Your Guide to Cellular Immunotherapy
Bezos Family Immunotherapy Clinic

Seattle Cancer Care Alliance
Fred Hutch · Seattle Children's · UW Medicine
Welcome to the 
Bezos Family Immunotherapy Clinic

In this guide, you’ll find information to help you and your caregiver during your cellular immunotherapy treatment.

Your care team will review this information with you during your first appointment and many times throughout your treatment.

Please bring this guide with you to each appointment and keep it in a convenient location in your home.
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Treatment Overview
Important phone numbers

If you need to speak with someone urgently, after hours, or in an emergency, use the following information:

Urgent symptoms

<table>
<thead>
<tr>
<th>When</th>
<th>Numbers</th>
<th>Hours</th>
</tr>
</thead>
<tbody>
<tr>
<td>Business hours</td>
<td>(206) 606-6000</td>
<td>8 am to 10 pm, Mon-Fri</td>
</tr>
<tr>
<td></td>
<td>Ask for the triage nurse</td>
<td>8 am to 6 pm, Sat &amp; Sun</td>
</tr>
<tr>
<td></td>
<td></td>
<td>8 am to 5 pm, holidays</td>
</tr>
<tr>
<td>After hours</td>
<td>(206) 598-8902</td>
<td>10 pm to 8 am, Mon-Fri</td>
</tr>
<tr>
<td></td>
<td></td>
<td>6 pm to 8 am, Sat &amp; Sun</td>
</tr>
<tr>
<td></td>
<td></td>
<td>5 pm to 8 am, holidays</td>
</tr>
</tbody>
</table>

Medical emergency

Call 911
Ask to be taken to University of Washington Medical Center

For a list of urgent symptoms and medical emergencies, please refer to the Quick Reference for Symptoms in this guide.
Your immunotherapy care team

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

- Attending physician
- Advance practice provider
- Team nurses
  - Nurse coordinator
  - Infusion nurse
  - Transition nurse
- Pharmacist
- Scheduler
- Dietitian
- Social worker

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

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 nurse coordinator 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 on the next page.
Your care team

Attending physicians or “attendings” rotate at Seattle Cancer Care Alliance (SCCA) and at University of Washington Medical Center (UWMC) 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, lead 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 SCCA. 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).

You will see 3 team nurses during your treatment, including a clinical nurse coordinator, an infusion nurse, and a transition nurse.

- Your clinical nurse coordinator (CNC), is the person you see the most throughout your visits and is the main contact for your care. They are also your link to other members of your care team. Besides being the primary face of your care team, your nurse coordinator monitors your symptoms and response to treatment and medications and provides education and support during your treatment. Your nurse coordinator is often the first person you contact when you have questions for your care team.

- Your infusion nurse will take your vitals (blood pressure, temperature, etc.), draw your blood, and provide your chemotherapy, electrolytes, blood products, and hydration support.

- Your transition nurse will give you resources for home infusion, medical equipment and home health care, if you need them. If you are admitted to the hospital, they will also provide your hospital discharge education.

Your social worker helps you access the non-medical parts of your care at SCCA, including services such as housing, transportation, and finance. Your social worker can also connect you to supportive care services such as psychology, smoking cessation, and spiritual health. Spiritual health provides emotional, ethical, and spiritual care for patients and families through a variety of services.
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. 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 **scheduler**, also called a team coordinator, schedules your appointments. Schedulers are your main contact for any scheduling questions.
Cellular immunotherapy

Introduction
Your immune system protects your body against infection and abnormal cellular changes, such as cancer. Cancer cells can hide from the immune system and even trick it into helping—rather than harming—these cells. Immunotherapy helps your immune system work harder and smarter to attack cancer. We offer 3 types of cellular immunotherapies; some of them are approved by the US Food and Drug Administration (FDA) and others are in clinical trials:

- Chimeric antigen receptor (CAR) T-cell
- Tumor Infiltrating Lymphocytes (TIL)
- T-cell receptor (TCR)

Each of these therapies changes the T cells in your immune system to become disease-fighting cells.

The image above describes how CAR T-cell therapy works.
What you can expect

Your experience is unique
The information below is meant to give you a general idea of the cellular immunotherapy experience at SCCA. Keep in mind that your experience is unique. It will differ from others based on your disease, treatment plan, and response to treatment.

Phases of immunotherapy
Cellular immunotherapy is made up of several phases:

- Evaluation
- Cell collection or cell harvesting
- Cell engineering
- Chemotherapy
- Cell infusion
- Monitoring for side effects
- Follow-up
- Long term follow-up

Your appointments
During each of the phases noted above, you may have one or more appointments. It is important that all appointments are kept as scheduled. We suggest bringing someone with you to help listen and take notes. Most appointments will take place at SCCA. Some of your outpatient care may be provided at the University of Washington Medical Center (UWMC). Your care team will talk to you about your specific treatment plan and appointment locations.

If needed, your inpatient care will be provided at SCCA Hospital or UWMC, which has a team of cellular immunotherapy nurses and physicians, just like our outpatient clinic.

Your location during treatment
For your safety, from the time you start chemotherapy, until the time you are discharged from day-to-day care, you are expected to live within a 30-minute drive to SCCA. If you are coming to Seattle from out of town, we recommend arranging temporary housing as soon as you know your arrival date. You may not be allowed to drive for 4 to 8 weeks following your cell infusion, depending on your treatment plan and condition. Your care team will discuss this with you in more detail.

We encourage you to visit our website, seattlecca.org/housing-information, to learn about SCCA’s housing options and to view our housing guide. If you choose a different accommodation, there are a variety of hotels and extended-stay options within a 30-minute drive to our clinic.

Visit scca.io/imtxvideo to watch a video about the cellular immunotherapy experience at SCCA.
Your caregiver
Due to the intensity of the treatment, you will need to have a caregiver with you 24 hours a day during chemotherapy, cell infusion, and for several weeks after your cell infusion. Your care team will determine how long you will need a caregiver following cell infusion (generally, based on our experience with other cellular immunotherapy patients, it's about 4 weeks). This is the same time that you are also expected to live within a 30-minute drive to SCCA.

A caregiver provides around-the-clock monitoring, emotional support, and physical care, if needed. You may find it helpful to have one main caregiver, with assistance from other family members, friends, or hired caregivers. Before treatment starts, your team will teach you and your caregiver the symptoms to look for as you undergo treatment.

We recommend bringing your caregiver to appointments even before you start chemotherapy to meet your care team and learn about your treatment plan. See Caring for a Person Receiving Cellular Immunotherapy for more information about the role of a caregiver during treatment.

Evaluation
As a first step, you will meet with your care team to discuss your medical history, current disease status, and undergo a series of tests to evaluate your health and eligibility to receive cellular immunotherapy. Examples of the types of tests or procedures you might have include:

- Bone marrow biopsy
- Blood draws
- Chest X-ray
- DEXA bone scans
- EKG (electrocardiogram)
- Lumbar puncture
- MUGA scan or echocardiogram
- PET/CT scan
- Pulmonary function tests

After this is complete, you will have a conference with your care team to discuss whether cellular therapy is a good treatment option for you. We recommend bringing your caregiver with you to this meeting. Your physician will review information about treatment and side effects. You will be asked to sign consent forms before beginning therapy. The conference is a time for you to ask questions about the forms you are signing and about your treatment. Please read the forms carefully, but do not write on or sign them before your meeting.
Cell collection
T cells are collected from you through either apheresis (ay-fer-ee-sis) or a surgical procedure. Your cells will be collected through apheresis if you are getting CAR T-cell or TCR therapy. Your cells will be collected (also called “harvested”) through a surgical procedure if you are getting TIL therapy.

During apheresis, blood is taken from your body, sent through the apheresis machine that separates and collects your T cells, and the rest of the cells are returned to your bloodstream. Apheresis generally takes 3 to 6 hours. Your apheresis nurse will have a better idea of how long your cell collection will take once you have started the process. Apheresis will take place on the 5th floor of the SCCA clinic.

After your cells are collected or harvested, they are sent to a lab where scientists work to turn them into cancer-fighting cells.

Cell engineering
It generally takes 2 to 4 weeks for scientists/manufacturers to grow your new cells in the lab. Your care team will let you know how long you can expect to wait to receive your cells. During this phase, you will be seen in our clinic to make sure your body is ready for your treatment. If your care team approves and you live out of town, you may be able to go home until your cells are ready.

Chemotherapy
Before receiving your new T cells, you may get lymphodepleting chemotherapy. The purpose of this is to decrease the number of immune system cells in your body to create space for your new cells. You will meet with a nurse before chemotherapy to talk about potential side effects and how to manage them.

You will receive your chemotherapy through a central line. A central line allows you to have long-term intravenous (IV) access for the chemotherapy, cell infusion, and administration of medications that might be needed after cell therapy. If you do not have a central line, you will have one placed (see Central Line Care for more information).

Cell infusion
A few days after chemotherapy, your cells are infused. Depending on your treatment plan, your infusion may take place at the Immunotherapy Clinic at SCCA, or at the UWMC or SCCA Hospital. Once your cells are infused, you will need to be monitored for side effects.

Monitoring for side effects
Cellular immunotherapy can have serious side effects such as high fevers, unstable blood pressure, and changes in speech, behavior, and memory. Based on our experience, these side effects typically occur within the first 2 weeks after your infusion. We will give you contact information for who to call, day or night, if you experience urgent side effects.
You and your caregiver will be taught how to monitor for fever and what to do if you get one. If you experience a fever after receiving your T cells, you will be admitted to SCCA Hospital or UWMC. Your caregiver is not required to be with you if you are admitted, but you may find it comforting to have your caregiver with you in the hospital. UWMC and SCCA Hospital are designed for them to stay overnight.

The two main side effects that you will be monitored for are cytokine release syndrome (CRS) and neurotoxicity.

**CRS** is a severe inflammatory response that can lead to dangerously high fevers and extremely low blood pressure. Sometimes it goes away on its own with medical intervention and monitoring. But in rare cases, it can be severe and fatal. The most common first symptom of CRS is a fever. If you get a fever, you will be admitted to the hospital for monitoring. Severe symptoms may require intensive care unit (ICU) level care.

Another potential side effect is neurotoxicity. If this occurs, you will be admitted to the hospital. The cause of neurotoxicity is unknown, but it typically develops after CRS. When you have neurotoxicity, you can experience symptoms such as confusion, difficulty speaking, memory loss, unsteadiness, or seizures. Often, these symptoms may last less than a few days, are mild, and only need close monitoring. Sometimes, the symptoms may be more severe and last more than a few days. For example, you may not remember where you are, not recognize the people around you, or have difficulty getting to the bathroom on your own.

For symptoms of both CRS and neurotoxicity, you may be treated with steroids which can help slow down the growth of T cells. You may also receive medications to help reduce the risk of seizures during treatment.

You may feel weak and fatigued, which can impact your ability to perform your routine, daily activities. Based on the type and severity of side effects you experience, you may need to have special equipment at home (such as a walker, shower chair, or raised toilet seat) and you may require additional help, home care, and/or a physical therapist. Your care team can help you access these resources.

**Follow-up**

We are committed to providing you the best possible treatment and follow-up care. Following your infusion of T cells, your care team will monitor you closely. Most patients visit the clinic daily. If you are in the hospital, a Transition nurse will coordinate follow-up appointments with your care team from the immunotherapy clinic.

Based on your progress and treatment plan, we will determine your recommended follow-up plan after you leave SCCA. We will provide your referring physician a discharge summary. You will receive a packet with your medication list and most recent lab values, other medical records, and a disk with your radiology images.
**Long term follow-up**
After you are discharged from the clinic, the Immunotherapy Long Term Follow-up (LTFU) staff will be a resource for you and your local provider. They are available during business hours to answer your questions and concerns related to cellular immunotherapy. You can reach LTFU staff by email at imtxlftu@fredhutch.org or by phone at (206) 667-5811.

You may be asked to participate in one or more long-term follow up studies. These types of studies help us learn about the long-term effects of cellular immunotherapy. The follow-up may be done through e-mail, regular mail, and/or appointments with your primary care physician, oncologist, or SCCA care team.

**Frequently asked questions**

**What is a T cell?**
A T cell is a type of white blood cell in the immune system that destroys viruses, bacteria, and cancer. Sometimes, T cells don’t do their job, and viruses, bacteria, and cancer can take over. Using cellular immunotherapy, scientists alter T cells to become cancer fighters.

**What is tumor infiltrating lymphocyte (TIL) therapy?**
Tumor Infiltrating Lymphocytes (TIL) are T cells that can be found in your tumor. During TIL therapy, TILs are collected or “harvested” from your tumor and treated with substances that make them grow to large numbers quickly. The cells are given to you and used to target and kill cancer cells.

**What is CAR T cell therapy?**
CAR T-cell therapy is similar to TIL therapy, but your T cells are changed in the lab so that they make a type of protein known as CAR before they are grown and given back to you. CAR stands for chimeric antigen receptor. CARs are designed to allow the T cells to attach to specific proteins on the surface of the cancer cells, improving their ability to attack the cancer cells.

**What is T cell receptor (TCR) therapy?**
TCR is similar to CAR T-cell therapy, but instead of attaching to specific proteins on the surface of the cancer cells, TCRs can recognize tumor specific proteins on the inside of the cells.

