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Important phone numbers

Seattle Cancer Care Alliance (SCCA) clinic
6th floor reception desk (206) 606-7600
Mon to Fri, 8 am to 10 pm
Sat to Sun, 8 am to 6 pm
Holidays, 8 am to 5 pm

After hours (SCCA Hospital/University of Washington Medical Center [UWMC]) (206) 598-8902
In the unlikely event of an SCCA phone outage (206) 467-8762
Health Information Management/Release of Information (206) 606-1114
Institutional Review Board for Fred Hutch (206) 667-6567
Interpreter Services at SCCA (206) 606-6419
Long Term Follow-Up (206) 667-4415
Medical Nutrition Therapy Services (206) 606-1148
Patient and Family Resource Center (206) 606-2082 fax: (206) 606-2105
Patient Financial Services (206) 606-1113
Patient Relations (206) 606-1056
Pharmacy (206) 606-6500
Physical Therapy (206) 606-6373
Radiation Oncology (206) 606-7318
Receptionist 1st floor (206) 606-1000
Security (lost and found) (206) 606-1111
Social Work Office (206) 606-1076
Spiritual Health (206) 606-1099
Transition Services (206) 606-2125
Volunteer Services (206) 606-1075

SCCA Hospital and University of Washington Medical Center (UWMC)

UWMC Human Subjects (206) 543-0098
UWMC Office of Regulatory Guidance (206) 616-8222
UWMC Pharmacy (206) 598-4363
Welcome to the Blood and Marrow Transplant Program

Welcome to the Blood and Marrow Transplant Program at Seattle Cancer Care Alliance (SCCA). We’re here to support you and your family throughout your treatment, and we created this manual as one of the first steps in that process. We hope you find it helpful.
Steps of allogeneic transplant
The cells that are being transplanted are stem cells, which are made in the bone marrow. Stem cells are immature cells that grow and mature into red blood cells, white blood cells, platelets or plasma cells. Stem cells are an essential part of a person’s immune system. Names you will hear include:
- Bone marrow transplant (BMT)
- Marrow transplant
- Peripheral blood stem cell transplant
- Stem cell transplant
- Hemopoietic stem cell transplant

Type of transplant
There are several types of transplant. You may hear others discussing a process different from yours. Below is a chart reviewing each type:

<table>
<thead>
<tr>
<th>Type of transplant</th>
<th>Cell source</th>
<th>Goals</th>
</tr>
</thead>
<tbody>
<tr>
<td>Allogeneic Related</td>
<td>Another person</td>
<td>Deliver highest dose of chemotherapy &amp; radiation to eliminate disease.</td>
</tr>
<tr>
<td></td>
<td>Family member</td>
<td>New cells replace patient’s immune system.</td>
</tr>
<tr>
<td>Unrelated</td>
<td>Another person</td>
<td>Deliver moderate dose of chemotherapy &amp; radiation to set up a mixed immune system.</td>
</tr>
<tr>
<td></td>
<td>Usually anonymous</td>
<td>New immune system attacks cancer.</td>
</tr>
<tr>
<td>Mixed Chimerism (Mini)</td>
<td>Another person</td>
<td></td>
</tr>
<tr>
<td>Related</td>
<td>Family member</td>
<td></td>
</tr>
<tr>
<td>Unrelated</td>
<td>Another person</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Usually anonymous</td>
<td></td>
</tr>
<tr>
<td>Autologous</td>
<td>Patient</td>
<td>If patient has cancer: deliver highest dose of chemotherapy &amp; radiation to eliminate disease.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>If patient has an autoimmune disease: halt progression of disease and reset the immune system.</td>
</tr>
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</table>

The transplant process can be divided into steps. Each step has its own purpose and challenges. The steps are:

Planning
This step begins when you first think about transplant as a treatment option. You start to organize yourself and your family and friends to undertake this journey.

Preparation
Once you arrive at the clinic, you will begin the process of medical evaluation, orientation, informed consent, and get ready to begin conditioning therapy. Family members and friends prepare to assume the caregiver role.

Conditioning
High-dose chemotherapy and/or radiotherapy are given.

Transplant
Stem cells harvested from the bone marrow or collected from the circulating bloodstream are infused.
**Before engraftment**
You will receive close monitoring, supportive treatment and management of complications while waiting for signs that the transplanted stem cells are engrafting (growing and developing).

**After engraftment**
This is the time after the first signs of engraftment when your new white cells, red cells, and platelets are being produced and the immune system is starting to recover. You still need close monitoring and supportive treatment.

**Long-term recovery**
You will leave the clinic and further care and treatment will be provided by your hometown physician. The challenges in this stage include managing possible late complications and resuming life at home.

**Preparation**
When you first arrive, you and your family will go to the Seattle Cancer Care Alliance (SCCA) outpatient clinic to begin the pre-transplant evaluation. You will learn the proposed treatment plan, meet with the healthcare team, and get answers to your questions about treatment. You and your family members can attend classes on how to manage symptoms at home and prevent infection. All of this is to prepare you for the next step: conditioning therapy. As a courtesy to the large number of patients with weakened immune systems in the clinic, please refrain from bringing family members or caregivers with even minor infection symptoms (cold or otherwise) into the clinic. Also, please do not bring any animals but service dogs to the clinic.

**First clinic appointments**
Your first visit to the clinic will consist of meeting your primary physician and your team nurse. Your nurse will take your vital signs, draw blood, take a short history, and give you an orientation of the clinic. Your primary physician will complete a health history and physical examination. You will be given a schedule of visits, and consent forms that give permission to conduct the pre-transplant evaluation. In the first few days, you will meet with a social worker who will answer questions you may have about your housing and social issues, describe resources you may access, and offer support for you and your family members.

**Arrival conference (meeting with physician and care team members)**
After your health history and physical exam are done, you will be scheduled for a conference with your attending physician. This usually takes place on the second day after you arrive at the clinic. You may invite members of your family, including the donor, to attend. We discourage small children from attending. The attending physician will talk to you about the process of having a bone marrow transplant. He or she will discuss the plan of treatment including the risks and benefits.

**Evaluation and work-up**
The evaluation for transplant includes blood draws for tissue typing and clinical tests, a bone marrow aspiration and possible biopsy, chest X-rays, an electrocardiogram (ECG), pulmonary function tests, and other tests the physician may order. You will meet with a dietitian and possibly have a dental checkup. When the results of these tests are available (5 to 7 days) you will be scheduled for placement of a central venous line catheter.
Informed consent conference

You will be scheduled for a second conference to review your test results before you proceed with treatment. The physician must share information with you so that you will be well informed and able to make the decision to go ahead with transplantation. The conference provides you and your family the opportunity to ask questions. After the conference, you (or your legal guardian) will be asked to sign consent forms giving permission to proceed with treatment. You and your family will:

- Receive copies of all protocol consent forms for the protocols in which you are participating;
- Be offered copies of all protocols for the protocols in which you are participating; and
- Be offered a copy of the dictated “Data Review Conference” summary.

