face drooping on one side
- Arm weakness
- Difficulty speaking

When to check for a fever

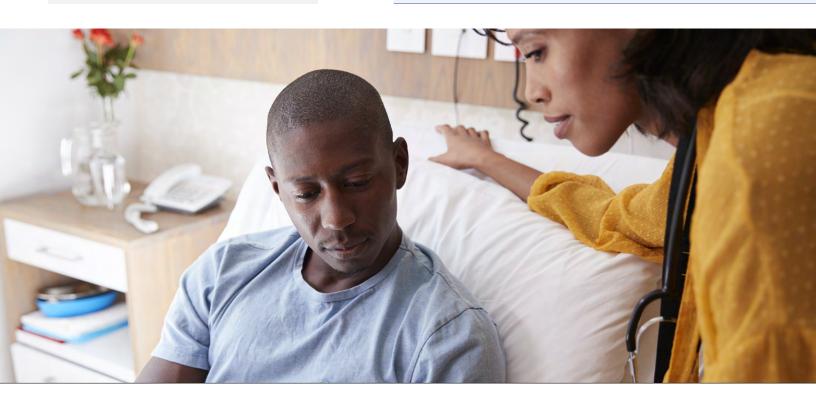
A fever is a body temperature of 100.4 degrees F or 38 degrees C or higher. Take your temperature 2 to 3 times each day. Also take it if you do not feel well.

• Before taking acetaminophen (brand name Tylenol) for any reason, check your temperature. This medicine can make it seem like you do not have a fever when you really do.

If you need to come to the hospital

You may need to come back to the hospital, you should know:

- This is common for people who have a transplant or CAR T-cell therapy
- It is for your safety
- You and your caregiver did not do anything wrong
- You may go home as soon as it is safe for you



When Your Stem Cells Come from a Donor

This is for allo transplant patients only. If you had an auto transplant or CAR T-cell therapy, skip to page 49.



Immune system medications

Please DO NOT take these medications on days you come to the clinic. However, please bring your medication with you, to be taken after your labs are drawn. We will check your levels and dose at your appointment. Then we will let you know if it needs to be changed.

What is graft versus host disease?

Graft versus host disease, or GVHD, can be a side effect after you receive donated stem cells. It happens because the new, healthy cells come from a different immune system than your own.

A healthy immune system attacks cells that are not its own. In GVHD, the new immune system attacks your body.

GVHD is common. About half the people who have stem cell transplants get it. It can happen soon after transplant (acute GVHD) or later (chronic GVHD).

About acute and chronic GVHD

Signs or symptoms of GVHD include

- Diarrhea (more than 3 episodes in a day)
- Skin rash
- Yellow skin

Call the clinic right away if any of these symptoms develop or increase in the first 100 days post transplant.

Acute GVHD happens fairly soon after your transplant, in the first 100 days. This is about 3 months. It usually affects the skin, digestive system and liver.

Chronic GVHD happens more than 100 days after your transplant. This is about 3 months. It usually affects the skin, liver, eyes and lungs.

Medications

Medications that suppress your immune system

Your transplant team will prescribe medication to treat GVHD.

These may include:

- Methotrexate
- Prednisone or methylprednisolone
- Cyclosporine or tacrolimus
- Mycophenolate

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For any life threatening emergencies, call 911.

Foods that may affect your medication

Some foods can affect how well your medications work.

Tacrolimus and cyclosporine are especially likely to be affected.

Please avoid the foods listed next.

FOODS TO AVOID

Grapefruit and grapefruit juice

Seville oranges — Ask a grocery store worker if you are not sure what type they are.

- It is OK to eat regular (navel) oranges, lemons and limes.

Starfruit

Pomelo

Pomegranates and drinks with pomegranate juice.

Possible side effects of GVHD medications

Medications to prevent GVHD can cause side effects. It is important to continue taking these medications and let your provider know of the side effects you are experiencing.