**How effective is cellular immunotherapy for cancer patients?**
When you meet with our team, we will go over the potential benefits and risks of cell therapies and discuss if they are the right treatment for you.

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**How much do cellular therapies cost?**
The cost varies based on the intensity of your treatment and insurance coverage. Our Intake team will discuss insurance and other financial considerations with you before your first appointment. You can also contact SCCA’s Patient Financial Services team directly to help you understand what treatments might cost you.

**What is the FDA?**
The FDA is the US Food and Drug Administration. The FDA makes sure that safe and effective drugs are available to improve the health of people in the Unites States.³

**What is a clinical trial?**
A clinical trial is a type of research study that tests how well new medical approaches work in people.⁴ These studies test new methods of screening, prevention, diagnosis, or treatment of a disease. Clinical trials for drugs and medical devices often occur in 4 phases, and each phase has specific research goals. The goals of each phase are to evaluate:

- **Phase I:** Safety, dosage, and side effects
- **Phase II:** Side effects and effectiveness
- **Phase III:** Effectiveness compared to standard treatment
- **Phase IV:** Long term effects

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³ [https://www.fda.gov/drugs](https://www.fda.gov/drugs)
Caring for a person receiving cellular immunotherapy

In this section, you will learn about your role caring for a person receiving cellular immunotherapy and the responsibilities that come with it. If you’d like more general information about being a caregiver, we encourage you to read our Caregiver Companion Guide.

Your role
As a caregiver, you play an important role during immunotherapy treatment. You will provide around-the-clock monitoring, emotional support, and physical care, if needed, during certain phases of treatment. Because treatment can last several weeks, you may find it helpful to talk to the person you are caring for about coordinating help from other family members, friends, or professional home health care.

While you are not required to join the person you’re caring for during the first two phases of therapy (evaluation and cell collection), we encourage you to come to all appointments, beginning with the first time they come to the clinic. Most people receiving treatment find it helpful and comforting to have someone with them during this time as details about the therapy, what to expect, and the schedule of appointments are reviewed. As the primary caregiver it is helpful to hear this information as early as you can. This is also an opportunity for you to develop a relationship with the care team and learn about the treatment plan.

Housing and driving
You and the person you’re caring for are expected to live within a 30-minute drive of the Seattle Cancer Care Alliance (SCCA) clinic from the time chemotherapy begins until discharge. If you are coming to Seattle from out of town, we recommend arranging temporary housing as soon as you know the date of the first appointment at the clinic. Please see the SCCA Housing Guide, available at seattlecca.org/housing-information, to learn about SCCA housing options that may be available. If you choose to find different accommodation, there are a variety of hotels and extended-stay options within a 30-minute drive to our clinic.

You and the patient you’re caring for are responsible for your own transportation. To help you get to and from appointments, we offer 2 free shuttles – one goes between the clinic and University of Washington Medical Center (UWMC) and SCCA Hospital, and the other goes between the clinic and SCCA residences (SCCA House and Pete Gross House). The shuttles do not run after hours, or on weekends or holidays.
Monitoring

Cellular immunotherapy includes 7 phases:

- Evaluation
- Cell collection/harvesting
- Cell engineering
- Chemotherapy
- Cell infusion
- Monitoring
- Follow-up

See *Cellular Immunotherapy Overview* for more information on each of these phases.

You will be monitoring the person you’re caring for from the time they receive chemotherapy until when they are discharged from our day-to-day care. During this time, you will monitor for fever, nausea, and any other new symptoms related to the cell infusion, such as cytokine release syndrome and neurotoxicity. Based on our experience, these side effects typically occur within the first 2 weeks after infusion. Your care team will explain how to address these side effects should they occur. You will receive an *Immunotherapy Clinic Packet* that details when and who to call if the person you’re caring for experiences symptoms during or immediately following chemotherapy or cell infusion.

Depending on how the person you’re caring for reacts to chemotherapy and their cell infusion, they may be admitted to the hospital. If this is the case, you are not required to stay, however, many people who are receiving treatment find it helpful to have their caregiver with them. UWMC and SCCA Hospital are designed for you to stay overnight.

Once discharged from the hospital, the person you are caring for 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. If you are admitted to the hospital, they will also provide you hospital discharge education.

People receiving cellular immunotherapy should not drive for 4 to 8 weeks following their cell infusion, depending on their treatment plan and condition.
Caregiver responsibilities
The checklist below provides an overview of some responsibilities you will have as an immunotherapy caregiver. If you need help with any of the actions listed below, please contact your immunotherapy clinical nurse coordinator or Transition Nursing Services.

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.
• Recognize the most common symptoms of immunotherapy 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 immunotherapy medications, when 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 yourself in stressful situations.
• Know about preventing falls and lifting the person you’re caring for safely.

SCCA’s Transition Nursing Services provides a class for caregivers. Call Transition Nursing Services at (206) 606-2125 with any questions about the class or other transition-related questions.
Getting admitted to the hospital

You may be hospitalized during your immunotherapy treatment. If needed, your inpatient care will either be provided at SCCA Hospital or a specialized unit of University of Washington Medical Center (UWMC). Both are located at UWMC and provide the same high-level quality of care. The immunotherapy specific care units are located on 7 NE and 8 NE in the Muilenburg Tower, 1959 Pacific Avenue NE, Seattle, WA 98195. If your admission to the hospital is scheduled in advance, you will be notified of the time and date to go to the hospital. At times, you may need to wait for an available hospital room.

Hospital services

Inpatient phone numbers
To reach 7 NE, call (206) 598-7770
To reach 8 NE, call (206) 598-8902
Calls to the nurses’ station are answered 24 hours a day.

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

Making outside local calls

<table>
<thead>
<tr>
<th>Phone number</th>
<th>Dial</th>
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</thead>
<tbody>
<tr>
<td>Outside number</td>
<td>9 + phone number</td>
</tr>
<tr>
<td>SCCA Hospital or UWMC number</td>
<td>8 + 4-digit extension number</td>
</tr>
<tr>
<td>Or dial “6190” and ask the hospital operator to connect you</td>
<td></td>
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</tbody>
</table>

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

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

Valet parking is offered the front of UWMC on weekdays from 7:30 am to 5:30 pm. The cost is the same as parking in the Triangle Garage. There is no extra fee for valet services.
The hospital offers free shuttles to Roosevelt clinics, Harborview, SCCA, Seattle Children’s and Fred Hutch. Staff at the front desk of your unit can give you a schedule and tell you where to catch the shuttle.

All SCCA Hospital and UWMC garages (Surgery Pavilion and Triangle) and the SCCA clinic garage offer same-day reciprocal parking. Simply bring your receipt from a participating garage to your next appointment, and it will be honored. You can get a validation sticker at the nurses’ station.

**Food services**
Nutrition Services will provide meals and snacks. You will receive a pre-printed menu daily, from which to order your meals. The menu you receive is designed to comply with your diet order. Other food choices are available from a special write-in list. Food safety is important, so it is preferred that your food and beverages be served from the kitchen. If you feel you require foods from outside the hospital, talk with your dietitian or physician.

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

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

**Television**
As part of an ongoing commitment to patient education, SCCA Hospital and UWMC regularly offer a wide selection of health care information. You will get a program guide that lists the channels that SCCA Hospital and UWMC offer as well as movie guides.

**Family room/lounge**
A family room/lounge is found on each unit for recreation and relaxation. There is a microwave oven, refrigerator, coffee maker, telephone, and television for your use. A shower and a baby-changing table are located on 8 NE. Washers and dryers are available for use (one patient’s belongings at a time) on 7 NE and 8 NE.

**Smoking policy**
SCCA Hospital and UWMC are smoke- and tobacco-free facilities. If you are a patient and you smoke or use tobacco, you may request nicotine patches during your hospital stay. We are here to support you if you would like information about how to quit.
Your daily routine

You may wonder what the normal routine day is like while you are an inpatient. What procedures are often done? What tests are usually run? What routine activities will be a part of everyday life on the unit? These questions will be explained in more detail by the inpatient nurse, but in the meantime, here is what you can expect:

Routine blood tests
Early morning, before 3 am, the nurses will draw daily routine blood tests from your central line. We will disturb you as little as possible, but our medical team needs to review your laboratory findings as early in the day as possible. Some routine tests will be drawn other times of the day as well.

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

Physical examinations
The nurses and physicians will need to listen to your heart, lungs, and abdomen with the stethoscope.

Daily weight
A daily morning weight check is important to monitor the amount of fluid in your body. You may need to have your weight checked twice per day.

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

Central line care
The central line dressing will be changed when needed to guard against bacterial growth. This gives us a chance to inspect the skin around the central line.

Measuring output
Your urine, stool, and emesis (vomit) will be measured and tested. Tests will be done on a regular basis. Please do not dispose of this output; the nurse will do it for you.

Exercise
We encourage you to arrange with the nurse a time to take a walk and exercise in the halls. Your physician may order Physical Therapists to work with you to help you keep your activity level up.
**Nutrition**
Dietitians will talk to you about your food likes and dislikes and provide specific recommendations based on oral and/or gastrointestinal symptoms. Nutrition support, either through a feeding tube or through your central line, is recommended if you are not able to eat.

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

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

**Transfusions**
Blood and platelet transfusions will be given to you as needed until you are able to make your own blood cells. Your blood counts will be checked every morning.

**Making the transition to the SCCA clinic**
A transition nurse from the SCCA clinic will meet with you and your caregiver to help with plans for discharge from SCCA Hospital or UWMC. Your care will then be coordinated by your team nurse until you are discharged to your home physician.

**Visitor guidelines**

**Open visiting hours**
There are no set visiting hours. We encourage families to keep their own health in mind and to get a good night’s sleep. A nurse will contact family members at home if any problem occurs. Family members should make sure that the Nurses’ Station has their correct phone number on file for emergency use. Visitors must wear a hospital ID badge between 9:30 pm and 5:30 am. Visitors can get a badge at the Information Desk on the third floor.

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

- **Clean hands frequently by washing with soap and water or by using alcohol hand sanitizer.** As a minimum standard, everyone should wash or use hand sanitizer upon entering and exiting the patient’s room. Clean hands are safe hands.

- **Keep surfaces clear of belongings.** Some organisms can survive a long time on the surfaces and equipment in the patient’s room. It is very important that these surfaces be cleaned daily by our Environmental Services (ES) staff. The ES staff cleans bed rails and other items close to the patient if the patient is not present. To help them do a complete cleaning, please leave the room if possible. Take a shower, a walk, or sit in a chair.

- **Minimize the number of personal belongings in the room.** To help keep your room as clean as possible, we encourage patients to have cards and pictures posted on the wall of their room. Other items should be placed in the bedside cabinet. Family members can help by taking items sent to the patient by other family members and friends back to the home or apartment shortly after the patient sees them.

- **Clean or wash your belongings.** ES staff does not clean your belongings. Daily, a family member or friend should wipe off the patient’s belongings with a cloth or paper towel dampened with soap and water. Items such as clothing or quilts should be washed periodically or when they become soiled.

Here are a few reminders of procedures which also prevent the spread of infection:

- Place used tissue in the trash can (not on other surfaces such as the bedside table or floor).
- Wash hands frequently (before eating and after using the bathroom or urinal).

Families and other visitors need to take special precautions during respiratory virus season. A sign-in sheet will be placed at the nurses’ station desk. Families and visitors will need to sign in daily. The questions regarding flu and cold symptoms will help determine whether or not visitors are sick. If visitors are sick, they are not allowed to visit the unit. This is for the safety of all the patients with weakened immune systems, and for staff who could risk infecting these patients if they catch a cold or the flu.

**Child visitors**

Any family member or visitor who has a fever or cold, or who is not feeling well, should not visit. Even minor colds and infections carry a risk to the patient. Children, in particular, are known to get many viruses. Please evaluate the health of children, and their exposure to other children who may have been ill, before letting them come to the hospital. Children with any symptoms of respiratory virus infections should not visit. Since allergy symptoms and respiratory virus symptoms are very similar, children should not visit even if it is thought that their symptoms are allergy-related.
These guidelines are for child visitors:

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

**Fresh flowers and plants**

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

**Money and valuables**

Money and valuables should not be left in your room or the family room due to risk of theft.

**Using the family room**

Please keep the family room keep clean. Label your food in the refrigerator with your name and the date. Food left too long will be thrown away.

**Getting help from a nurse**

Please use the “nurse call button” for help if an alarm rings in the patient’s room. The patient will have medications and fluid running on infusion pumps. These pumps have alarms that will beep for various reasons. Family members should not correct the pump alarms.

**Recording intake and output**

If you have water or ice, notify the nurse of the amount given. It is important to keep accurate records for your fluid intake and output—never empty a urinal, bedpan, or emesis basin.

**Medications**

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

**Release of medical information**

You can get your inpatient health record from Health Information Management at UWMC. There is no charge to send copies to your physician.
Participating in research

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

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

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

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

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

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

You may feel uncomfortable about having aspects of your treatment decided by random computer selection. You might believe that the “new” treatment is likely to be better than the “standard” treatment, or you might be concerned that the “new” treatment may increase the chance of side effects. For either of these reasons, you may prefer to choose one treatment or the other. These feelings are understandable; however, we hope you will understand that there is no factual basis for any preference between treatments in this situation. If there were, we would not need to do a research study to find out which treatment is actually better.
Long-term participation in research
Being involved in research will likely extend beyond your stay, especially if you have problems that need ongoing treatment. We are able to carry on this research by working with your physician. You may be asked to return for a periodic check-up.