Central venous line placement

You will be given specific instructions about what to eat or drink before the procedure. Your nurse will also guide what medications you can take before the procedure. You will return to the clinic the next day so that one of the nurses can teach you how to take care of your line.

Conditioning

Conditioning consists of high-dose chemotherapy with or without total body irradiation. The purpose of conditioning therapy is to remove cancer cells or to remove the remaining immune system, so that new marrow can grow. Conditioning can be received in the clinic or in the hospital. Your nurse and physician will discuss your treatment plan with you.

Chemotherapy

All chemotherapies and radiation have some effects on normal cells as well as on diseased cells, and unpleasant effects can be expected. Each of the chemotherapy drugs has different effects. The specifics of the chemotherapy prescribed for you will be explained when your therapy program is planned. Common side effects include nausea, vomiting, diarrhea, dry mouth, fatigue, hair loss, and skin changes. Some of the side effects of chemotherapy happen right away and can be managed with other drugs.

Nausea and vomiting are major concerns for patients. Several drug therapies are available to relieve nausea and keep you comfortable. Diarrhea can result from chemotherapy and is treated with fluid and electrolyte replacement. Hair loss is temporary, and your hair should start growing back a few months after the transplant.

Safe management of chemotherapy at home

Because chemotherapy (chemo) is made up of dangerous elements that can harm you, it is important to take precautions, especially at home. Only you (the person receiving treatment) or your caregiver should touch chemo and the items used to deliver it, such as syringes and needles. Pregnant women, children, and pets should avoid touching chemo and contaminated waste. In this section, we’ll teach you how to handle your medication safely at home.

Note: If you are taking biotherapy or immunotherapy, some of the information below may not apply to you. If this is the case, your care team will review the information that you should know.
Storing your chemo
Below are some tips for storing chemotherapy safely:

- Keep your chemo pills in their original container; do not transfer them to a pill box.
- Do not crush or open your chemo medication.
- Some medications need to be refrigerated or kept away from light; check your medicine labels for special instructions; follow additional instructions from your care team.
- Store your chemo and equipment in a safe place and out of reach of children and pets.
- Do not store chemotherapy in your bathroom because humidity may damage the drugs.

Disposal of your chemo
Because chemotherapy is dangerous, it shouldn’t be thrown away in your trash. If you are receiving intravenous (IV) chemo at home, IV equipment and gloves should be put in the hard, plastic containers that come with your supplies. The container should say “Chemotherapy Waste” or something similar.

If the waste is too large to fit in the plastic container, put all sharps in the hard, plastic container. Put the other equipment in a separate, leak-proof plastic bag (such as a garbage bag) and seal it tightly with rubber bands.

The company supplying your chemo and equipment will tell you who will remove the waste containers. If you take oral chemotherapy, ask your care team how to dispose of it or refer to How to Safely Dispose of Prescription Medications and Sharps.

Managing chemo spills
The company that supplies your IV chemo will include a spill kit with your medicine. If your chemo spills, follow the instructions on the kit and inform your care team. If, for some reason, you don’t have a spill kit available, follow these steps:

- Put on 2 pairs of disposable gloves.
- Clamp the IV tubing.
- Turn off the pump if you’re using one.
- Place the following in a leak-proof plastic bag, such as a garbage bag:
  - All the tubing and containers
  - The pump
  - The carrying case, if you have one
- Soak up the spill with paper towels.
- Clean the area with soap and water.
- Rinse with clean water.
- Put all the supplies used to clean up the spill in a separate leak-proof plastic bag.
- Remove your gloves and wash your hands with soap and water.
- Call you care team for instructions on how to manage the spilled chemo, the equipment, and the dirty cleaning supplies.
Other instructions

Body wastes
Your urine and stool contain chemotherapy while you’re receiving treatment, and for up to 2 days after you’ve finished treatment. Traces of chemotherapy may also be present in vomit, vaginal fluid, and semen. You may use the toilet (septic tank or sewer) as usual. For the first 48 hours (2 days) after you receive chemo, flush the toilet twice with the lid closed each time you use it. Be sure to wash your hands with soap and water each time you use the bathroom.

Laundry
Wash your clothing and bedding normally unless they become soiled with chemotherapy. If that happens, put on disposable gloves and handle the laundry carefully to avoid getting chemo on your skin. Soiled items should be washed separately from other clothes. If you don’t have a washing machine, place the dirty items in a sealed, leak-proof plastic bag until they can be washed.

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

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

Questions and answers

Is it safe for family members to have contact with me during chemotherapy?
Yes. If you wish to, spending time with others is encouraged. Living, eating, and doing activities with others is safe. Hugging and closed mouth kissing is safe, too.

Is it safe for my family to use the same toilet as me?
Yes. We understand your family may have concerns, but as long as any chemotherapy waste is cleaned from the toilet, it is safe to share a bathroom.

What should I do if I don’t have control of my bladder or bowels?
Use a disposable, plastic-backed pad, adult or pediatric diaper, or sheet to absorb urine or stool. When it gets soiled, put on gloves, remove the soiled piece, remove the gloves, and then wash your skin with soap and water. If you have an ostomy, you or your caregiver should wear gloves when emptying or changing the bags. Empty any urine or stool into the toilet, and close the lid and flush the toilet twice. Discard disposable ostomy supplies in the chemotherapy waste container.

What if I use a bedpan, urinal, or commode?
If you’re using one of these, it’s important for your caregiver to wear gloves when they empty and clean the containers. Your caregiver should rinse the container with water after each use and wash it with soap and water at least once a day.

What if I vomit into a basin?
It’s important for your caregiver to wear gloves when emptying and cleaning your basin. Your caregiver should rinse the basin with water after each use and wash it with soap and water at least once a day.
Is it safe to be sexually active during my treatment?
Please ask your care team this question, as this depends on the type of treatment you are on. Because traces of chemotherapy may be present in your vaginal fluid or semen for up to 48 hours after treatment, you may need to take special precautions.

Is it safe to throw IV chemotherapy in the trash?
No. Chemotherapy waste is dangerous and should be thrown away separately. If you are receiving IV chemotherapy at home, you should have received a special waste container for the chemotherapy and equipment (such as used syringes, needles, tubing, bags, cassettes, and vials). This container should be hard plastic and labeled “Chemotherapy Waste” or something similar.

Can I travel with my chemotherapy?
Traveling with chemo is usually fine but check with your care team or home infusion supplier to confirm it is OK. Ask your care team for a letter that says you need to travel with your medications and that it’s safe for you to do so. The letter should list the names of your medications. Some chemotherapy requires special storage, so you may need to make plans, such as traveling with a cooler. Regardless of how you travel (by plane, car, or another mode of transportation), always seal your chemotherapy drugs in leak-proof plastic bags.