These can include:

- High blood pressure
- Tremors
- Changes in thinking or memory
- Dry mouth
- Changes in your bones They can become thinner, weaker and more likely to break. You can develop a condition called "osteoporosis."

Possible Treatment Side Effects

What to do and how to prevent and manage side effects

The information that follows talks about different side effects of cancer and treatment. The column on the right tells you what to do for each problem.

At the bottom of each table, find information on how to prevent or manage specific side effects.



Bleeding and Breathing Problems

| BLEEDING | BREATHING PROBLEMS | WHO AND WHEN TO CALL |
|--|---|--|
| POSSIBLE CAUSES Low platelet count Medications Infections Accidents or falls Deep massage Other causes | POSSIBLE CAUSES Allergies or asthma Infections Extra fluid in your lungs Bleeding Low red blood cell count Other causes | |
| Uncontrolled or constant bleeding Losing consciousness | ChokingCannot breathe or take a deep breath | Call 911. This is an emergency. |
| Blood in urine (pee), bowel movements (poop) or vomit Nosebleed that will not stop Bruising more often than usual Fall or injury Headache that does not go away Changes in vision | Cough that does not go away Dry cough (no mucus comes up) Difficulty breathing when you lie flat Cannot catch your breath or get enough air Wheezing, chest tightness | Call the clinic or doctor on call immediately. |
| Small red or purple spots on your skin Frequent nosebleeds (you can control them, but they happen often) New bruises | A new cough or cold symptom New shortness of breath when you are active Decrease in stamina, or more shortness of breath when you are active | Call the clinic or doctor on call within 24 hours. |

Help prevent and manage bleeding problems

Avoid the following:

- Aspirin, ibuprofen (Advil) and naproxen (Aleve)
- Strenuous exercise and weight lifting
- Falling down or hurting yourself
- Enemas, rectal suppositories, rectal exams and rectal thermometers
- Deep massage
- Tampons and douching

Help prevent and manage breathing problems

- Avoid pollution, smog, burning and construction zones
- Stay away from smokers and do not smoke. This includes marijuana, vaping and cigars.
- Exercise each day, even if it is just sitting upright in a chair.
- Use your incentive spirometer.
- Avoid people who have colds or cold-like symptoms.

Diarrhea, Nausea and Vomiting

| DIARRHEA | NAUSEA AND VOMITING | WHO AND WHEN TO CALI |
|---|--|---|
| POSSIBLE CAUSES Medications Diet Graft versus host disease Other causes | POSSIBLE CAUSESMany different causesMay be persistent or come and go as you get better. | |
| • Passing out (fainting) | ChokingUnable to breathe easily | Call 911. This is an emergency. |
| Bloody, dark red, or black bowel movements Cramps, stomach pain or fever Constant diarrhea, or not being able to control your bowels Feeling confused or lightheaded or passing out (fainting) Urinating less than normal, dark urine | Vomiting up medications Nausea or vomiting that medication does not help Feeling dizzy, weak, faint, or lightheaded Bloody or dark brown vomit Severe stomach pain | Call the clinic or doctor on call immediately. |
| Cannot eat or drink as usual Undigested pills in bowel movements More than 3 bowel movements in 24 hours New start of diarrhea Cramps that do not get better or that keep coming back | Nausea that does not go away, even when you take anti-nausea medications. | Call the clinic or doctor on call within 24 hours. |

- · Avoid caffeine, bran, other high fiber foods, and milk
- Drink at least 2 liters of fluid a day, preferably sports drinks or Pedialyte
- Take your medications the way they are prescribed
- Practice good hand washing
- Keep the rectal area clean

and vomiting

- Take anti-nausea medication as prescribed
- Try visualization, meditation, deep breathing exercises, or distraction
- Eating and drink small amounts slowly
- Avoid extremes in food temperature, smell, or flavor
- · Avoid alcohol and foods that are fatty, fried, or very sweet or spicy