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

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

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

Financial interest in medical research
Medical researchers occasionally have financial relationships with private industry, such as:
• Owning shares of stock
• Serving on advisory boards or consulting for companies
• Receiving consulting fees and payments

A medical researcher who has such an interest or relationship is required to disclose it. Institutions carefully review these disclosures. Decisions are made as to whether the study can be carried out by the medical researchers and whether the personal financial interests and relationships can continue. We do this to safeguard patients and the integrity of the medical research.

Connection with private industry
For many years, medical researchers and private industry have worked together to study ideas that might become useful to science and patients. Drug companies and biotechnology firms sometimes pay for medical research studies. This financial support can lead to new ways to prevent, diagnose, and treat illness.
**Our commitment to you**
SCCA and its member institutions are committed to protecting the rights and well-being of participants who volunteer for medical research studies. SCCA’s member institutions have policies and procedures for the disclosure, review, and management of the financial interests and relationships between medical researchers and private industry.

**If you wish to learn more about policies and procedures**
Each member institution has its own methods for review of financial relationships and interests. If you wish to learn more about these policies and procedures, you may contact the resources listed here.

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

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

SCCA respects the rights of all our patients equally and individually.
Seattle Cancer Care Alliance (Fred Hutchinson Cancer Research Center, UW Medicine, and Seattle Children’s) was formed to provide state-of-the-art, patient-focused cancer care, support the conduct of cancer clinical research and education, enhance access to improved cancer interventions, and advance the standard of cancer care, regionally and beyond. Seattle Cancer Care Alliance (SCCA) staff is committed to work as a team that includes you, as a patient and your family members. SCCA respects the rights of all our patients equally and individually. The SCCA does not discriminate against any patient or patient’s family member on the basis of race, color, religion, creed, national origin, sex, age, disability, marital or veteran status, sexual orientation, gender identity. If you feel you experienced discrimination as a patient at SCCA, please contact SCCA Patient Relations at (206) 606-1056.

Patient rights
As a patient at Seattle Cancer Care Alliance you have the right to:

• Reasonable access to medical care within the capability of our mission, purpose, and principles, and in compliance with the appropriate laws and regulations;
• Medical care guided by the best medical practice;
• Confidentiality regarding your care and medical records;
• Understand how SCCA uses and discloses your health information (“Notice of Privacy Practices”);
• Access your medical records (upon request) and an explanation of this information as necessary, except when doing so is restricted by law;
• Receive information in a manner that you can understand;
• Access interpreter services if you are non-English speaking or with vision, speech, hearing or cognitive impairment;
• Voluntary participation in all medical research studies;
• Care that is respectful of your cultural, psychosocial, and spiritual preferences;
• Care that supports privacy, personal dignity, and individual needs;
• Delivery of care that is free from mental, physical, sexual, or verbal abuse, neglect, or exploitation;
• Security and protection of your physical person and rights;
• Priority of medical needs over the objectives of any research study;
• Participate and make informed decisions in all aspects of your care;
• Open discussions about your care;
• Refuse treatment or services to the extent permitted by law, and be informed of the potential consequences of such an action;
• Treatment that does not prolong suffering, if your medical condition reaches a point where recovery is not realistically possible;
• End-of-life care that maximizes comfort, dignity, and quality of life as defined by you and your family;}
• Appropriate assessment and management of pain;
• Be informed of options for ongoing medical care if the SCCA cannot meet the request or need for care, treatment or services (including discharge or transfer);
• Inspect and clarify your billing statements.

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

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

Social Work Staff are available to assist you with advance directives. The SCCA will respect the intent of your directives to the extent permitted by law and SCCA policy.

Conflict resolution
• Investigate any wrongful actions against your rights;
• Address concerns regarding patients’ rights. SCCA encourages you, the patient, to talk with your health care team initially. If this course of action does not meet your needs, we encourage you to speak with Patient Relations at (206) 606-1056.

Patient responsibilities
As a patient at SCCA, you share in the responsibility for your care. You have the responsibility to:
• Participate in decisions involving your care;
• Provide complete information about your health, symptoms, and medications;
• Ask your provider questions when you do not understand the planned treatment, care, or what is expected of you;
• Follow the treatment plan, which you and your provider have agreed upon;
• Keep appointments or let us know if you cannot make them;
• Take responsibility for the outcomes if you do not follow the treatment plan;
• Be considerate of the rights of other patients, personnel, and property;
• Follow SCCA rules and regulations;
• Provide accurate and timely information about sources of payment and your ability to meet financial obligations;
• Promptly meet any financial obligation agreed to with the SCCA;
Let your providers know if you have concerns or complaints about any aspect of your care. SCCA encourages you, the patient, to talk with your healthcare team initially. Your nurse or social worker can be an advocate for you. If this course of action does not meet your needs, we encourage you to speak with Patient Relations at 206-606-1056.

You may also make complaints to the Washington State Department of Health at 1-800-633-6828 or to the Joint Commission by calling 1-800-994-6610 or on-line at www.jointcommission.org, or by e-mailing your concerns to complaint@jointcommission.org.

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

Attn: KEPRO
5700 Lombardo Center Dr., Suite 100
Seven Hills, OH 44131
Phone: 1-888-305-6759
TTY: 1-855-843-4776
Fax: 1-844-878-7921
Web: https://www.keproqio.com/bene/

Personal valuables
- SCCA (including Fred Hutchinson Cancer Research Center, UW Medicine, and Seattle Children’s) is not responsible for any loss or damage to your personal property including money, jewelry, watches or other items of value. We strongly recommend that you not bring any of these items with you when you are being treated at SCCA.

Weapons and illegal substances
- Weapons and illegal substances are not allowed on SCCA property (including Fred Hutchinson Cancer Research Center, UW Medicine, Seattle Children’s, Pete Gross House and SCCA House). To report or request assistance in handling a suspected case or actual observed violation contact our 24/7 Security Control Room. The existence of a concealed weapons permit does not exempt a person from this policy. Please secure weapons prior to entering the Clinic.
Symptoms
# Quick Reference for Symptoms

<table>
<thead>
<tr>
<th>Areas of concern</th>
<th>Critical emergency</th>
<th>Call clinic now</th>
<th>After hours</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Alertness, consciousness, activity</strong></td>
<td>DIAL 911</td>
<td>During business hours</td>
<td>After hours</td>
</tr>
<tr>
<td>Unconscious</td>
<td></td>
<td>(206) 606-6000</td>
<td>(206) 598-8902*</td>
</tr>
<tr>
<td>Unable to arouse</td>
<td></td>
<td>8 am to 10 pm, M-F</td>
<td>See instructions below</td>
</tr>
<tr>
<td>Seizure</td>
<td></td>
<td>8 am to 6 pm, Sat, Sun</td>
<td></td>
</tr>
<tr>
<td>Sudden change in vision</td>
<td></td>
<td>8 am to 5 pm, Holidays</td>
<td></td>
</tr>
<tr>
<td>Numbness, tingling, or loss of movement in limbs</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>One-sided facial drooping</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unable to speak</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• New or increased confusion</td>
<td></td>
<td>Difficulty swallowing</td>
<td></td>
</tr>
<tr>
<td>• Change in level of alertness</td>
<td></td>
<td>Tremors/shakiness</td>
<td></td>
</tr>
<tr>
<td>• Sleeplessness</td>
<td></td>
<td>Dizziness</td>
<td></td>
</tr>
<tr>
<td>• Mood changes: irritable, tearful, agitated</td>
<td></td>
<td>Not able to get around</td>
<td></td>
</tr>
<tr>
<td>• Change in ability to walk</td>
<td></td>
<td>Lethargic or weak</td>
<td></td>
</tr>
<tr>
<td>• Trouble finding words</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

| **Bleeding**                |                    |                  |             |
| Uncontrollable bleeding     |                    |                  |             |
| Patient is unconscious      |                    |                  |             |
| • New or increased bleeding |                    | Bloody diarrhea  |             |
| • Bloody urine              |                    | Vomiting of blood |             |
| • New bruising              |                    | 1 or more feminine pads per hour are used |             |
| • Little red or purple spots on the skin | | | |
| • Unable to stop nosebleed  |                    |                 |             |

| **Blood sugar**             |                    |                  |             |
| Blood sugar lower than 50 and unable to awaken | |                  |             |
| • High or low blood sugar  |                    |                  |             |
| • Hard to wake up - use glucagon | |                  |             |

| **Breathing**               |                    |                  |             |
| Not breathing               |                    |                  |             |
| Choking – not moving air into chest | |                  |             |
| • Trouble breathing         |                    | Wheezing with breaths |             |
| • Gets “winded” more easily with minimal activity | | New or recurrent cough |             |
| • Feeling as if can’t get enough air | | Persistent continuous cough |             |
| • Trouble breathing when lying flat | | Coughing blood or green/yellow material |             |

| **Central line**            |                    |                  |             |
| Line open to air and patient short of breath (Clamp line immediately) | |                  |             |
| • Line broken or leaking    |                    | Headache related to infusions |             |
| • Face, neck, exit site swelling | | New redness, swelling, or tenderness at exit site |             |
| • Inability to flush        |                    | Drainage from exit site |             |
| • Line fell out             |                    |                 |             |

| **Diarrhea**                |                    |                  |             |
| Constant or uncontrolled diarrhea | | Greater than 5 times each day |             |
| New onset diarrhea          |                    | Stool which is bloody, burgundy, or black |             |
| Diarrhea with fever and abdominal cramping | | Abdominal cramping |             |
| Whole pills passed in stool |                    |                 |             |

| **Fall**                    |                    |                  |             |
| Hit head during fall and change in consciousness after fall | |                  |             |
| • Did not hit head and no changes in consciousness after fall | |                  |             |
| • Report all falls          |                    |                  |             |

| **Fatigue**                 |                    |                  |             |
| Unable to wake up           |                    |                  |             |
| • Dizziness                |                    |                  |             |
| • Fatigue is getting worse |                    |                  |             |
| • Staying in bed all day    |                    |                  |             |
| • Too tired to get out of bed or walk to the bathroom | |                  |             |

| **Fever/chills**            |                    |                  |             |
| Temperature taken by mouth between 38 to 38.2°C (100.4 to 100.8°F) for one hour or more, or a temperature that is 38.3°C (100.9°F) or above | |                  |             |
| Temperature taken under the arm between 37.5 to 37.7°C (99.5 to 99.9°F) for one hour or more, or a temperature that is 37.8°C (100°F) or above | |                  |             |
| Chills or shaking chills    |                    |                  |             |
| Cold symptoms (runny nose, watery eyes, sneezing, coughing) | |                  |             |

*If you are calling after hours for fevers or other medical symptoms, press “1” when prompted to reach a medical provider; you should receive a call back within 30 minutes. If the provider doesn’t pick up after 4 rings, you will be transferred to the UWMC paging operator, who will ask for your service (say “Immunotherapy”), name, and phone number. The operator will page the provider with your phone number. For non-medical questions, press “2” to leave a voicemail for the Charge Nurse. If you do not receive a call within 30 minutes, call (206) 598-8902 again.
**Quick Reference for Symptoms**

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<td>DIAL 911</td>
<td>During business hours</td>
<td>See instructions below</td>
</tr>
<tr>
<td></td>
<td>Tell medics to take patient to UWMC Emergency Department if:</td>
<td>(206) 606-6000 8 am to 10 pm, M-F 8 am to 6 pm, Sat, Sun 8 am to 5 pm, Holidays</td>
<td>(206) 598-8902*</td>
</tr>
<tr>
<td>Mouth pain/ mucositis</td>
<td>Not breathing Severe difficulty breathing</td>
<td>• Difficulty breathing • Bright red blood in mouth • Pain not controlled by medication</td>
<td>• White patches or sores appear on gums or mouth • Difficulty swallowing food or fluid</td>
</tr>
<tr>
<td>Nausea and vomiting</td>
<td>Vomiting that leads to choking or difficulty breathing</td>
<td>• Nausea persists without control from anti-nausea medications • Projectile vomiting • Uncontrolled, constant nausea and vomiting • Blood or “coffee ground” appearing material in the vomit</td>
<td>• Medicine not kept down because of vomiting • Weakness or dizziness along with nausea and vomiting • Severe stomach pain while vomiting</td>
</tr>
<tr>
<td>Pain</td>
<td>Severe chest or arm pain Severe squeezing or pressure in chest Severe sudden headache</td>
<td>• New or uncontrolled pain • New headache • Chest discomfort • Pounding heart • Heart “racing” feeling • Burning in chest or stomach</td>
<td>• Pain or burning while urinating • Painful central line site or area of “tunnel” • Pain with infusion of medications or fluids into central line</td>
</tr>
<tr>
<td>Rash</td>
<td></td>
<td>• New rash</td>
<td>• Rash with pain and/or itching</td>
</tr>
<tr>
<td>Swelling</td>
<td>Throat swollen with feeling unable to get a breath</td>
<td>• Sudden swelling with or without pain • Swollen legs, arms, and hands</td>
<td></td>
</tr>
<tr>
<td>Urination</td>
<td></td>
<td>• Unable to urinate for more than 8 hours</td>
<td>• Pain or burning while urinating • Bloody urine</td>
</tr>
</tbody>
</table>

*If you are calling after hours for fevers or other medical symptoms, press “1” when prompted to reach a medical provider; you should receive a call back within 30 minutes. If the provider doesn't pick up after 4 rings, you will be transferred to the UWMC paging operator, who will ask for your service (say “Immunotherapy”), name, and phone number. The operator will page the provider with your phone number. For non-medical questions, press “2” to leave a voicemail for the Charge Nurse. If you do not receive a call within 30 minutes, call (206) 598-8902 again.*
Symptom sheets

Bleeding

Just the facts
Chemotherapy slows the production of platelets. Platelets help the blood to clot and stop flowing if there is an injury. Bleeding problems can be triggered by certain medications, injuries, vigorous exercise, or deep massage when your platelet count is low.