Sources
Safe handling and Administration Considerations of Oral Anticancer Agents in the Clinical and Home Setting, Clinical Journal of Oncology Nursing, 2012, 16(6), pages 192-197. Joanne Lester, PhD, CRNP, AOCN
Safe Handling of Chemo at Home, 2018, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4324350
Safe Handling: Implementing Hazardous Drug Precautions. Clinical Journal of Oncology Nursing, 2012, 16(3) pages 251-254. Anne Marie Watson, RN, MPH, OCN, CHES, Susan Mason, RN, MSN, OCN, Michele Busshart, RN, OCN, Angela Spruill, RN, BSN, OCN, Summer Cheek, RN, BSN, OCN, Ashley Lane, RN, OCN, Kathy Sabo, RN, BSN, CPHON, ATC, and Amanda Taylor, RN, BSN, CPHON

Total body irradiation (TBI)
This radiation therapy utilizes high-energy X-rays for your cancer treatment. TBI is radiation given to the entire body. TBI is given according to your treatment plan. It can vary from 1 to 3 times a day, 20 to 40 minutes at a time, for a length of 1 to 4 days. The treatment length is dependent on your body size and prescribed radiation dosage. However, once determined, the amount of time you spend in treatment will be the same.

What are TBI treatments like?
There is no pain or discomfort during your treatment due to radiation. You will not have any unusual sensations while the radiation machine is on. You do not become “radioactive.” A family member, spouse, significant other, or friend may accompany you to the radiation therapy department. However, it is necessary for you to be in a room by yourself during treatment. You may feel alone during your treatment. Monitors are outside so that your nurse and radiation technician see and hear you at all times. You will be given detailed instructions when your nurse teaches you about your radiation course.
Side effects of TBI

Nausea: Most often occurs 1½ to 2 hours after a dose of TBI. You will be started on medication to keep nausea from being too much of a problem. The day before TBI begins; your team nurse will review the medications you should take before each TBI treatment.

Dehydration: TBI can cause dehydration similar to being exposed to the sun for too long. Other side effects such as diarrhea and nausea add to this problem. Some of your hydration may be given through an IV during each day of TBI to help prevent dehydration. Your caregiver will learn to manage the pump at home, but some of your hydration can be given in the clinic.

Skin sensitivity: TBI acts as a heat source even though you will not feel this right away. You will notice your skin may appear flushed, or darker following radiation therapy. Following treatment, your skin will be more sensitive, especially to sunlight. You can take precautions to avoid skin burns during treatment. This includes wearing loose fitting clothing, removing all jewelry, glasses, and contacts. The clamp used to hold your central catheter will also be removed. The nurse or physician will assess your skin frequently. Avoid using lotion and deodorant before TBI.

Alopecia: Temporary hair loss may occur gradually over two weeks following treatment.

Parotitis: The parotid glands are located near and in front of your ears. Parotitis is swelling of the parotid gland, and it can cause headaches, fevers, tiredness, and appetite loss. Parotitis is not a common side effect but has been seen in TBI patients. Symptoms will occur from 4 to 24 hours after TBI. Ice packs and Tylenol help to relieve the discomfort from the swelling. Parotitis will resolve in 24 to 72 hours following treatment.

Diarrhea: Usually develops within the first week following TBI and can be treated with medications.

Mucositis: Mucositis is painful swelling or ulceration of the glands that secrete mucous and the fast-growing cells that line the mouth and throat are altered by TBI and/or chemotherapy and cause dryness, swelling, and a painful mouth and throat. Mucositis is treated with salt-water rinses and pain medication. If pain continues, narcotics will be used.

Transplant
The transplant takes place a day or two after the chemotherapy and/or radiation treatment. The goal is to infuse stem cells from which all types of blood cells grow. Stem cells are cells from which all types of blood cells grow. These cells can be collected from bone marrow, circulating blood, or umbilical cord blood after a baby’s birth. Stem cells are infused through your central venous line in the same way that any blood transfusion is given. The stem cells “rescue” your bone marrow from the toxic effects of the chemotherapy/radiation regimen. Depending on your treatment plan, your infusion may take place at SCCA’s outpatient clinic or at the hospital (also called inpatient care). If you are at the hospital, you care will either be provided at SCCA Hospital or a unit of University of Washington Medical Center (UWMC). Both are located at UWMC and provide the same high-level quality of care.

In allogeneic transplants, the cells are harvested from the donor (either from a family member or an unrelated person) on the same day it will be given to you.
Bone marrow donor
Donors will receive their own educational materials when they arrive at the clinic. The bone marrow donor is the person who makes an allogeneic transplant procedure possible. He or she is the person who most closely matches the genetic type of the patient. The donor may be an immediate family member, often a brother or sister. In some cases, the donor and patient are not related but are still closely matched in tissue type. Most families arrive knowing who the donor will be. Even with a known donor, it is still important that some typing be repeated. This information assures the medical team that the best possible donor has been selected. There are no age restrictions for donors.

Marrow harvesting
The actual marrow harvesting is performed in surgery where marrow is taken from the hip bones. Marrow is obtained through needles inserted through the skin into the hip bones. Most donors go home from the hospital the same day after marrow harvest unless an overnight stay is medically necessary.

Stem cell donor
Stem cells are produced in the bone marrow and circulate in the bloodstream. The stem cells that circulate in the bloodstream are called peripheral blood stem cells, or PBSCs. Normally, small numbers of stem cells circulate in the bloodstream. In addition to obtaining stem cells by harvesting them from the bone marrow, it is possible to obtain them by collecting them from the bloodstream. However, before that can be done it is necessary to stimulate the movement of stem cells into the bloodstream. This is called mobilization.

Stem cell mobilization
Stem cells are mobilized by giving the donor special proteins called growth factors. It takes a few days for the body to respond to the mobilization therapy. When blood tests show that the cell count is high enough, collection can begin. Sometimes a stem cell donor must go through more than one cycle of mobilization to collect enough stem cells for transplant.

Collecting stem cells
Stem cells are collected in the Apheresis Unit. Before beginning collection, the donor has a catheter (tube) placed into a large vein. The catheter may be placed several days before or right before the collection procedure. The collection process takes about three hours. During the procedure the donor relaxes in a chair or bed and can watch television or read.

The donor’s blood is withdrawn through the catheter and circulated through a machine that separates and collects stem cells. The remaining blood cells are returned to the donor through the catheter. The procedure is painless. When the procedure is over, the donor can resume normal activities.