Fever and Infections, Memory and Thinking Problems

| FEVERS AND INFECTIONS | MEMORY AND THINKING PROBLEMS | WHO AND WHEN TO CALL |
|--|---|--|
| • Stem cell (bone marrow) or CAR T-cell transplant makes immune system less able to fight infections for at least 6-12 months after transplant. | CAUSED BY Stress, anxiety, medications, chemotherapy, radiation, and other causes. | |
| | Signs of a stroke:Face droopingArm weaknessDifficulty speaking | Call 911. This is an emergency. |
| Fever of 100.4 F or aboveShaking chills, teeth chatteringEarache, headacheStiff neck | Feeling confused or disorientedArm or leg weaknessDifficulty talking | Call the clinic or doctor on call immediately. |
| Cough, runny nose, sneezing, or cold symptoms Mouth or throat sores, blisters on lips, sore throat Pain or burning when you urinate (pee) Pain or redness around your central catheter Blisters, rashes or sores anywhere on your body | Cannot do simple tasks or remember how to do them Cannot follow simple directions Cannot remember or repeat what you read Sudden change in ability to think or concentrate Difficulty finding words | Call the clinic or doctor on call within 24 hours. |

What you can do about fevers and infections

- Take your temperature each morning and evening if you are not feeling well.
- Take proper care of your central catheter.
- Avoid people who have cold symptoms or other illnesses.
- Wash your hands often.
- Take your medications as prescribed.

What you can do about memory and thinking problems

- Have a friend or family member come with you to clinic visits.
- Put important numbers on your refrigerator. Write appointments on a calendar.
- Write down any changes in your medication or treatments.
- Use lists.

Mouth Pain and Mucositis (Mouth Sores), Fatigue

| MOUTH PAIN AND MUCOSITIS (MOUTH SORES) | FATIGUE | WHO AND WHEN TO CALL |
|--|---|--|
| • Chemotherapy | CAUSED BY Medications Low red blood cell counts Changes in sleep pattern Poor nutrition Depression | |
| | • Unable to wake up | Call 911. This is an emergency. |
| Drooling Unable to swallow Pain that your pain medication does not control Bleeding in your mouth | Feeling too tired to get out of bed or walk to the bathroom Feeling dizzy | Call the clinic or doctor on call immediately. |
| Sores on your lips, tongue or the inside of your cheeks Mouth is dryer than usual Trouble swallowing, eating or drinking | Staying in bed all dayFeeling like your fatigue is getting worse | Call the clinic or doctor on call within 24 hours. |

Prevent and manage mouth pain and mucositis

- Rinse your mouth often with a salt water solution
- Use a soft toothbrush. Do not floss your teeth until your platelet level is over 50,000.
- Avoid any mouthwash with alcohol in it.
- Take pain medication as prescribed.
- Make sure you are drinking and eating enough. Try soft foods.
- Avoid all dental work until your team says it is OK.
- Keep your lips and mouth moist at all times.

Prevent and manage fatigue

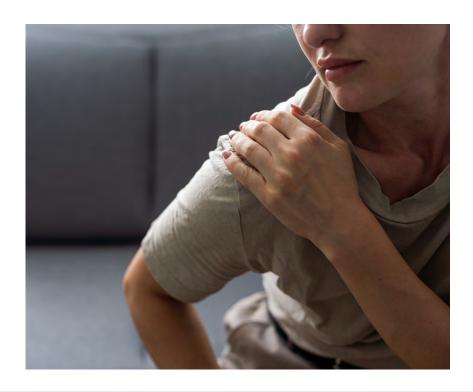
- Stay as active as you are able.
- Save your energy for important activities.
- Create a regular rest and sleep pattern.
 Try background noise to help you sleep.
- Rest between activities.
- · Maintain good nutrition.
- Let family and friends help with household tasks.
- For longer outings, use a wheelchair or available scooter, such as a mobility scooter at the store.