Your goals
• Prevent bleeding
• Control bleeding if it starts
• Call for professional help when needed

Emergency signs and symptoms
Call 911 immediately if:
• Uncontrolled, constant bleeding
• Patient is unconscious

Urgent signs and symptoms
Call the clinic or the after-hours clinic now if:
• New or increased bleeding or bruising
• Bloody urine
• Little red or purple spots on the skin
• Unable to stop nosebleed
• Bloody diarrhea
• Vomiting of blood
• Patient falls or is injured
• One or more feminine pads per hour are used

Important signs and symptoms
Report symptoms to a physician or nurse during clinic hours today:
• Little red or purple spots on the skin or in the mouth
• New bruising
What you can do at home

Prevent bleeding:

- **Do not take over-the-counter medications** without first consulting your physician, nurse or pharmacist. Certain medications can increase your risk of bleeding. Do not take aspirin, ibuprofen, naproxen (Aleve®), Alka-Seltzer®, or cold remedies containing these drugs. Talk to your physician or nurse before taking any over-the-counter medications. This is only a partial list of medications that can affect your platelets.
- Take blood pressure medications as ordered; high blood pressure can trigger bleeding.
- Use a soft bristle toothbrush.
- Do not use razorblades; use electric razors for shaving.
- Use caution to avoid falls.
- No vigorous exercise; follow activity guidelines from physical therapist or physician.
- Do not engage in deep massage.
- Do not blow nose hard or scratch inside of nose.
- Women who are menstruating should use pads, not tampons.
- Women are not to resume sexual intercourse if they have experienced breakthrough bleeding (any vaginal bleeding) within 2 weeks.
- No anal sex until platelets are stable.
- No rectal insertion of suppositories, enemas, or thermometers.

Control bleeding if it starts:

- Apply pressure to the bleeding site. For example, for a nosebleed, press the nostrils together firmly with the fingers. Or wrap ice in a soft cloth and press it firmly against the nostrils.
- Hold pressure on bleeding site for a full 5 minutes before checking to see if bleeding has stopped.
- Remain calm.

Call for professional help when needed:

- If a nosebleed doesn’t stop after 30 minutes of applying pressure, contact the SCCA clinic, SCCA Hospital, or UWMC.
- When transporting a patient with a bleeding problem, keep pressure on the bleeding site. Keep the patient quiet and minimize activity.
Constipation

Just the facts
It is common for a person with cancer to develop constipation, especially when opioids (narcotics) are being used. Bowel movements can become infrequent, hard and small in volume. It is important to avoid letting this become a problem.

Constipation can develop because of inactivity, some pain medications, changes in the body, lack of fluids/fiber and depression. Excessive use of laxatives can make the colon less sensitive to its natural reflexes, so always discuss use of laxatives with your doctor or nurse.

Your goals
• Prevent constipation and recognize symptoms early
• Get professional help when needed

Important signs and symptoms
Report symptoms to a doctor or nurse during clinic hours today:
• Distended abdomen and/or abdominal pain
• No bowel movement for more than 2 to 3 days
• Dizziness and/or confusion
• Back pain
• Leaking stool
• Fever
• No bowel movements with nausea and vomiting

What you can do at home
Prevent constipation:
• Drink plenty of fluid. Try to drink at least 8 cups of liquid daily. Drinking hot water upon rising in the morning can stimulate the bowels.
• Eat food high in fiber when possible. Fiber includes: fruits, figs, dates, prunes or prune juice, vegetables, and grains. Ask your nurse if you would to consult with a dietitian.
• If you are taking pain medication, ask your doctor or nurse about the use of laxatives and stool softeners.
• Keep physically active as possible.

Ask your doctor or nurse if you need a laxative.
Diarrhea

Just the facts
Diarrhea is frequent bowel movements with the stools having a more or less fluid consistency. Diarrhea is caused by chemotherapy, radiation, medications and sometimes emotional distress. It is important to report diarrhea because it can lead to dehydration and loss of electrolytes. It is not always possible to prevent diarrhea.

Your goals
• Prevent dehydration
• Prevent infection
• Call for professional help when needed

Urgent signs and symptoms
Call the clinic or the after-hours clinic NOW if you are experiencing:
• Constant or uncontrolled diarrhea
• New onset of diarrhea
• Fever and abdominal stomach cramping
• Whole pills passed in stool
• More than 5 bowel movements a day
• Stool that is bloody, burgundy or black
• Abdominal cramping

Important signs and symptoms
Report symptoms to a doctor or nurse during clinic hours today:
• New onset of diarrhea
• Diarrhea more than 5 times a day
• Mild abdominal stomach cramping
• Whole pills passed in the stool

What you can do at home

Prevent dehydration
• Drink fluids (in suggested amounts). Drink soothing beverages, decaffeinated teas.
• Follow dietary recommendations. Note any food allergies or intolerances and discuss with your doctor, nurse or dietitian.
• Limit foods that are spicy or fatty.
• Avoid drinks and food that cause gas, such as carbonated drinks and gas-forming vegetables. Limit the use of foods that have sorbitol, such as sugar free gum.
• Limit caffeine and alcohol.
Prevent infection and irritation
• Wash hands often, with warm water and soap
• Keep anal area clean with mild soap and water
• Do not use ointment or creams on the anal area unless directed by the nurse or doctor
• Use white, non-perfumed toilet paper

Call for professional help when needed
Describe the type of diarrhea to health care staff by including frequency, consistency, color and presence of cramping.
Fall prevention

Just the facts
You may be at risk for falls because of:
• Different environments than you are used to
• Medications that make you tired, dizzy, or confused
• Weak muscles from taking steroid medications
• Low red blood cells or a low blood pressure that could make you dizzy

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

Your goals
• Prevent injury
• Prevent permanent disability
• Prevent death

Emergency signs and symptoms
Call 911 immediately at home if:
• You fell and are bleeding.
• Any loss of consciousness occurs, or you experience any loss of consciousness.
• You think you have a broken bone.
• You have fallen and hit your head, have low platelets, and/or are on anti-coagulant medications.

Do not attempt to get up alone, because you might hurt yourself.

Important signs and symptoms
Report symptoms to your physician or nurse during clinic hours today:
• If you have fallen, even if you think that nothing is wrong.
What you can do at the clinic

• **Wear safe shoes!** This is one of the most important things you can do to prevent falls while you are here. Our floors can be very slippery. Closed-toe, closed-heel shoes with non-skid soles are the best choice (like tennis shoes). Flip-flops or open sandals are very dangerous.
  
  o It is OK with us if you put your shoes on our exam tables and beds so that your shoes are always on to keep you safe. We don’t want you to EVER walk around in your socks or with bare feet.
  
  o Non-skid slippers are available if you forgot your good shoes. Please ask for a pair.

• **Ask for help.** It does not bother the staff for you to ask for help. Even if you get around at home by yourself, you might need extra help while you are in our clinic. We can help you get from one place to another in our clinic, or get on an exam table, or walk you to the bathroom.

• **Move around with care.** A lot of equipment here is on wheels. Be careful that you don’t lean on wheeled equipment for support. Wheelchairs are available to use in the clinic.

• **Get up slowly after treatments and procedures.** Wait to see if you feel dizzy or weak. You might need help from a staff person.

• **Use your assistive devices.** If you use a hearing aid, glasses, prosthesis or walker/cane, be sure to bring it to the clinic and use it while you are here.

If you see anything that is hazardous in our clinic (like a spill on the floor), tell staff right away.

Call for professional help when needed

• If you are groggy, dizzy, or feeling faint.

• If you fall, let staff know RIGHT AWAY by yelling or asking anyone around you to help.

• Do not attempt to get up alone. You might hurt yourself trying to get up.

What you can do at home

• Think about the shoes you are wearing. Make sure you do not wear footwear that adds to your risk for falls such as slippery slippers, slippery socks, high heels, shoes without backs, or flip-flops. Wear sturdy, non-skid shoes such as tennis shoes. Wear them inside and outside the house. Avoid going barefoot, even inside the house.

• Move furniture so you have clear paths.

• Keep the floor, pathways, and stairs clear of objects. Remove things you can trip over (like paper, books, clothes, and shoes) from stairs and places where you walk.

• Never put small objects inside/outside your house, especially on the stairs.

• Fix loose or uneven steps inside and outside your house.
• Have sturdy handrails and lights in all stairwells/staircase areas. Make sure carpet on the stairs is attached firmly to every step.

• Consider using reflective tape at the top and bottom of stairs.

• Tape cords and wires to the floor/wall away from your path.

• Remove small throw rugs or use double-sided tape to keep the rugs from slipping.

• Enhance/add to the existing lighting in your home. As you get older, brighter lights will be needed to see well. Hang lightweight curtains or shades to reduce glare.

• Place a lamp next to your bed within easy reach and turn on the light when getting out of bed.

• Install nightlights all the way to the bathroom (bedroom, hallways, and bathroom).

• Put a non-slip mat in the bathtub and on shower floors.

• Consider installing a grab bar in the bathtub, shower, and near the toilet.

• If you have balance problems, consider using a shower seat or urinal for showering and dressing.

• Keep items that you use often in cabinets and on shelves that are within easy reach, without use of a step stool.

• Never stand on a chair.

• Get up slowly after sitting up or lying down.

• Consider painting doorsills and other flooring level changes a different color so you don’t trip.

• Review medications regularly with your physicians to identify medicines that cause sleepiness, dizziness, or confusion so you can be extra-safe after taking these medicines.

• Don’t drink alcohol if taking sedating medications.

• Talk to your physician about seeing a physical therapist for mobility aid and balance and strengthening. Practice approved exercises regularly to improve your strength, balance, and coordination.

• If you live alone, consider getting an emergency system that you can wear around your wrist or neck to alert help immediately if you fall.

References:
Fatigue

Just the facts
Being tired is a very common experience for patients. Fatigue is a daily lack of energy, an unusual or excessive whole-body tiredness not relieved by sleep. There are a number of possible causes for fatigue: the intensive treatments, medications, a lower than normal number of circulating red blood cells, stress, decreased nutrition, nausea, vomiting, mouth sores, taste changes, heart burn, diarrhea, disruption of normal resting and sleep habits, or feelings of depression. It usually takes time to work out ways to live with fatigue.

Your goals
- Establish regular rest and sleep periods
- Conserve energy
- Get professional help when needed

Emergency signs and symptoms
Call 911 immediately if:
- If you are the caregiver and cannot wake your patient.

Urgent signs and symptoms
Call the clinic or the after-hours clinic NOW if:
- Dizzy
- Too tired to get out of bed or walk to the bathroom

Important signs and symptoms
Report symptoms to a doctor or nurse during clinic hours today:
- Fatigue is getting worse
- Staying in bed all day
- Other symptoms occur with increased fatigue
- Increased weakness or exhaustion
- Drowsiness or confusion
- Loss of balance
- Catching your breath
What you can do at home

Establish regular rest and sleep periods:
- Set up a regular daily schedule for nap and sleep times.
- Keep active during the day to sleep better at night.
- Play soft music, put on the TV as a background sound, engage in meditation or prayer, or ask a nurse or family member for a back rub to help you sleep or rest.
- Keep a diary for one week to monitor fatigue levels. Note what you think may be contributing factors.

Conserve energy
- Rest between bathing, treatments and exercise.
- Do things or be active only for a short time.
- Plan activities, such as exercise, visits or trips when feeling the most rested and energetic.
- Decide on the most important activities for the day. Be realistic.
- Regular exercise helps reduce fatigue. It sounds contradictory, but it helps.
- Eat snacks between meals to keep up energy.
- Plan ahead and organize your work.
Fever

Just the facts
A fever and chills are signs of possible infection. A patient is very vulnerable to infection after chemotherapy, radiation, or while on immunosuppressive medications, and when blood counts are low. Act promptly when a fever occurs because the patient cannot fight infection when his/her number of white blood cells is low.

Your goals
• Monitor the patient’s temperature.
• Call for professional help when the patient has a fever.

Urgent signs and symptoms
Call the clinic or the after-hours clinic now if:
• Temperature taken by mouth between 38 to 38.2°C (100.4 to 100.8°F) for one hour or more, or a temperature that is 38.3°C (100.9°F) or above.
• Temperature taken under the arm between 37.5 to 37.7°C (99.5 to 99.9°F) for one hour or more, or a temperature that is 37.8°C (100°F) or above.
• Chills or shaking chills, with or without a fever.
• Cold symptoms (runny nose, watery eyes, sneezing, coughing).