Infusion of donated cells
Marrow or stem cells are infused into you as soon as available from the donor. You may receive more than one bag of cells. In some cases, the bone marrow is processed before infusion. Based on recommendation of the Transfusion Services office, if the blood type between the patient and donor does not match, red blood cells may be removed from the marrow before infusion. The nurse attaches IV tubing to the bag of cells and connects the tubing to your central catheter line. Each bag of cells is infused one after the other. During the infusion, the nurse will check vital signs: blood pressure, pulse, respiration, and temperature. You may be connected to a heart monitor, so nurses can observe your heart rate and rhythm.
The length of the infusion depends on the volume, or amount of stem cells to be given. The infusion takes 30 minutes to 2 hours to complete. You may receive stem cells on more than one day because of the donor collection process.

Before engraftment
Signs that the new stem cells are growing (engrafting) and beginning to produce blood cells are expected from 10 to 28 days after transplant. Often the first sign of engraftment is a rising white blood cell count. While watching for the first signs of engraftment, you require careful monitoring. The goals are to support you until you are producing blood cells again, to provide prompt treatment if complications occur, and to prevent infections. You may feel uncertain, stressed, defenseless, and vulnerable while waiting for the engraftment to occur. Some families feel a loss of personal control associated with the daily monitoring, medical procedures, and treatments following your transplant. Coping at this time can be a challenge. Keep talking to your team about your concerns.

Blood counts: what are they and what do they mean?
Blood counts are numbers that show the amount of blood cells circulating in the blood stream. Blood will be drawn from your central line to check the level of your counts. The blood counts that are monitored closely are the total number of white blood cells (ANC), the hematocrit, and the platelet count.

<table>
<thead>
<tr>
<th>Blood component name</th>
<th>Function</th>
<th>Normal ranges</th>
<th>Transplant transfusion guidelines</th>
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</table>
| **Hematocrit (HCT)** | • Carry oxygen to the body  
• Give color to the skin  
• Give energy to the body | Adult: 37% to 52% | Transfuse:  
• If HCT less than 26%  
• If patient symptomatic |
| % red blood cells per volume of whole blood erythrocytes | | | |
| **Platelets (PLTS)** | • Prevent bleeding  
• Help blood to clot | 150,000 to 500,000/mm³ | Transfuse:  
• If less than 10,000, or  
• For bleeding, or  
• If otherwise indicated |
| thrombocytes | | | |
| **White blood cells (WBC)** | Fight infection | Adult: 5,000 to 10,000/mm³ | Not applicable |
| **Absolute neutrophil count (ANC)** | Type of WBC that is first to respond to potentially fatal infections | Over 1,000 | Very rare occurrences; Only if life threatening infection is present with no signs of white cell recovery |
| neutrophils  
polys  
bands  
segs  
granulocytes | | | |
Effects of chemotherapy and radiation on blood counts

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

Red blood cell transfusions

When your red blood count is low, the physician will order packed red blood cell (RBC) transfusions. This consists of a bag or bags of concentrated red blood cells, each transfused over 2 to 4 hours. This blood has been typed and cross-matched with yours to minimize the chance of reaction. This means that the RBC donor and you have a compatible blood type. It’s still possible that you may have a reaction. Symptoms include fever, chills, hives, itching, and/or breathing problems. If you have any of these symptoms during transfusion, be sure to report them right away to your nurse.

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

Platelet transfusions

Collection of platelets is done at the Puget Sound Blood Bank. Platelet transfusions come from three types of donors:

- **Random pooled platelets**: From 2 to 6 volunteer donors in the community, which are pooled in the same bag
- **Random apheresis platelets (RAP)**: From 1 volunteer donor in the community.
- **Matched apheresis platelets (MAP)**: From 1 HLA matched unrelated donor in the community.

Infections

Infections remain one of the major complications of transplantation. You are high risk for infections because of low white blood cell counts and a poorly functioning immune system.

All people have different types of bacteria, viruses, and yeast growing on their skin and in their bodies. Many of these organisms are needed for proper functioning of our bodies. Our immune system controls the growth of the organisms so that they do not make us sick. The source of infection in many patients is their own organisms. Routine cultures are important because the results keep physicians informed about the bacteria, viruses, and yeast you have growing in your body that may be causing infections. Culture results help physicians to prescribe the right antibiotic when you have an infection. You may have negative culture results, but you may still clinically look and feel like you have an infection.

Another source of infection is organisms from other people. Hand washing plays a key role in stopping the spread of infection from one person to another. It is important that everyone entering and leaving your hospital or clinic room washes their hands, including yourself. This is why visiting between you and other patients is not allowed in the hospital and why your family members should not go into other patients’ hospital rooms.
The medications used to treat infections include antibiotic, antifungal, and antiviral medications. Respiratory viruses, which cause the common cold or the flu in people with normal immune systems, can lead to pneumonia in transplant patients. These viruses include parainfluenza, adenovirus, and respiratory syncytial virus (RSV). If you develop symptoms of an upper respiratory infection, such as stuffy nose, sore throat, cough, chills, fatigue or fever, we will get a naso-pharyngeal and throat (NPT) culture to determine if there is a specific viral infection. You will be in isolation as soon as symptoms develop and remain in isolation until the cultures are negative and you no longer have symptoms. Family members or friends with cold or flu symptoms should stay away from you until they are well.

**Cytomegalovirus (CMV)**

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

Once a person has a CMV infection, the virus usually lies dormant (inactive) in the body but can be “reactivated” and cause serious illness in people who have weakened immune systems due to illness, chemotherapy, or transplant.

All stem cell transplant patients are monitored weekly for reactivation, regardless if they are CMV positive or negative. This is done with a blood test called CMV PCR. In stem cell transplant recipients, the antiviral drug ganciclovir or foscarnet can be given intravenously to treat the reactivation. It will be recommended to continue monitoring for CMV reactivation for one year after transplant. This can be coordinated with the patient’s referring physician.

**Sinusoidal obstruction syndrome (SOS)**

Sinusoidal obstructive syndrome is a disease caused by injury to the liver, which involves the partial blockage of blood flow through small veins. Congestion results in post-sinusoidal obstruction and liver damage.

The cause of this problem is the chemotherapy and/or radiation used to prepare you for transplant. High levels of conditioning therapies are needed for successful transplant. Such intensive therapy can damage otherwise healthy tissues in addition to its desired effects. The liver is especially susceptible. The signs of SOS are fluid retention, weight gain, and an increase in liver function test values.

**Gastrointestinal (GI) problems**

The chemotherapy and/or radiation used in the high-dose regimen also affect the entire GI tract. These side effects range from mild sore mouth and throat, nausea/vomiting and diarrhea, to more severe forms, which can include inflammation and mucosal breakdown throughout the GI tract. Narcotics are used for pain control, and intravenous nutrition (TPN) is often indicated. These side effects get better with engraftment.