Skin Changes or Rash

| SKIN CHANGES OR RASH | WHO AND WHEN |
|---|--|
| • Reaction to medications or possibly the start of GVHD. | |
| Rash that has blistering or has progressed to your entire body | Call the clinic or doctor on call immediately. |
| Faint rash on your neck, ears, shoulders, palms of your hands or soles of your feet | Call the clinic or doctor on call within 24 hours. |

How to prevent and manage skin changes or rash

- Wear sunscreen at all times, for the rest of your life, when outdoors
- Avoid scented lotions or perfumes



Introduction to CAR T-Cell Therapy

Please call us at **503-494-5058** if your caregiver gets sick. We will talk with you about how to stay safe and get the help you need.

About CAR T-Cell Therapy

What is CAR T-cell therapy?

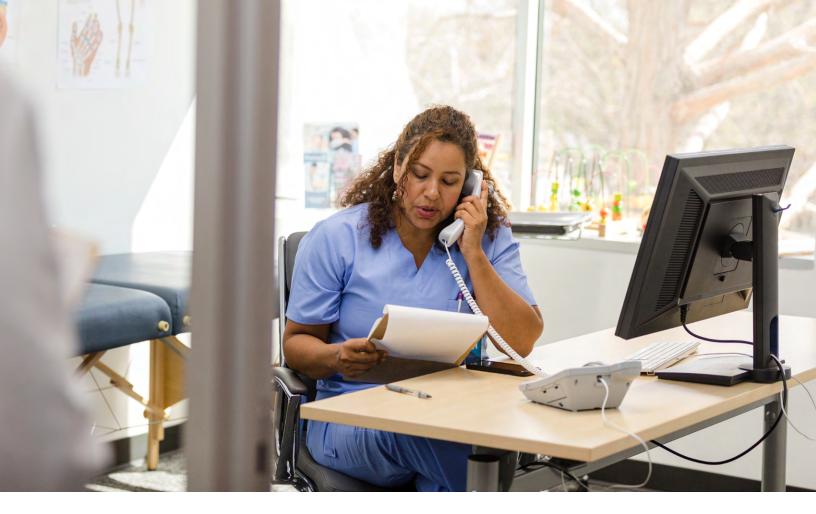
CAR T-cell therapy is a treatment that works with your body's immune system. This is the system that fights infections and diseases like cancer.

How CAR T-cell therapy works:

CAR T-cell therapy is a treatment where your T cells are taken, and then changed by adding a receptor to them. T cells are a type of cell in your immune system. This process of adding a receptor, then placing the changed cells back into your body will help the T cells recognize and destroy cancer cells.

You may have your CAR T-cell therapy in our clinic and go home afterward. Or you might need to stay in the hospital. If so, your doctor will let you know.





If your caregiver gets sick

You need a caregiver 24 hours a day, 7 days a week. So, please call us at **503-494-5058** if your caregiver gets sick or cannot take care of you. We can tell you how to stay safe.

Treatment Timelines

Your treatment schedule

Your cells may be collected and sent to a lab that modifies the cells so they are ready for your treatment.

Your T-cells are ready in anywhere from 2–8 weeks, depending on the product.

Your nurse coordinator will call you and arrange for your treatment.

Do I need treatment while I wait for my T-cells?

Your doctor will let you know. You might have treatment while you wait, or you might not. Treatment while waiting for your T-cells is called bridging therapy.

Possible side effects of CAR T-cell therapy

CAR T-cell therapy can cause two significant types of side effects:

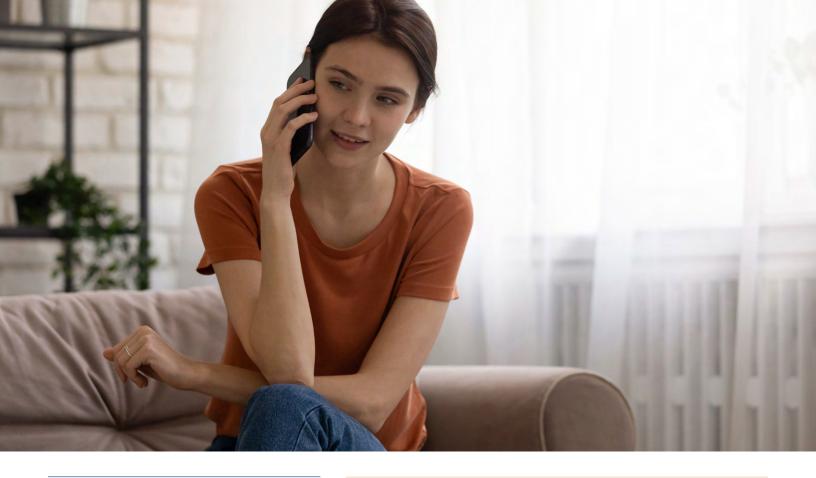
- Cytokine release syndrome (CRS). You may feel like you have an infection. You might have a fever and feel faint.
- Toxic effects on the nervous system, or neurotoxicity. You may feel confused or have other problems thinking and understanding things. You might have a seizure (fit). Nervous system side effects can be life-threatening.

If you think you have side effects, if you feel confused or have problems thinking, **call 911** or come to the OHSU Emergency Department immediately. Have your caregiver drive you to the hospital, and call us at **503-494-5058** and tell us you are on your way to the emergency department.

Do not drive yourself.

Your CAR T-cell team will watch you closely after you receive your cells. We will do this for many weeks. We will also take the best possible care of any problems you notice. This helps us prevent side effects and treat them if you have them.





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For urgent issues after hours, weekends and holidays, call the OHSU operator at 503-494-8311 and ask to have the medical oncologist on call paged.

For any life threatening emergencies, call 911.

When to call us

You or your caregiver should call if you have:

- A fever of 100.4 degrees F or 38 degrees C or higher, chills, or "the shakes"
- Blood in your pee (urine) or poop (stool)
- Breathing problems, such as wheezing, cough or congestion
- Diarrhea Call if you have a bowel movement more than 3 times in 24 hours, especially if you had a donor transplant
- A skin rash, especially if you had a donor transplant
- Trouble drinking at least 2 liters of fluids each day, unless otherwise advised by your provider or care team
- · Confusion or a feeling of being disoriented

For any of these signs, we will let you know if you should come to the clinic or emergency department.



When to call 911

Signs of a problem

Call 911 right away if you or the person you care for:

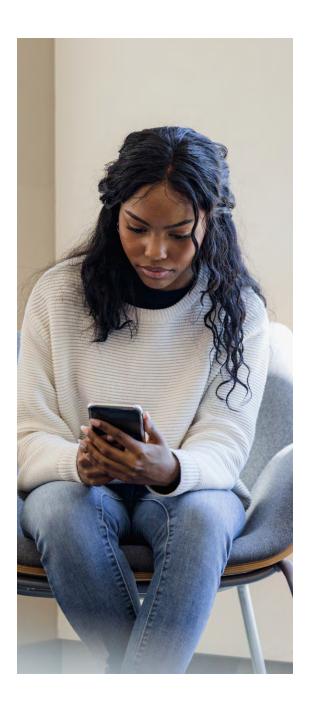
- Has bleeding that will not stop
- Passes out or does not wake up
- Is choking or cannot breathe
- Has chest pain
- For a possible stroke

Signs that someone is having a stroke

- Face drooping, usually on 1 side
- An arm that is weak or they cannot lift
- Difficulty talking

Call 911.

Tell the Emergency Department staff that you had CAR T-cell therapy at OHSU.



Keeping information on your CAR T-cell therapy

We will give you a card to carry with you, saying you had CAR T-cell therapy. Please keep it in your wallet or purse, or somewhere else you will always have it. You can take a photo of the card to keep on your phone. We recommend that you share this wallet card with your caregivers.

Tell all your health care providers you had CAR T-cell therapy. They need to know what date you had it and the name of your main doctor for this treatment.

Contacting us with problems or questions

Do not use MyChart for anything urgent. Call us right away if you have any of the urgent problems previously discussed. Please call us at **503-494-5058** with questions. We will take your information and talk with you about your concerns.