Important signs and symptoms
Report symptoms to a physician or nurse during clinic hours today:
• Any new redness or swelling on the skin or at an intravenous (IV) site
• Cold symptoms (runny nose, stuffy nose, watery eyes, sneezing, coughing)
• New abdominal or back pain
• Toothache
• Cloudy or foul-smelling urine. Pain with going to the bathroom
• Sinus pain

What you can do at home
• Monitor the patient’s temperature.
• Take the patient’s temperature twice a day, morning and evening.
• Take oral (mouth) or axillary (under the arm) temperatures only. Do not take rectal temperature as the thermometer may injure membranes inside the rectum.
• Keep a record of the patient’s temperature.
• Use the thermometer for the patient only.
• If using a glass thermometer, wash the thermometer after each use with warm (not hot) water and soap.
Get professional help when you have a fever

- Always check with the clinic before trying measures to bring down a fever.
- Do not give Tylenol® (unless directed by the physician or nurse).
- When transporting a patient with chills to the clinic or the after-hours clinic, keep the patient warm and comfortable.

Where to take your temperature

The best way to take a temperature is to place the thermometer into the mouth under the tongue in the sublingual pockets. The sublingual pockets are in the lower jaw, under the tongue (see image below). If you have any questions, please ask your physician or nurse.
### Fever and temperature conversion chart – oral (taken by mouth)

<table>
<thead>
<tr>
<th>°F</th>
<th>°C</th>
<th>Directions for oral temperature (taken by mouth)</th>
</tr>
</thead>
<tbody>
<tr>
<td>96.8</td>
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<td>Greater than or equal to 100.9°F (38.3°C)</td>
<td>Call when temperature is this high or higher.</td>
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Note: Do not take Tylenol® unless instructed by your care team.
Call for chills or shaking chills, with or without a fever.

**SCCA contact information**

<table>
<thead>
<tr>
<th>Hours</th>
<th>Immunotherapy phone numbers</th>
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<tbody>
<tr>
<td>8 am to 10 pm, Mon-Fri</td>
<td>(206) 606-6000</td>
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<td>8 am to 6 pm, Sat &amp; Sun</td>
<td>Business hours</td>
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<td>8 am to 5 pm, holidays</td>
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<tr>
<td>10 pm to 6 am, Mon-Fri</td>
<td>(206) 598-8902</td>
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<td>6 pm to 8 am, Sat &amp; Sun</td>
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<td>5 pm to 8 am, holidays</td>
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**Temperature tracking chart**

Use an oral thermometer to take your temperature twice daily by mouth. Track your temperature on the chart below. If you have a fever, do not take Tylenol® (acetaminophen) unless instructed by your care team. Call your care team if you are experiencing any chills or shaking chills.

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Neutropenia

What is neutropenia?
Neutrophils are a type of white blood cell (WBC) that is on the frontlines at preventing infections in our body. Neutropenia is a decrease in the number of neutrophils. Neutropenia is common after receiving chemotherapy and increases your risk for infections. Neutropenia is usually considered an absolute neutrophil count (ANC) <1500 cells/microL (written as 1.5 thousand/microL in our system). Severe neutropenia is considered an ANC <500 cells/microL (0.5 in our system).

Why does chemotherapy cause neutropenia?
These cancer-fighting drugs work by killing fast-growing cells in the body—both good and bad. These drugs kill cancer cells as well as healthy white blood cells.

How do I know if I have neutropenia?
Your provider or nurse will tell you. Because neutropenia is common after receiving chemotherapy, your doctor may draw some blood to look for neutropenia.

When will I be most likely to have neutropenia?
Neutropenia often occurs between 7 -- 12 days after you receive chemotherapy. The level of neutropenia and time period can be different depending upon the therapy you get. Your provider or nurse will let you know exactly when your white blood cell count is likely to be at its lowest. You should carefully watch for signs and symptoms of infection during this time.

How can I prevent neutropenia?
There is not much you can do to prevent neutropenia from occurring, but you can decrease your risk for getting an infection while your white blood cell count is low.

What are common signs and symptoms of an infection?
For patients with severe neutropenia (ANC <500), even a minor infection can quickly become serious.

Fever may be the only indicator that you are sick! Call your care team right away if you have:
- Fever that is 101° F (38.3 C) or higher OR
- Fever that is 100.4°F (38°C) or higher for more than one hour
Other common signs of infection are:
- Chills and sweats
- Change in cough or new cough
- Shortness of breath
- Sore throat or new cold symptoms
- Nasal congestion
- Stiff neck
- Burning or pain with urination
- Unusual vaginal discharge or irritation
- Increased urination
- Redness, soreness, or swelling in any area, including surgical wounds and ports
- Diarrhea
- Vomiting
- Pain in the abdomen or rectum
- New onset of pain
- Changes in skin, urination, or mental status

How can I prevent an infection?
The following suggestions can help prevent infections:

- Clean your hands frequently using soap and water or hand gel.
- Try to avoid crowded places and contact with people who are sick.
- Do not share food, drink cups, utensils or other personal items, such as toothbrushes.
- Shower or bathe daily and use an unscented lotion to prevent your skin from becoming dry and cracked.
- Cook meat and eggs all the way through to kill any germs – refrigerate leftovers within 2 hours.
- Carefully wash raw fruits and vegetables – avoid salad bars, buffets, deli counters, bulk foods.
- Avoid direct contact with a child or pet’s bodily waste (urine or feces). If unable to do so, protect yourself by wearing vinyl or household cleaning gloves when cleaning up after your child or pet. Wash your hands immediately afterwards.
- Avoid gardening and no fresh flowers or plants in the home (or keep in a separate room).
- Clean your teeth and gums with a soft toothbrush, and if your provider or nurse recommends one, use a mouthwash or saline rinse to help prevent mouth sores.
- Try and keep all your household surfaces clean – best to use bleach-based solution. Avoid housework that may disturb dust or mold – try to have this cleaning done while you are outside of the home if possible.
- Avoid the use of humidifiers, air conditioners, and fans.
• Avoid swimming in recreational water – public pools, hot tubs, lakes, ponds, and the ocean.
• Get the seasonal flu shot if clinically indicated.

**What if I have to go to the emergency room?**
Cancer patients receiving chemotherapy should not sit in a waiting room for a long time. While you are receiving chemotherapy, fever may be a sign of infection. Infections can become serious very quickly. When you check in, tell them right away that you are getting chemotherapy and have a fever. This may be an indication of an infection.
Pain

Just the facts
You may experience pain during the course of your illness. Most pain can easily be treated with pain medication and/or other treatments. Your care team will assist you to find the best possible way to control your pain. On occasion your physician may ask a physician who specializes in cancer pain management to manage your pain.

Pain is an unpleasant sensation that only you can feel. It is what you say it is. A change or increase in pain does not necessarily indicate that your cancer has returned or is progressing. Pain may be caused by a number of things including cancer, treatment of the cancer, or a medical problem not related to the cancer diagnosis.

Myths about narcotics/opioids:
• Some people will think they will become addicted. Research has shown that this is not true. If you use your pain medication the way your physician prescribes it, it is very rare for you to become addicted.
• Some patients do not want narcotics because they fear the side-effects. Nausea, vomiting, sleepiness, constipation, and itching are common side effects, but these can easily be managed by changing your medication or adding other treatments.

Patient rights and responsibilities
As a patient of SCCA, you have the right to:
• Information about pain and pain management
• Have your pain treated promptly
• Have physicians and nurses who believe your report of pain

As healthcare providers, we expect you to:
• Describe and rate your pain
• Ask about pain management
• Discuss options with your physician or nurse
• Ask for pain relief when you first experience pain
• Inform us if pain treatment is not working
• Help us develop a treatment plan for you

Your goals
• Report your pain
• Rate your pain; keep track of what triggers it and what makes it better
• Have pain treated promptly
• Maintain optimal level of physical activity
Rate your pain
Your physician or nurse will ask you to “rate” your pain using a simple method. Remember, only you know what and where your pain is, and you need to help us help you.
Your physician or nurse will ask you to “point” to the area of your pain. They will also ask you the following questions:
• What will cause the pain?
• What do you think will get rid of the pain?
• What is the quality of your pain (burning, radiating, throbbing, or stabbing)?

It is the staff’s goal to provide you with the best possible treatment of your pain. We ask that you help us do so by telling us about your pain when you first experience it.

How can we treat your pain?
Your pain can be treated/managed in many different ways. Your physician may choose to prescribe Tylenol®, ibuprofen, or narcotics/opioids such as morphine. Sometimes he/she may choose to use a local anesthetic. The method depends on the location and severity of your pain.

Non-drug methods of pain relief
• Hot or cold packs
• Massage/therapeutic touch
• Hypnosis
• Relaxation and music therapy

Pain medication may be given different ways, including:
• Pills
• Patch (like a bandage placed on the skin)
• Intravenous
• SQ (under the skin)
• PCA-intravenous (a small computerized pump that lets you control how much pain medication you receive)
• Epidural (a small tube inserted into your back)

Some pain medications should be taken on a regular basis (long-acting medication), while others should be taken only when you begin to feel the pain (break-through medication).

Emergency signs and symptoms
Call 911 immediately if you have:
• Severe chest/arm pain
• Severe squeezing or pressure in chest
• Severe sudden headache
Urgent signs and symptoms
Call the clinic or the after-hours clinic now if you have:
• New or uncontrolled pain
• New headache
• Chest discomfort/heart “flip-flop” feeling
• Pounding heart
• Painful central line site or area of “tunnel”
• Burning in chest or stomach
• Strong stomach pain
• Pain with infusion of medications or fluids into central line

What you can do at home
• Maintain your treatment plan; take medications as ordered. Do not increase your dose of medication without talking to your nurse or physician.
• Keep a pain journal.
• Use hot or cold packs.
• Find a relaxation technique that works for you such as meditation, guided imagery, hypnosis, massage, or therapeutic touch.
• Listen to relaxing music.
• Taking care of your pain will help you sleep better, feel stronger, and be better able to cope with your illness.
• Continue activities that are meaningful to you. These activities may help you notice less pain or discomfort.
• Before taking pain medication or opioids, ask your nurse or physician about ways to prevent constipation.
White blood cells

Just the facts
A white blood cell count with differential provides information about your white blood cells. White blood cells help protect the body by fighting bacteria and viruses that cause infection. It is important to protect yourself against infection. When your white blood count is low, your body is more prone to infection.

Your goals
- Recognize signs of infection
- Get professional help when needed

Important signs and symptoms
Report symptoms to a physician or nurse during clinic hours today:
- Shaking or chills
- Cough
- Temperature taken by mouth between 38 to 38.2°C (100.4 to 100.8°F) for one hour or more, or a temperature that is 38.3°C (100.9°F) or above
- Temperature taken under the arm between 37.5 to 37.7°C (99.5 to 99.9°F) for one hour or more, or a temperature that is 37.8°C (100°F) or above
- Sore throat
- A general feeling of tiredness or “flu-like” symptoms
- Painful or frequent urination

What you can do at home
Preventive measures:
- Look at your mouth and skin for signs of infection. Exercise excellent mouth care. See Mucositis information sheet.
- Brush your teeth after each meal and at bedtime. Use a soft-bristle toothbrush and be careful to avoid injury to the gums. Avoid use of mouthwashes that contain alcohol.
- Keep your skin clean and avoid cuts and scratches. Report any changes in skin including rashes, sores, and cuts.
- Wash hands frequently.
- Wear gloves when washing dishes.
- Shave with an electric razor.
- Use lotion for dry skin.
- If you have hemorrhoids, ask your physician or nurse for advice before you self-treat.
- Check with your physician or nurse regarding dental work.

Information adapted from: Pharmacia and Upjohn Company
Exercise and blood value precautions

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

Exercise guidelines based on platelet counts
Platelets are a type of cell found in your blood that help your blood clot.

<table>
<thead>
<tr>
<th>Platelet count range</th>
<th>Exercise guideline</th>
</tr>
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</table>
| 50,000 – 100,000     | Cardiovascular exercises and strength training with weights/elastic tubing are okay.  
Do not exercise if you have any signs of bleeding (i.e. from the nose). Contact your care team if you have any signs of bleeding. |
| 20,000 – 49,999      | If you have no signs of bleeding, cardiovascular exercise and strength training with weights/elastic tubing are OK as long as you are not straining or holding your breath. Straining can increase your blood pressure and risk for stroke or major bleeding.  
Talk to your physician before getting a massage. Gentle comfort massage is typically okay as long as your skin is not fragile or prone to easy bruising for other reasons (such as chronic steroid medications). Deep tissue massage is not okay. |
| Less than 20,000      | You may have an increased risk of bleeding with certain types of exercise. The bleeding could become serious and even life threatening.  
Do not do any intense cardiovascular exercise (power walking, running, cycling, dancing, etc.) or strength training with weights or elastic tubes. |
| 10,000 – 19,999      | Strength training without weights/elastic tubing or strain, and cardiovascular exercise without strain are OK if you are steady on your feet and have no signs of bleeding. |
| Less than 10,000      | Do not do any cardiovascular exercise and strength training until your platelets are in a safe range.  
You may walk around your room and go to the bathroom with help from a caregiver if you are steady on your feet and have no sign of bleeding. |
Exercise guidelines based on hematocrit (Hct) and hemoglobin (Hgb)

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

<table>
<thead>
<tr>
<th>Hct/Hgb range</th>
<th>Exercise guideline</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hct less than 25%</td>
<td>Talk to your doctor, physical therapist, or occupational therapist about what type of exercise is safe for you. They may recommend restrictions in strength training or cardiovascular exercise.</td>
</tr>
<tr>
<td>Hgb less than 8.0</td>
<td>When your Hct or Hgb are below these ranges, you may need a red blood cell transfusion. It can be difficult to predict how much a transfusion will increase the level of Hct and Hgb, so a follow-up blood count is recommended.</td>
</tr>
</tbody>
</table>
Guidelines
Guidelines for preventing infection

During and after immunotherapy treatment, your immune system may be weak (immunocompromised). This means you may have a higher risk for getting infections. If you get an infection during or after your immunotherapy treatment, it can be more serious than when a healthy person gets an infection. Because of this, it is important to follow the basic guidelines below.