**Lung problems**

You will be monitored closely for signs of any breathing difficulties due to fluid overload, pneumonia, or side effects of chemotherapy or radiation. Daily physical examinations and routine chest X-rays will be done.

**Skin problems**

The skin is a sensitive organ often prone to some damage from chemo and radiation. These side effects range from a mild redness like a sunburn to red, dry, and peeling skin.
Kidney problems
Kidneys are organs that produce urine, remove bodily waste, and process some drugs out of the body. Some drugs affect kidney function. Your nurses and physicians keep a close watch on your kidney function through blood tests, the careful monitoring of the quantity and quality of urine, and frequent measurement of body weight. These and other factors help guide them to prevent and treat kidney problems and help return kidney function to normal.

After engraftment
As your new immune system develops, the goal is to support your recovery and manage any complications that may arise. Your immune system is immature, and you are still vulnerable to infections. You may need infusions of red blood cells or platelets, as well as fluids and nutritional support until you are eating and drinking enough.

It is common to feel tired during this phase. Even though you feel tired, try to keep as active as possible. Being active helps prevent some complications. You may also feel “down” or depressed at times during the recovery period. You may grieve because of changes in physical functioning or dependence on others for care or even changes in relationships with your family members. These are all common reactions to the intense experience of having a transplant. You also may experience decreased concentration at this time. See the sections on Fatigue, Depression, and Memory and Concentration for more information.

Progress may seem slow. You may feel frustrated because you want to get well rapidly. It just takes time to recover. Former patients tell us that they coped by taking one day at a time. They found that if they set a simple and realistic goal to achieve each day, it was easier for them to see the progress. It is helpful talking with staff about what is a realistic goal.

As you recover and no longer need close monitoring and treatment, the team will help you to prepare to leave and return to the care of your regular physician. Despite the eager anticipation, you may experience separation anxiety as you prepare to leave!

Possible complications

Graft-versus-host disease (GVHD)

What is acute graft-versus-host disease (GVHD)?
GVHD is caused by immune cells from the donor that attack tissues and organs in the patient who has received a transplant. Acute GVHD can occur any time after engraftment, but usually begins within the first three to four weeks after transplant. GVHD is often the major problem after bone marrow, cord blood, or blood stem cell transplantation. It may affect the skin, liver, stomach, and intestines. After transplant, you will take two or three different medicines that suppress your new immune system to prevent acute GVHD. Despite taking these medicines, two out of three patients with a related donor and four out of five patients with an unrelated donor develop GVHD and need additional treatment.
What are the treatments for acute GVHD?
The usual treatment for GVHD is a steroid called prednisone (taken by mouth as an outpatient) or methylprednisolone (given by IV as an inpatient). The goal of this treatment is to control symptoms of GVHD. The dose is reduced (tapered) over weeks or months depending on your response. We want to limit the number of days that you take high-dose steroids to reduce your risk for serious infections and other side effects.

What is mild GVHD?
Mild GVHD does not affect the liver. Mild GVHD occurs in 1 out of 3 patients with a related donor and 1 out of 5 with an unrelated donor. Mild GVHD symptoms include:

- Rash
- Loss of appetite
- Nausea
- Vomiting
- Mild diarrhea

What is the treatment for mild GVHD?
Mild GVHD of the skin may be self-limiting and not require treatment. Alternatively, it may be treated with ultraviolet light called PUVA or topical creams. If it persists, low-dose prednisone may be used. Mild GVHD of the stomach and intestines can also be treated with low-dose prednisone. In this case, physicians might add a special steroid called beclomethasone for the stomach, and another special steroid called budesonide for the intestines. Sometimes these special steroids are called “B&B.” This use of B&B generally allows the doses of prednisone to be tapered more quickly.

What are the signs of more than mild GVHD?
In addition to the symptoms listed under mild GVHD, symptoms might include:

- A more intense, itchy, and inflamed rash
- Large amounts of frequent and sometimes bloody diarrhea
- Abdominal cramping
- Liver damage resulting in jaundice (yellow skin, tears, and urine)
- This grade of GVHD occurs in 1 out of 3 patients with a related donor and 3 out of 5 patients with an unrelated donor.

What is the treatment for more than mild GVHD?
GVHD with more than mild symptoms is treated with high-dose prednisone. If GVHD does not improve, additional treatment may be needed. High-dose prednisone increases the risk for infections and other complications. Whether or not standard prednisone therapy controls the GVHD, we try to decrease the dose of prednisone over weeks or months, depending on your response.

Failure to engraft
Failure of the transplanted cells to grow and develop is an uncommon complication. At first, there may be signs of engraftment such as increasing blood counts, but later the blood counts decrease. Generally, it takes a number of weeks after the transplant to find out the success of the graft. It takes longer for some patients to engraft than others. The production of blood counts is not a steady climb. Blood counts normally fluctuate after transplant. Also, certain medications influence the production of blood cells.
If failure to engraft is indeed the diagnosis, then you will be offered other therapies. Some treatment plans (research protocols) are focused on just this situation and aim to boost the production of blood cells. Other treatment plans involve stopping the drugs which interfere with bone marrow function or the infusion of reserve marrow or more stem cells if available.

**Transitioning back to SCCA**

You may be hospitalized (also called inpatient care) during your transplant. If needed, your inpatient care will either be provided at SCCA Hospital or a specialized unit at University of Washington Medical Center (UWMC). Both are located at UWMC and provide the same high-level quality of care. A transition nurse will meet with you and your caregiver to help with plans for discharge from the inpatient unit and transition back to the SCCA clinic. After discharge, clinic nurses will again coordinate your care.

Before leaving the inpatient unit, you and your caregiver will receive the information you need and have an opportunity to learn and practice the skills to manage your care at home. Classes are taught covering these skills, and we want your caregiver to know that he or she is welcome to attend any of the classes a second time to “brush up” on information or skills.

A transition nurse will schedule your first clinic visit before the day of your discharge from the hospital. You will be scheduled to see a physician or physician’s assistant and your team nurse at the clinic at least once a week, and other times as needed. This clinic visit includes an exam and time for you to share your questions and concerns with staff. Also, on your first clinic visit, you will be given your usual weekly schedule for clinic times, blood draws, and routine chest X-rays. You will have a nutrition visit scheduled. You may also need to be at the clinic for care other than your scheduled weekly visit.

Your blood will be drawn at the clinic in the morning, two to seven times a week. Bone marrow aspirations around day 28 and day 80 post-transplant are done by your nurse at the clinic to determine the status of your new marrow. Spinal taps (LPs) may be scheduled to administer therapy to your central nervous system. Intravenous medications, infusions, growth factors, study drugs, and blood product transfusions are also given in the clinic.

**Preventing infection**

Even though you are well enough to recover at home, your immune system is still recovering, and you will need to take precautions to guard against infection for up to a year or longer after your transplant. There are many strategies you can use to decrease infection risk to yourself during this time:

**Hand hygiene**

According to the CDC, clean hands are the single most important factor in preventing the spread of germs and the infections they can cause, especially in people with weakened immune systems. These are the most important times for you and people around you to clean your hands:

- Before preparing or eating food (*use soap and water*)
- Before touching your eyes, nose or mouth (*soap and water or alcohol hand sanitizer*)
- Before and after changing dressings that cover wounds or medical devices implanted in your body (like the Hickman catheter) (*soap and water or alcohol hand sanitizer*)
- After using the restroom (*use soap and water*)
- After blowing your nose, coughing or sneezing (*soap and water or alcohol hand sanitizer*)
• After touching hospital or clinic surfaces such as bed rails or hand rails, door handles, counters, elevator buttons, phones, pens (soap and water or alcohol hand sanitizer)

For hand hygiene to be effective, it must be done carefully, so here is how we recommend that you do it:

If using soap and water:

If using alcohol hand sanitizer:

1. Dispense one or two pumps of gel or foam into palm of one dry hand.
2. Rub hands together covering all surfaces of hands and fingers until dry, about 15 seconds.

Note: Soap and water should be used whenever the hands are visibly dirty or after using the restroom. Soap and water should also be used after touching someone with a gastrointestinal infection like clostridium difficile, norovirus or rotavirus.

Hand sanitizer is a quick, easy way to reduce the number of germs on your hands. Please be sure to use alcohol hand gel or foam that is at least 60% alcohol.

A word about finger nails: please keep them short and do not wear artificial nails. Long nails and artificial nails can attract fungus growth. Nail polish may be worn as long as it is unchipped. Nail polish chips are good germ collection areas.
Avoid crowds
The more people you come into contact with, the greater the opportunity to encounter infections from others, including other patients. For this reason, it is best to minimize social gatherings and visiting places that will have crowds. If it is necessary to go to a social gathering or public location, try to plan your outing and visit for when it will be least crowded. Bring your own hand sanitizer. Avoid being near anyone with obvious infectious symptoms (coughing, sneezing, etc.) Avoid shaking hands and touching items touched by other people (pens, door handles, elevator buttons, shopping cart handles). After touching items touched by other people, clean your hands as soon as possible with hand sanitizer.

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

Plants
Avoid plants. Do not keep fresh flowers and plants in your home. The organisms that may grow in water, dirt, and on plants can cause infections. After the immediate post-transplant period, you may have plants in your home, but you are discouraged from touching them.

Pets
Avoid being around any animals that did not live with you before your transplant. Do not clean up after animals and wash your hands after touching an animal or if an animal touches you. Avoid all contact with birds and reptiles. (They are known to carry salmonella.) Delegate the majority of pet care to other family members or friends. Please do not bring pets to the clinic.

Avoid dusty and moldy areas
Aspergillus is a mold that is widespread in nature, especially in decaying matter, water and soil. In patients with weakened immune systems, Aspergillus can cause infections of the lungs, sinuses or brain. Aspergillus can be found in dust, such as that at construction and remodeling sites

- If you live near construction, keep your windows closed.
- If you use air conditioning, please ensure machines are cleaned regularly according to manufacturer’s instructions.
- Keep your car windows closed when driving past construction sites.
- Avoid being around home remodeling projects
- Housecleaning that will disturb dust and mold—vacuuming, dusting, scrubbing down showers—should be done by other people when you are not around
- Clean your hands after touching items that may be dusty.

Water concerns
Some germs grow especially well in wet, room-temperature or warm areas. Here are some things to avoid:

- Decorative fountains
- Hot tubs
- Swimming pools, lakes, rivers
- Room humidifiers or dehumidifiers (both have reservoirs with standing water where bacteria may grow)
Please see the Water Safety Guidelines section for more information about safe household water use.

**Vaccination of caregivers and family members**
Although no vaccination is completely effective in preventing a disease, vaccinations are the most effective tools available to prevent the following diseases:

- Influenza (“the flu”)
- Varicella (chicken pox) (for those who have not already had chicken pox)
- Measles (for those born after 1957)
- Mumps (for those born after 1957)
- Rubella
- Tetanus
- Diphtheria
- Pertussis (“whooping cough”)
- Pneumococcal

Vaccinated caregivers and family members will be less likely to become infected with the above diseases and expose the patient with a weakened immune system.

**Other health maintenance activities**

**Daily exercise**
Regular exercise is important to your recovery. Physical therapy may be ordered. If you are taking prednisone (steroids), you may need physical therapy to maintain your muscle strength.

**Sun safety**
Use sunscreen with sun protection factor (SPF) 30 when you are outside and apply it to all exposed skin areas. Even if it is not especially sunny out, it is important to protect your skin from the sun’s rays. Your skin is sensitive to the sun for 2 to 3 months after transplant. There is an increased risk of skin cancer after a transplant, so you must continue to use sunscreen for the rest of your life. A GVHD rash appears from sunburn, even from slight overexposure.

**Symptom management**
Review the Managing Care at Home section for more information on symptom management. The Quick Reference Guide in the pocket of this manual should be used for reference. If in doubt, give us a call. Keep your emergency card with you.

**Readmission**
You may need to be readmitted to the hospital for management of symptoms that cannot be safely taken care of in the home setting or the clinic. As soon as you are medically stable, the medical team will work with the transition nurse to have your care returned to the clinic.
Departure evaluation
Before leaving the SCCA clinic to go home, you will have a special series of tests done to detect any chronic graft-versus-host-disease (GVHD). Chronic GVHD usually starts around day 80 after transplant and can be present without causing any obvious problems to you. These screening tests can find early signs of GVHD, so if needed, you can receive treatment before further problems develop. These tests are scheduled around day 80 and take about one week to complete, and about 10 working days for the results to be available:

- Pulmonary function tests
- Skin biopsy
- Final bone marrow aspiration
- Blood tests
- Oral examination

The results of these tests are evaluated by a physician who performs a physical exam and will make recommendations for chronic GVHD as you make the transition to your home.

Departure conference and clinic visit
About 2 weeks after your chronic GVHD workup is done, you and your family will have a summary conference with the attending physician and primary nurse. At this conference, you will receive the results of your day 80 work-up and you will be given recommendations and/or instructions for continued self-care and monitoring at home. You will also have the opportunity to ask any remaining questions about your condition or your return home. You may be offered protocols for your long-term care at home at this conference. Following this conference, you will have one final clinic visit with your attending physician, primary physician or physician’s assistant, and nurse.

Long-term follow-up (LTFU) departure class
After you have left the clinic and you are home, the LTFU staff will be a resource for you and your physician. They are available during business hours to answer questions and concerns. You will be scheduled to attend the LTFU class to learn how to take care of yourself during the coming year.