Please note: Everyone’s risk for infection varies and is based on their treatment plan. Your care team will help you understand your specific risk.

What is an infection?

An infection is caused by germs—such as bacteria, viruses, and fungi—that enter your body and multiply. It is very important to keep yourself safe from germs during and after immunotherapy by:

• Limiting contact with things that might cause an infection, and

• Contacting your care team when you develop symptoms of an infection, such as fever, chills, sore throat, body aches, runny nose, or cough.

• To learn more about the signs of infection, visit SCCA’s Patient Education YouTube page and watch “Immunocompromised: What does it mean?” at Youtube.com/c/SCCAPatientEducation.

Guidelines

It is not possible to prevent all infections, but you and the people around you can limit your risk by following these guidelines:

Clean your hands often

Cleaning your hands (also called hand hygiene) is one of the best ways to prevent infections. Hand hygiene is especially important during the first 6 months after immunotherapy.

You and anyone you interact with, including all members of your household and your care team, should clean their hands often. You should also keep your nails short (do not wear fake nails) because germs can collect under them. You can wear nail polish as long as it isn’t chipped (germs can collect under chipped nail polish).
When to clean your hands

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

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

Ways to clean your hands

There are two ways to clean your hands:

1. Wash them with soap and water.

2. Use alcohol hand sanitizer (gel) such as Purell® that contains at least 60% alcohol.

Note:

• Soap and water should be used when your hands are visibly dirty or after using the restroom. Soap and water should also be used after touching someone with a gastrointestinal infection like C. diff or norovirus.

• As a general rule, it is OK to use hand gel with alcohol when your hands do not look dirty. When your hands do look dirty, clean them with soap and water. Hand gel does not prevent some gastrointestinal infections, such as C. diff and norovirus. People with these infections and their caregivers should wash their hands with soap and water instead.
How to clean your hands

Cleaning your hands correctly is important. Read the steps below and practice them. Make the process a habit. As a reminder, it is OK to use hand gel with alcohol when your hands do not look dirty. When your hands do look dirty, clean them with soap and water.

Using alcohol gel:
• Place 1 or 2 pumps of gel into your dry palm.
• Rub your hands together. Cover all surfaces of your hands and fingers until they are dry. This takes about 15 seconds.

Using soap and water:
• Wet your hands with warm water.
• Pump soap into your palm.
• Lather up by rubbing your hands together for 15 seconds.
• Cover all surfaces of your hands and fingers.
• Rinse your hands thoroughly.
• Dry your hands with paper towel.
• Use a towel to turn off the faucet.
• Throw your dirty towel in the trash.

Maintain your personal hygiene

Maintaining your personal hygiene (keeping yourself clean) is an important part of preventing infection. Follow the personal hygiene guidelines below:
• Take a shower or bath once a day. Use soap. Wash your hair. Rinse thoroughly.
• Cover your central line when showering or bathing to keep your line dry. Ask your care team for instructions or look in your central line packet (if you received one) to learn how to cover your central line.
• Change your clothes once a day.
• Have a towel that is just for you. Change the towel daily.
• DO NOT self-treat for vaginal infections or discharge. Tell your care team if you think you have a vaginal infection. DO NOT douche unless it is a part of your prescribed treatment plan.
• Tell your nurse if you use a CPAP (continuous positive airway pressure) machine to sleep. It needs to be cleaned a certain way to prevent infection.

It is OK to ask staff, friends, and family to wash their hands!
Keep your home clean

Your goal is to decrease the number of microorganisms present and avoid spreading organisms on the surface of objects into the air.

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

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

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

The following activities can put you at risk for a life-threatening infection, especially during the first 6 months after immunotherapy. Avoid these activities during this time:

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

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

- **Avoid close contact with people who have respiratory illnesses (cough, cold, etc.).** Be especially careful around children who go to school and/or daycare. They are often exposed to other children who are ill.

- **Avoid getting a manicure** at a spa or salon. It is OK to paint your own nails or have a friend/family member paint them.

- **Avoid direct contact with soil and plants and activities such as gardening, raking, mowing, farming.** These activities create plant or soil aerosols which increase exposure to fungi and bacteria. Avoid working in green houses. Ask friends and visitors not to bring fresh flowers and potted plants as gifts.

- **Avoid wood-burning fireplaces** because wood contains fungus. If a wood stove is your only source of heat, have someone else touch the wood and manage the fire.

- **Avoid house cleaning that causes dust and mold to be stirred up in the air.** This includes activities like vacuuming, dusting, and scrubbing down showers. If your house needs to be cleaned, ask someone else to do it and leave the house when they clean if you can. Ask them to clean with wet washcloths or wipes because they capture dust. Do not use feather dusters. Once you have the energy, it is OK to iron, wash clothes, dry clothes, and wash dishes.

- **Avoid dusty or moldy areas and construction sites, including homes or buildings that are being repaired or remodeled.** Construction can disturb soil and create bursts of airborne dust containing fungal spores called *Aspergillus*. *Aspergillus* is widespread in nature especially in decaying matter, water and soil. If you have a weakened immune system, *Aspergillus* can cause infections in your lungs, skin, sinuses, or brain.
  - If you live near construction, keep your windows closed.
  - Keep your car windows closed when driving past construction sites.

- **Avoid using a humidifier because bacteria lives in the water.**

- **Avoid swimming in recreational water** such as ponds, rivers, lakes, swimming pools, and hot tubs.
• Avoid human or animal feces. Do not:
  o Change a baby’s diaper; if you must change a diaper, wear gloves and wash your hands after you throw the diaper away
  o Empty and clean litter boxes
  o Clean up after pets
  o Touch bird droppings
  o Clean a fish tank

• Avoid tobacco and marijuana use. The use of these substances, along with exposure to environmental tobacco smoke (second-hand smoke), increases your risk for bacterial and fungal infections.

Preventing infections from animals
• Wash your hands immediately after petting animals.
• You do not need to get rid of your pets. Avoid getting any new pets during treatment.
• Do not sleep with your pets.
• Ask someone else to do most of the pet care.
• If you have a cat, do not place the litter box in kitchens, dining rooms, or other areas where you prepare food and eat. Have someone clean the litter box during the first 6 months after transplant. Keep your cats inside and do not adopt or handle stray cats.
• Reduce the amount of direct contact you have with animals, especially animals that are sick.
• Avoid contact with reptiles (turtles, snakes, lizards), ducklings, or chicks to prevent exposure to bacteria called salmonella. If you have other pets, please discuss this with your team.

Wearing a mask at the SCCA clinic

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

• Sit in the designated respiratory isolation areas in the lobby. Ask a staff member if you have questions.
• Avoid high-traffic areas in the clinic, such as the food service area, crowded elevators and classes and SCCA shuttles.
• Use hand gel or wash hands often.
If I am not coughing, sneezing, or do not have a cold or the flu, should I wear a mask in the clinic?
No. Masks are not an effective way to prevent you from catching a respiratory infection.

What type of mask should I wear in the clinic?
You should wear a surgical or procedure mask. These masks cover your mouth and nose loosely and have a strap that goes behind your ears or head. Surgical or procedure masks are made of soft materials and are comfortable to wear.

How do I put on a surgical or procedure mask?
• Place and hold the mask over your nose, mouth, and chin.
• Stretch the bands around your ears and secure them comfortably.
• Fit the flexible nosepiece to your nose bridge.

How should I get rid of a mask?
Throw it away next to a place where you can wash your hands or use hand gel before touching surrounding areas.
• To remove the mask, grasp the ear bands on both ears and pull the mask off your face. Do not handle the front part of the mask. If you touch the front of the mask, the bacteria or virus may now be spread with your fingers.
• Throw the mask away in nearest trash can.
• Use hand gel or wash your hands after removing the mask.

Special note on wearing masks
Masks help prevent the spread of infection when worn for short periods of time, usually an hour. They lose their effectiveness when they get wet from saliva, talking, coughing, or sneezing. If you will be in the SCCA clinic for more than an hour, change your mask every hour. Masks are available at the front desk on each floor or at the hand hygiene station on the 1st floor.

You may feel safer wearing a mask when you are outside, but you aren’t required to wear one. Masks do not provide effective protection against activities with a high risk for infection. If you choose to wear one, you should still avoid the situations and activities described above.
Food safety guidelines

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

Bacteria and other organisms exist commonly in foods. Most of these organisms are of little risk to the average healthy person. However, persons undergoing chemotherapy, radiation, or a hematopoietic cell transplant are at increased risk for infections, including foodborne illness. By following safe food practices, patients and caregivers can reduce the risk of foodborne illness.

Some immunotherapy patients will be recommended to follow the “immunosuppressed patient diet”. In addition, it is recommended that all patients follow the food safety guidelines discussed below. If you have any questions regarding food safety and diet guidelines, talk to your dietitian.

Steps to food safety
• Wash hands and surfaces often
• Avoid cross-contamination of foods
• Keep foods at safe temperatures

Tools for food safety
• Food and refrigerator thermometers
• Hand soap
• Clean towels (cloth or paper)
• Bleach solution* (for washing countertops, cutting boards and other items)

* Dilute bleach solution: Mix 1/3 cup unscented household bleach with 3 1/3 cups water. This will make a total of 3 2/3 cups of bleach solution. This solution must be remade daily.

Hand hygiene
• Wash hands frequently with soap and warm, running water and rubbing motion (friction) for 15 seconds before and after every step in food preparation. This is critical before and after handling raw meat, seafood and poultry.
• Wash hands before eating and after using the rest room, handling garbage, and touching pets.
• Dry hands with a paper towel or cloth hand towel that is changed daily.
Kitchen cleanliness

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

Cutting boards
- Wash cutting boards with hot, soapy water after each use; then rinse and air-dry or pat dry with fresh paper towels. Non-porous acrylic, plastic or glass boards and solid wood boards can be washed in a dishwasher (laminated boards may crack or split).
- Sanitize both wooden and plastic cutting boards with the dilute bleach solution*. This should be done every time the board is used for raw meat, fish and poultry. Sanitize cutting boards used for other purposes at least once weekly. Flood the surface with the bleach solution and allow it to stand for at least 2 minutes, then rinse and air-dry or pat dry with fresh paper towels. Alternatively, use a commercial sanitizing agent (that contains bleach) and follow the directions on the product.
- Replace worn cutting boards, including boards with cracks or grooves.
Safe food handling: from the grocery store to your home

Grocery store

- Shop for shelf-stable items first (shelf-stable refers to unopened canned, bottled, or packaged food products that can be stored at room temperature before opening; the container may require refrigeration after opening.)
- Select frozen and refrigerated foods last, especially during the summer months.
- Check “Sell By” and “Use By” dates on dairy products, eggs, cereals, canned foods, and other goods. Select only the freshest products.
- Check packaging dates and “use by” dates on fresh meats, poultry, and seafood. Do not purchase if they are outdated.
- Do not use damaged, swollen, rusted, or deeply dented cans. Check that packaged and boxed foods are properly sealed.
- Select fruits and vegetables that are not moldy, bruised or damaged. Fresh fruits and vegetables should look fresh. Wilted salad greens may be an indication that the product is old and not properly handled.
- Avoid unpasteurized juice (unless prepared at home with washed produce).
- Choose shelf-stable salsa rather than salsas found in the refrigerator section of the grocery store.
- Avoid unpasteurized milk, yogurt, cheese, other unpasteurized milk products, including Mexican-style cheese made from unpasteurized milk (such as queso fresco).
- Do not use foods with any mold present, including blue cheese.
- Avoid unrefrigerated, cream- and custard-filled pastry products, such as fresh bakery cream pies, Éclairs, cream-filled donuts and pastries. Commercial, shelf-stable items such as Danish pastries are allowed. Follow the “use by” date and store them according to the manufacturer’s guidelines after opening.
- Avoid foods from “reach in” or “scoop” bulk food containers. Avoid food from any type of bulk food container if it will not be cooked prior to consumption.
- Do not taste unpackaged food samples.
- Choose eggs that are refrigerated in the store. *Do not use cracked eggs.* Pasteurized eggs, liquid pasteurized egg products (such as EggBeaters®) and powdered egg whites may be used in recipes calling for raw eggs in foods that will not be cooked.
- Place meat, poultry and fish in plastic bags. Ask to have these items placed in separate bags from the fresh produce and ready-to-eat foods when at the checkout stand.
- Never leave perishable food in the car. Refrigerate or freeze them promptly.
Home
• Wash the tops of canned foods before opening. Clean the can opener after each use.
• Throw away eggs with cracked shells.
• Throw away foods older than their “use by” expiration dates.
• Throw away entire food packages or containers with any mold present, including yogurt, cheese, cottage cheese, fruits (especially berries), vegetables, jelly, bread, cereal and pastry products.

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

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

• Review the processing procedure if preparing home-canned foods. Be sure the procedure is appropriate for the acidity of the food, size of the bottle, and elevation above sea level. Look for mold and leaks. Check seals. *If you suspect a home-canned food may not have been properly processed (for example, if the lid bulges or if the food has any bad odor or unusual characteristics after opening), THROW IT AWAY. It is recommended to use home canned foods within one year of canning as chemical changes may occur.*

**Avoid cross contamination**

• Use a clean knife for cutting different foods (for example, use different knives for cutting meat, produce and bread).

• During food preparation, do not taste the food with the same utensil used for stirring. Use a clean utensil each time you taste food while preparing or cooking.

• In the refrigerator, store raw meat separately from ready-to-eat foods.

• When grilling, always use a clean plate and utensils for the cooked meat.

**Keep foods at safe temperatures**

**Proper thermometer use**

• Test a thermometer’s accuracy by putting it into boiling water. It should read 212°F.

• Read the manufacturer’s instructions. Insert the meat thermometer into the middle of the thickest part of the food to test for doneness. The entire part of the stem, from the dimple to the tip, must be inserted into the food. For thin foods, insert the thermometer sideways.

• A refrigerator thermometer should be placed on a shelf toward the back of the refrigerator. It should read 40°F or less.

**Refrigeration**

• Keep the refrigerator temperature between 34°F to 40°F.

• Keep the freezer temperature below 0 to 2°F.

• Never leave perishable food out of the refrigerator for over two hours. Throw away food left out longer than two hours.

• Marinate foods in the refrigerator.

• Thaw foods in the refrigerator, never on the counter.

• Thaw meat, fish or poultry in the refrigerator away from raw fruits and vegetables and other prepared foods. Place on a dish to catch drips. Cook defrosted meat right away; do not refreeze. If you are in a hurry you can thaw meat in the microwave. The meat must be cooked immediately after thawing.
Cool hot foods uncovered in shallow containers in the refrigerator. Cover storage containers after cooling. Make sure that covers seal tightly.

Throw away all prepared food after 72 hours (3 days). Use labels or masking tape to write dates on containers.

Freeze foods that will not be used within 2 to 3 days.

NEVER TASTE FOOD THAT LOOKS OR SMELLS STRANGE!

Cook foods adequately

Cook meat until it is no longer pink, and the juices run clear. These are signs that the meat may be cooked to a high enough temperature. However, the only way to be sure that the meat has been cooked to the proper temperature is to use a food thermometer (See Table 1 on the next page).

Thoroughly heat until steaming (165°F) all hot dogs and “ready to eat” luncheon meats, cold cuts and “deli-style” meats before eating.

Do not eat raw, lightly cooked, or soft-boiled eggs.

Do not eat uncooked foods containing raw or undercooked eggs, such as raw cookie dough, cake batter or salad dressings containing raw or coddled eggs.

Pasteurized eggs and liquid pasteurized egg products (such as EggBeaters®) may be used in recipes calling for raw eggs in foods that will not be cooked.

Hold food at safe temperatures: hot food above 140°F, cold food below 40°F.
## Recommended minimum cooking temperatures

<table>
<thead>
<tr>
<th>Product</th>
<th>Cooking temperature or visual characteristics</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Eggs, egg dishes, and casseroles</strong></td>
<td></td>
</tr>
<tr>
<td>Eggs</td>
<td>Cook until yolk and white are firm</td>
</tr>
<tr>
<td>Casseroles, foods containing eggs,</td>
<td></td>
</tr>
<tr>
<td>custards, and egg sauces</td>
<td>160°F</td>
</tr>
<tr>
<td><strong>Veal, beef, pork, lamb, rabbit, goat, game</strong></td>
<td></td>
</tr>
<tr>
<td>Whole pieces meat</td>
<td>160°F</td>
</tr>
<tr>
<td>Ground veal, beef, lamb, pork, rabbit,</td>
<td></td>
</tr>
<tr>
<td>goat, game</td>
<td>160°F</td>
</tr>
<tr>
<td><strong>Poultry (chicken, turkey, duck, goose)</strong></td>
<td></td>
</tr>
<tr>
<td>Chicken and turkey: whole bird and dark</td>
<td>180°F</td>
</tr>
<tr>
<td>meat (leg, thigh, wing)</td>
<td></td>
</tr>
<tr>
<td>Breast, roast</td>
<td>170°F</td>
</tr>
<tr>
<td>Ground chicken, turkey</td>
<td>165°F</td>
</tr>
<tr>
<td>Stuffing (always cook in separate</td>
<td></td>
</tr>
<tr>
<td>container outside of bird)</td>
<td>165°F</td>
</tr>
<tr>
<td><strong>Ham</strong></td>
<td></td>
</tr>
<tr>
<td>Fresh (raw)</td>
<td>160°F</td>
</tr>
<tr>
<td>Pre-cooked (to reheat)</td>
<td>160°F</td>
</tr>
<tr>
<td><strong>Seafood</strong></td>
<td></td>
</tr>
<tr>
<td>Fin fish (such as salmon, cod, halibut,</td>
<td>Cook until opaque and flakes easily with a fork</td>
</tr>
<tr>
<td>snapper, sole, bass, trout)</td>
<td></td>
</tr>
<tr>
<td>Shrimp, lobster, crayfish, crab</td>
<td>Should turn red and flesh should become pearly opaque</td>
</tr>
<tr>
<td>Scallops</td>
<td>Should turn milk white or opaque and firm</td>
</tr>
<tr>
<td>Clams, mussels, oysters</td>
<td>Cook until shells open (may be high risk food for people with low white count or immunosuppressed)</td>
</tr>
<tr>
<td><strong>Leftovers, hot dogs and luncheon meats</strong></td>
<td></td>
</tr>
<tr>
<td>Leftovers</td>
<td>165°F</td>
</tr>
<tr>
<td>Hot dogs, luncheon meat</td>
<td>Steaming hot</td>
</tr>
</tbody>
</table>
Microwave cooking

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

Dining out safely

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

Other foods

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

Overview
Public water quality and treatment varies throughout the United States, so always check with the local health department and water utility regarding the safety of household and community tap water and ice for use by immunosuppressed persons.

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

Well water
Well water from private or small community wells is not considered safe for consumption by persons considered immunosuppressed and at risk for infection unless it is tested daily and found to be negative for coliforms and Cryptosporidium organisms.

Examples of ways well water could become contaminated:
• Construction occurs near the well
• Well depth is shallow
• Well is located near a dairy farm or large numbers of livestock
• Flooding has recently occurred in the well area

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

Private and small community wells: The quality of well water from these sources cannot be guaranteed unless it is tested daily and found to be negative for coliforms and Cryptosporidium organisms.

It is recommended that other approved water sources be used instead, including: boiled water or bottled water (see guidelines below).

Not considered safe: Common home water filtration devices do not remove bacteria or viruses. If the well water supply is chlorinated per guidelines provided by your local health department, the chlorinated water treated with one or more of the following is considered safe to consume:
• Reverse osmosis treated
• Distillation
• Filtered through an absolute 1 micron or smaller filter (NSF Standard #53 for cyst removal)
See “Water filters” (below).
Safe water sources
The following sources of water are suggested if your water is not from a city water or municipal well supply:

- Boiled water
  At home, safe water can be made by bringing tap water to a rolling boil for 15 to 20 minutes. After processing, the water should be stored in a clean, covered container in the refrigerator; discard water not used within 72 hours (3 days).

- Distilled water
  Water may be distilled using a steam distillation system. After processing, the water should be stored in a clean, covered container in the refrigerator; discard water not used within 72 hours (3 days).

- Bottled water
  Acceptable forms of bottled water have been processed to remove organisms known to cause stomach or intestinal infection. Bottled water labels reading “well water”, “artesian well water”, “spring water”, or “mineral water” do not guarantee that the water is safe to drink. Water labeled as having been treated with one or more of the following are considered safe:
    o Reverse osmosis treated
    o Distillation
    o Filtered through an absolute 1 micron or smaller filter (NSF Standard #53 for cyst removal)

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

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

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

a. The filters must be designed to remove coliforms and Cryptosporidium. Any of the following are acceptable:
   - Reverse osmosis filter
   - Absolute pore size of filter 1 micron or smaller
   - Tested and certified by NSF Standard #53 for cyst removal

b. The water tap filter must be installed immediately before the water tap

c. Manufacturer directions must be followed for filter maintenance and replacement

Portable water filters (such as a Brita® or Pur® system) as well as refrigerator-dispensed water and ice machine systems do not meet filtration standards. Portable water systems filter out chemical impurities, not bacteria. If a portable water system (such as a Brita® pitcher) is used in combination with a safe water supply (to improve water flavor and remove chlorine and other impurities), it is recommended to change the system’s filters frequently according to manufacturer’s guidelines. For a list of approved filtration systems, call the National Sanitation Foundation International, at 1-800-673-8010 or visit their home page at www.NSF.org (go to the section entitled “Home Water Treatment Devices”).
Herbal and nutrient supplements

You may be using nutrient supplements or herbal preparations. Your dietitian and physician will ask about any supplements or herbals you use during their initial evaluation. **Stop use** of all herbal and nutrient supplements at this time. These supplements may affect treatment or even cause a serious infection.

There are 4 main concerns about the use of nutritional supplements, herbals and other preparations during marrow or stem cell transplantation or high dose chemotherapy:

1. Interactions between preparations and prescribed medications may reduce the effectiveness of drugs routinely used during transplantation or chemotherapy.

2. Potential contamination of preparations derived from plants may cause bacterial, fungal or parasitic infections because of inadequate purification and sterilization. Even boiling water may not destroy some infectious organisms that can contaminate these products.

3. A few specific preparations have been repeatedly associated with serious toxic side effects to the liver, blood, kidneys, heart, and other body organs.

4. The production, distribution, and labeling of herbal preparations and nutrient supplements are not regulated by the U.S. Food and Drug Administration. As a result, the dosage may vary from the dose listed on the label. Also, the product might contain ingredients not listed on the label.
Herbal and botanical preparations

Herbal and botanical preparations include a variety of products derived directly from plants. They may be sold as tablets, capsules, liquid extracts, teas, powders, and topical preparations. There are no manufacturing regulations for the cleanliness or purity of these products. There is a danger the products may be contaminated with fungus, bacteria, parasites or other chemicals, which can be life-threatening to a person with an impaired immune system, including persons receiving chemotherapy or transplantation. Even boiling water may not kill some organisms that can contaminate these products.

It is recommended that you avoid all herbal and botanical products during chemotherapy and as long as your immune system is impaired. Make the decision to use any preparation with your physician, who will consider how the product affects your kidneys, liver, and other organs, your risk of infection, and any interactions it may have with other medications.

Some herbals may decrease blood clotting. If you have low platelet counts, do not take garlic and gingko biloba. Do not use any product that is given as an injection into the central line or as an injection under the skin. Several herbal and botanical medications have very dangerous side effects and should not be taken under any circumstance. These include:

- Alfalfa
- Black Hellebore
- Borage
- Chaparral
- Chinese herbs
- Coltsfoot
- Comfrey
- DHEA
- Dieter’s Tea (including Senna, aloe, rhubarb root, buckthorn, cascara, castor oil)
- Echinacea
- Ephedra or Ma Huang
- Germander
- Ginseng
- Grape seed
- Groundsel or Life Root
- Heliotrope or Valerian
- Hemlock
- Kava kava
- Laetrile (apricot pits)
- Licorice root
- L-tryptophan
- Lobelia
- Marijuana/THC/CBD
- Maté Tea
- PC-SPES, SPES
- Pau d’arco
- Pennroyal
- Sassafras
- St. John’s Wort
- Yohimbe, Yohimbine
Resources
Map and directions to University of Washington Medical Center

To UW Medical Center from SCCA
1. Travel north on Eastlake Ave E.
2. Cross the University Bridge.
3. Turn right at NE Campus Pkwy.
4. Turn right at Brooklyn Ave NE.
5. Turn left at NE Pacific St.

To UWMC Triangle Garage:
Parking lot is across the street from the Medical Center on NE Pacific Place off of Pacific Street. After you park, you can access the hospital by walking through a pedestrian tunnel. Note: Garage height restriction is 6’ 8”.

Addresses:

SCCA
825 Eastlake Avenue East
Seattle, WA 98109
(206) 606-7222
Parking at SCCA is $4.00 with validation

SCCA Hospital and UWMC
1959 NE Pacific St.
Seattle, WA 98195
(206) 598-3000

SCCA, SCCA Hospital, and UWMC (Surgery Pavilion and Triangle) parking garages offer same day reciprocal parking. Simply bring your receipt from a participating garage to your next appointment and it will be honored.
Words you may hear

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

**Advanced practice provider (APP):** A mid-level provider, such as a nurse practitioner (NP) or physician assistant (PA); APPs manage patients’ physical care, perform health history and physical examinations, and make decisions about medical care together with the patient and attending physician (doctor).

**Antigen:** A harmful substance that causes your immune system to produce antibodies to protect it; it may be internal (inside your body), or external (outside your body, such as chemicals, bacteria, viruses, or pollen).