Discharge papers
Discharge papers consist of a packet of information that we ask you to take with you to give to your referring physician. They contain a summary of all your care and recommendations for your further care. These papers will be given to you during your final clinic visit.

Your transplant team and resources
There are many people helping in your care while you are having a transplant. Together they are your team. **You and your family members are the most important members of the team.** Talk with all of the other members of your team, and feel free to ask questions and share information. Your core team consists of an attending physician, primary physician or physician assistant, nurse, transition services (discharge planning), support staff, and consultants. Additional team members are described below.
**Child Life Program**  
Child Life promotes child development and helps your child maintain normal living patterns. This service helps your child cope with the stresses of illness. The Child Life Specialist uses medical play to explain treatment and procedures in language appropriate to their age and development. Child Life is available to help develop coping skills to care for a sick child.

**Clinical Pharmacist**  
The clinical pharmacist makes recommendations on drug therapy and provides information about medications.

**The Gift Shop**  
Product offerings at The Gift Shop, located on the 1st floor of the clinic, include quality goods and items, convenience sundries, books and newsstand, gift items, hats, scarves, apparel, jewelry, cookbooks, stationery, snacks, and toys and games for all ages. Store hours are Monday through Friday from 8:30 am to 4 pm.

**Guest Services**  
To learn about Seattle and services for patients and families, please speak with our friendly Guest Services Volunteers in the clinic’s main lobby. Volunteers suggest recreational activities, acquaint you with the clinic and surrounding areas, distribute donated tickets for Seattle attractions and special events, provide wheelchair escorts, give directions and call taxis and shuttles. They are available from 8 am to 4 pm Monday through Friday.

**Interpreter Services**  
Interpreters are available for non-English, limited English-speaking, and hard-of-hearing patients and donors during medical consults, consent and department conferences, and during donor screening. Interpreters are present during meetings with your team when you are learning how to manage your care and for getting updates on the progress of your treatment.

**Living Tobacco-Free Services**  
Living Tobacco Free services are available at no charge. If you, caregivers, or family members are thinking about stopping tobacco use you can call and speak with someone directly to discuss quitting, develop a quit plan, and get support during the quitting process. Free nicotine patches, gum, and lozenges are available to those who receive counseling.

**Medical Nutrition Therapy Services**  
The science of nutrition during cancer treatment is a specialized field. A dietitian will help you and your child understand the benefits of good nutrition to stay stronger and feel better during and after cancer treatment. Dietitians will work with your child to minimize side effects from treatment while helping choose foods your child enjoys eating. They also provide education on food safety while your child’s immune system is compromised. A dietitian can provide recommendations based on food preferences and tolerances, interest in food, and specific social, economic, and medical situations. A visit with a dietitian can provide you and your child with inspiration about how to make healthful eating work even while your child is undergoing treatment.
Medical care for family members
The clinic provides medical services to patients only. All other family members who need medical treatment while in Seattle have the following options. You may want to contact your insurance provider to find out which, if any, are covered under your health care plan.

- Go to your local doctor.
- Visit a walk-in, urgent care clinic in Seattle. These clinics are open 7 days a week for walk-ins and appointments. There are several options in Seattle including the following UW clinics.
  - **Urgent care.** You can wait in person, visit uwmedicine.org/services/urgent-care to get a place in line, or call to make an appointment. If you sign up online, you’ll receive a text message when it’s time for you to go to the clinic. For appointments at Seattle urgent care clinics, call:
    - Ballard (206) 789-7777
    - Ravenna (206) 525-7777
  - **Virtual clinic.** Call the UW Medicine Virtual Clinic 24/7 at (855) 520-5250. This costs $35 per call.
  - **Appointment-only clinic.** Belltown: (206) 443-0400. This clinic does not offer urgent care.

Oral Medicine (dental)
The oral medicine service assists with the management of mucositis (sore mouth).

Patient and Family Education
Knowledge is power! You have the right to disease-specific information regarding treatment options, side effects, and maintaining your health after treatment. Ask your nurse for materials such as the transplant manual, chemotherapy cards, or symptom sheets. You can also visit www.seattlecca.org/patient-education to access videos and documents about cancer care and treatment and other helpful information.

Patient and Family Resource Center
The Patient and Family Resource Center is located on the 3rd floor of the clinic. The Resource Center provides educational materials, computer workstations, a business center, notary, and a cancer literature lending library. It also offers wig fittings. Resource Center staff can provide listings for local and clinic events, as well as assistance locating support groups and other resources. All services and materials are free.

Patient Financial Services
Patient Financial Services staff works with you and your insurance company to obtain approval for procedures and maximize your reimbursement for your care. Many insurance companies have managed care or case managers for you and your care team to access during and after treatment. They will need to be notified of new admissions, medical updates, and treatments during your care. Your insurance plan will determine what you are eligible for, including care at the SCCA clinic, SCCA Hospital, and UWMC. They will also authorize payment.

Physical Therapy
Physical therapy plays a significant role in enhancing the quality of your life as you regain a sense of hope and health while you move towards improvement of your physical capacity. Our treatment is highly individualized, and interventions are informed and guided by the available evidence. To schedule physical therapy, you must be referred by a physician, physician assistant, or nurse practitioner.
Psychiatry and Psychology Services
Psychiatry and Psychology Services are available for you if you are experiencing difficulties coping. Specialized medication, coping skills, imagery, and behavioral techniques are some of the many options available for managing stress, depression, anxiety, pain, nausea, eating or sleeping difficulty, or other issues that are common during illness and treatment.

Shine
Shine is located on the 1st floor of SCCA House and provides an engaging assortment of products to serve you and your caregivers. Products include skin care, breast prosthetics, bras, hair alternatives, post-surgical apparel, sexual intimacy aids, compression garments, and light medical supplies. We carry physical therapy recommended products like light weights, exercise balls, heart monitors, and pedometers. Services include a private fitting room area and a head shaving station along with trained, certified, and supportive staff to assist and encourage customers in finding products that best enhance their treatment experience. Appointments are recommended for fittings of custom compression garments and breast prostheses. A shuttle departs from the clinic every 20 minutes for SCCA House. Store hours are Monday through Friday from 10 am to 6 pm, and Saturday from 10 am to 3 pm.

Social Work
Social Work services are available for you and your family. You may request social work assistance by calling the clinic social worker and leaving your name and phone number. The social worker can also be paged by clinic staff and may be able to see you in the clinic that day or will arrange another time to talk with you. Some of the services offered are:

- Information and referral to community resources
- Help with insurance questions and public assistance programs
- Counseling to help with coping with illness and life changes
- Patient and family meetings for short and long-term care planning
- Information on housing and transportation resources
- Advocacy and help with problem solving at any time during your treatment

Spiritual Health
Chaplains provide respectful spiritual and emotional care for people of all faiths and spiritualties, including those who identify as non-religious or non-spiritual. Worship and other services are provided, as well as assistance in locating religious and spiritual resources. Visit the Sanctuary, located on the 1st floor, for quiet prayer, reflection, or meditation.