**Antibody:** A protein produced by your body's immune system when it detects harmful substances (antigens).

**Apheresis:** A procedure used to collect certain types of blood cells (either red or white blood cells); blood is passed through a special machine to remove the specific blood cells, and the rest of the blood is returned back into the body.

**Attending physician:** A doctor that leads your care team, selects appropriate treatment plans, conducts patient and family conferences, obtains informed consent for procedures or clinical trials.

**B cell:** A type of white blood cell (lymphocyte) that produces antibodies that are used to attack invading bacteria, viruses, or toxins, such as cancer.

**Benign:** Not cancerous.

**Biologic therapy:** A treatment that uses substances made from living organisms to treat disease; these substances may occur naturally in the body or may be made in the laboratory; some biological therapies stimulate or suppress the immune system to help the body fight cancer, infection, and other diseases; other biological therapies attack specific cancer cells, which may help keep them from growing or kill them.

**Biopsy:** The removal of a sample of tissue that is tested to see if cancer is present.

**Blood draw:** A minor procedure done to take blood for testing, usually done as the first appointment each day you are at the clinic.

**Bone marrow:** The soft, spongy material in the center of bones that produce blood cells, such as white blood cells, red blood cells, and platelets.
**Bone marrow aspirate:** A procedure that uses a needle to remove bone marrow in *liquid form*, usually from the hipbone, to test if cancer is present; during the procedure, the hipbone will be numbed (using local anesthetic)

**Bone marrow biopsy:** A procedure that uses a needle to remove bone marrow *tissue*, usually from the hipbone, to test if cancer is present; during the procedure, the hipbone will be numbed (using local anesthetic)\(^5\)

**Carcinoma:** Cancer that begins in the skin or in tissues that line or cover internal organs

**Caregiver:** Responsible family member(s) or friend(s) who provides physical care, observation, and emotional support for the patient; a caregiver helps with logistics such as transportation, maintains the home environment, assists and supports other family and friends, and acts as a patient advocate

**Caresi:** SCCA’s iOS (for iPhone and iPad users) and web app that allows patients to access resources such as: appointment details, care team contact information, a symptom tracker, and patient education materials; if you have an iOS device, you can download the Caresi app; if not, you can access it online at caresi.com

**Catheter:** A rubber, silicone, or plastic tube that is inserted into the body (neck, chest, arm, or groin) to drain fluids (such as blood samples or urine), or deliver fluids (such as chemotherapy or other medication)

**CD-4, CD-8, CD-19, CD-20, and other CDs:** Target antigen receptors on the cancer cell surface for some immunotherapy cells or drugs\(^6\); CD stands for “cluster of differentiation” or “cluster of designation”, which is a naming process for certain cell molecules

**Cellular immunotherapy:** In cellular immunotherapy, white blood cells from your immune system are taken from your body, modified in a laboratory to improve their ability to fight cancer, and then returned to your body as “living drugs”; CAR T cell is one type of cellular immunotherapy

**Checkpoint inhibitor:** A type of immunotherapy that helps T cells (immune system white blood cells) recognize and destroy cancer cells

**Central venous catheter:** A small, flexible tube inserted into a large vein under the collarbone; it is used for giving chemotherapy and other medication, providing fluids, or for taking blood samples; there are several types of catheters used at SCCA: PICC (Peripherally Inserted Central Catheter), tunneled venous catheter like a Hickman, temporary central line like a Mahurkar, and implanted port (also called port-a-cath)
Chimeric: Made up of different origins (or pieces); chimeric antigen receptor T cells (CAR T cells) are “chimeric” because they are genetically engineered in a laboratory to add a specific receptor to a T cell.

Chimeric antigen receptor T cell therapy (CAR T-cell therapy): A type of immunotherapy that uses your T cells (immune system white blood cells) that have been engineered in a laboratory to have a special receptor to bind to and destroy cancer cells.

Clinical trial: A type of research study that tests how well new medical approaches work in people; these studies test new methods of screening, prevention, diagnosis, or treatment of a disease.

Clinical trial phases: Clinical trials for drugs and medical devices often occur in four phases, and each phase has a specific research goals; the goals of each phase are to evaluate:

- **Phase I**: Safety, dosage, and side effects
- **Phase II**: Side effects and effectiveness
- **Phase III**: Effectiveness compared to standard treatment
- **Phase IV**: Long-term effects

Computed tomography (CT or “CAT” scan): An X-ray done using special equipment and computers, the equipment takes a series of detailed X-ray pictures that provide a multidimensional look at a body part; may be used during the screening process to see if a patient is a candidate for immunotherapy.

Consent conference: A meeting between a physician and patient to talk about risks and benefits of a clinical trial or treatment plan; during a consent conference, the patient will sign consent forms and ask questions of their physician or care team.

Consent form: A document reviewing the proposed treatment plan or clinical trial that describes potential risks and benefits; patients sign consent forms to show understanding of the process and procedure and agreement to proceed with the proposed treatment or research.

Cytokine: A type of cellular protein that has an effect on the immune system; cytokines can stimulate the immune system or slow it down; they can also be made in the laboratory and are used to help the body fight cancer, infections, and other diseases; examples of cytokines are interleukins, interferons, and colony-stimulating factors.

Cytokine Release Syndrome (CRS): A side effect of CAR T-cell therapy that may result in fevers, low blood pressure, heart and breathing difficulties, and other potentially life-threatening issues.

Dual Energy X-ray Absorptiometry (DEXA) scan: An X-ray used to measure the mineral content in bones (a decrease in bone minerals may increase a person’s risk of breaking bones); may be used during the screening process to see if a patient is a candidate for immunotherapy.
**Electrocardiogram (ECG or EKG):** A test that measures the electrical activity of the heartbeat; it is used to find out if the heart is working normally; may be used during the screening process to see if a patient is a candidate for immunotherapy.

**Echocardiogram:** A test that uses high frequency sound waves (ultrasound) to make pictures of your heart and to see if the heart is working normally.

**Electrolyte:** Important minerals that help balance the amount of water in your body, move nutrients into your cells, and help nerves, muscles, the heart, and brain work correctly; examples are potassium, calcium, and sodium.

**Hickman catheter:** A type of tunneled central line used to give you chemotherapy, blood transfusions, and other medication; it is usually placed in your chest and remains there throughout your treatment.

**Hematocrit:** A measurement of red blood cells compared to your total volume of blood (including white blood cells, red blood cells, and platelets); if you have a low hematocrit, you may need a blood transfusion.

**Immune system:** A complex network of cells, tissues, and organs that work together to defend your body against infection, toxins, and cancer; it helps your body recognize, stop, and destroy foreign invaders (antigens).

**Immunotherapy:** Treatment that uses certain parts of your immune system to fight diseases such as cancer; this can be done by stimulating your immune to work harder or smarter, or by giving your immune system special tools, such as man-made proteins; there are many versions of immunotherapy, including: monoclonal antibody, cellular, checkpoint inhibitor, and vaccines; often, immunotherapy treatment is designed for an individual patient’s disease and immune system, this is known as “personalized medicine.”

**Implanted port:** A device placed under the skin that is used to deliver chemotherapy and other medications; it can also be used to draw blood; an implanted port is a type of central venous catheter.

**Informed consent:** The process of making sure a patient learns about and understands the purpose, potential risks, and benefits of a clinical trial, protocol, or procedure, and then agrees to participate.

**Intraperitoneal (IP) therapy:** Therapy that gives chemotherapy or medication, or takes blood, through the peritoneal cavity, which holds your abdominal organs (stomach, intestines, pancreas, and liver).

**Intravenous (IV) therapy:** Therapy that gives chemotherapy or medication, or takes blood, directly through your veins.
**Leukocyte:** Another name for white blood cells, a part of your immune system

**Leukapheresis:** A type of apheresis that passes blood through a special machine to remove white blood cells (leukocytes) and returns the rest of the blood cells and plasma back into the body\(^\text{18}\)

**Lumbar puncture (spinal tap):** A procedure that uses a needle to remove a small amount of fluid from the spinal cord to test for infections and other diseases or disorders; medicine may also be injected during this procedure\(^\text{19}\)

**Lymphodepletion (or lymphodepleting chemotherapy):** Chemotherapy to decrease the number of immune system cells in your body to create space for your new CAR T cells

**Lymphocyte:** A type of immune system white blood cell that helps the body fight infections; the two main types of lymphocytes are B cells and T cells\(^\text{20}\)

**Kymriah ® (tisagenlecleucel):** A commercial (FDA approved) immunotherapy drug for patients up to 25 years old with acute lymphoblastic leukemia (ALL) and adult relapsed or refractory diffuse large B-cell lymphoma

**Mahurkar:** A temporary central venous catheter typically placed in the blood vessels of the neck to collect cells through apheresis; placed in patients who do not have accessible veins or do not have a central line

**Malignant:** Cancerous

**Malignant melanoma:** Another term for melanoma, a type of skin cancer

**Melanoma:** A form of skin cancer that begins in melanocytes (cells that make the pigment melanin which cause coloration of human skin, hair, and eyes)\(^\text{21}\)

**Merkel cell carcinoma:** A rare type of cancer that forms on or just beneath the skin, usually in parts of the body that have been exposed to the sun; most common in people 50 years and older and in people with weakened immune systems\(^\text{22}\)

**Monoclonal antibody:** A type of protein made in the laboratory that can bind to substances in the body, including cancer cells; they can be used alone or to carry drugs, toxins, or radioactive substances directly to cancer cells to treat cancer\(^\text{23}\)

**Multi-gated acquisition scan (MUGA):** A type of scan to test how well the heart is pumping blood\(^\text{24}\)
**Neurotoxicity**: A potential side effect of CAR T-cell immunotherapies that can affect the nervous system; signs and symptoms can be mild or severe and include confusion, speech changes, headache, and/or movement or problems\(^{25}\)

**Neutropenia/neutropenic**: An abnormally low count of neutrophils (white blood cells)

**Neutrophil**: A type of white blood cell; the immune system’s first line of defense against bacteria and invaders in your body\(^{26}\)

**PD-L1 inhibitor**: PD-L1 inhibitors are a type of checkpoint inhibitor immunotherapy drug; they work by preventing PD-L1 proteins from hiding cancer, so T cells can identify and attack cancer cells\(^{27}\)

**Peripheral blood flow cytometry**: A type of blood test used to measure the amount of certain types of cancer cells in your blood (such as leukemia cells)

**Peripherally inserted central catheter (PICC or PICC line)**: A thin, soft, flexible tube inserted into the arm; it is used to deliver chemotherapy and medications, and draw blood; it is a type of central venous catheter

**Positron emission tomography (PET) scan**: A diagnostic imaging procedure to look for cancer cells in which a small amount of radioactive material is injected into a vein, and a scanner is used to make detailed, computerized pictures of areas inside the body where the radioactive material is taken up; also called positron emission tomography scan\(^{28}\)

**Platelet**: A type of blood cell that helps your blood clot and stop bleeding

**Protocol**: The “recipe” for a clinical trial; the outline, steps, or specific plan for treatment under a clinical trial

**Pulmonary function testing**: A series of breathing tests used to check the health of your lungs\(^{29}\)

**Refractory disease**: A disease that does not go away or improve after initial treatment

**Relapse**: The recurrence of disease after a period of improvement (when cancer “comes back”)

**Restaging**: The process used to find out how much cancer you have in your system after you’ve had treatment; restaging is usually done to see if the cancer came back, got worse, or went away\(^{30}\)

**Spinal tap (lumbar puncture)**: See “lumbar puncture”
**T cell**: A type of white blood cell in the immune system that fights infection and cancer; for some cellular immunotherapies, scientists engineer T cells to enhance their ability to target cancer cells

**T cell exhaustion**: A term describing the loss of T cell function over time, which makes it harder for the body to fight infections and other invaders

**T cell receptor (TCR) therapy**: A type of cellular immunotherapy where the T cells recognize tumor proteins on the *inside* of cells (unlike CAR T cell therapy which recognizes receptors on the *outside* of the cells)

**Team coordinator**: A care team member who schedules appointments

**Tumor infiltrating lymphocytes (TIL) therapy**: A type of cellular immunotherapy where a patient’s own tumor cells are collected from the patient, isolated and altered into tumor infiltrating lymphocytes (the TILs) and then reinfused back into the patient to attack cancer

**Tumor lysis syndrome**: Occurs during cancer treatment when cancer or tumor cells release their contents into the bloodstream and cause abnormal levels of electrolytes, which can cause kidney and heart problems, and have serious effects on other organs

**Vaccine (immunization)**: A substance used to boost your immune system and prevent serious, life-threatening disease; vaccines “teach” your body how to defend itself when germs, such as virus or bacteria, invade it; typically given as an injection

**Vital signs**: Your pulse rate, temperature, breathing rate, and blood pressure

**White blood cells**: Also called leukocytes; they are the cells of your immune system that help protect your body from infections

**X-ray**: A type of test using electromagnetic waves to create images of the inside of your body; it is used to look for cancer and other health issues inside your body

**Yescarta® (Axicabtagene ciloleucel, or axi-cel)**: A commercial (FDA approved) immunotherapy drug offered at SCCA to treat certain types of B-cell lymphoma in adults
References for the *Words you may hear* section:

6. LLS Immunotherapy Facts
10. Seattle Children’s Hospital Patient and Family Education “CT Scan”
15. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3437249/