Supportive and Palliative Care Services
The goal of palliative care is to prevent and relieve suffering and to support the best possible quality of life for you and your family, regardless of the stage of your disease. Palliative care can be delivered along with life-prolonging treatment. Goals include enhancing the quality of your life, helping with decision-making, and providing opportunities for personal growth. Talk to your team and let them know you are interested in seeing the Supportive and Palliative Care Service provider. Appointments can usually be scheduled within one to two weeks.

Volunteer Services
Volunteers provide practical and social support for patients, caregivers, and families in a variety of ways. Following are examples of ways that a volunteer can support you:
• Meet you at the airport when you arrive in Seattle. Provide rides to and from the airport for family members and friends who are your primary caregivers.
• Help you get to know the city, provide transportation for grocery shopping and errands once or twice a week.
• Offer social activities and opportunities to take relaxing breaks, such as going out to lunch, visiting parks, and enjoying movies and sightseeing).
• Offer weekly recreational outings for children and teens.
• Bilingual volunteers assist families who do not speak English, if available.
• Volunteers would like to help make your stay in Seattle as comfortable as possible. However, many volunteers work full-time and are unable to provide daily support.

Information and services
Organizations that offer information and services to people with cancer and their families are listed below. Inclusion on this list does not imply endorsement by SCCA.

Seattle Cancer Care Alliance
www.seattlecca.org
(206) 606-1000

Fred Hutch
www.fredhutch.org
(206) 667-5000

American Cancer Society
www.cancer.org
1(800) 227-2345

Cancer Hope Network
www.cancerhopenetwork.org
1 (800) 552-4366

Cancer Lifeline
www.cancerlifeline.org
(206) 297-2500
or 1 (800) 225-5505

Livestrong Fertility
www.livestrong.org/we-can-help/livestrong-fertility
1 (855) 220-7777

Cancer Pathways (formerly Gilda’s Club)
www.cancerpathways.org
(206) 709-1400

Save My Fertility
www.savemyfertility.org
(312) 503-2504

National Cancer Institute
www.cancer.gov
1 (800) 422-6237
Publications available at the NCI website include:

Facing Forward- Life After Cancer Treatment
When Someone You Love is Being Treated for Cancer
www.cancer.gov/cancertopics/coping/when-someone-you-love-is-treated
Taking Time: Support for People with Cancer
www.cancer.gov/cancertopics/takingtime
Eating Hints: Before, During and After Cancer
www.cancer.gov/cancertopics/coping/eatinghints
Chemotherapy and You: Support for People with Cancer
www.cancer.gov/cancertopics/coping/chemotherapy
Radiation Therapy and You: Support for People with Cancer
www.cancer.gov/cancertopics/coping/radiation-therapy-and-you

Caregiver Action Network (202) 454-3970
www.caregiveraction.org

Stupid Cancer 1 (877) 735-4673
www.stupidcancer.org

Treatment/diagnostic information
National Library of Medicine-Medline 1 (888)-346-3656

Radiology
www.radiologyinfo.org
Interventional Radiology 1 (800) 488-7284
www.SIRweb.org

Appearance
Beauty and Cancer Program (UW Medicine) (206) 598-3604
Look Good Feel Better 1 (800) 395-5665
www.cancer.org/treatment/supportprogramsservices/look-good-feel-better

Fitness/exercise
Team Survivor Northwest (206) 732-8350
www.teamsurvivornw.org

Insurance
America’s Health Insurance Plans 1 (202) 778-3200
www.ahip.org
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<th><strong>LGBT resources</strong></th>
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<th><strong>Prescription drug assistance and issues</strong></th>
<th>1 (800) 503-6897</th>
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<tbody>
<tr>
<td>Needy Meds</td>
<td><a href="http://www.needymeds.org">www.needymeds.org</a></td>
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<tr>
<th><strong>Travelers with disabilities and medical conditions</strong></th>
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<tr>
<td>Transportation Security Administration</td>
<td><a href="http://www.tsa.gov/travel/special-procedures">www.tsa.gov/travel/special-procedures</a></td>
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<tr>
<th><strong>Disease-specific websites</strong></th>
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<tbody>
<tr>
<td>National Bone Marrow Transplant Link</td>
<td>1 (800) 546-5268</td>
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<tr>
<td><a href="http://www.nbmtlink.org">www.nbmtlink.org</a></td>
<td></td>
</tr>
<tr>
<td>Leukemia &amp; Lymphoma Society</td>
<td>1 (800) 955-4572</td>
</tr>
<tr>
<td><a href="http://www.lls.org">www.lls.org</a></td>
<td></td>
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<tr>
<td>Multiple Myeloma Research Foundation</td>
<td>1(203) 229-0464</td>
</tr>
<tr>
<td><a href="http://www.themmr.org">www.themmr.org</a></td>
<td></td>
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<tr>
<td>Aplastic Anemia and Myelodysplastic Syndromes</td>
<td>1 (800) 747-2820</td>
</tr>
<tr>
<td><a href="http://www.aamds.org">www.aamds.org</a></td>
<td></td>
</tr>
<tr>
<td>Myelodysplastic Syndromes Foundation</td>
<td>1 (800) 637-0839</td>
</tr>
<tr>
<td><a href="http://www.mds-foundation.org">www.mds-foundation.org</a></td>
<td></td>
</tr>
<tr>
<td>Sickle Cell Disease Association of America, Inc</td>
<td>1 (800) 421-8453</td>
</tr>
<tr>
<td><a href="http://www.sicklecelldisease.org">www.sicklecelldisease.org</a></td>
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<tr>
<th><strong>Sites for support and networking for youth</strong></th>
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<tbody>
<tr>
<td>Livestrong Young Adults</td>
<td>1 (855) 220-7777</td>
</tr>
<tr>
<td><a href="http://www.livestrong.org/we-can-help/young-adults">www.livestrong.org/we-can-help/young-adults</a></td>
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<th><strong>Survivorship</strong></th>
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<tr>
<td>Livestrong Foundation</td>
<td>1 (855) 220-7777</td>
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<tr>
<td><a href="http://www.livestrong.org">www.livestrong.org</a></td>
<td></td>
</tr>
<tr>
<td>The National Coalition for Cancer Survivorship</td>
<td>1 (877) 622-7937</td>
</tr>
<tr>
<td><a href="http://www.canceradvocacy.org">www.canceradvocacy.org</a></td>
<td></td>
</tr>
<tr>
<td>The National Children’s Cancer Society</td>
<td>(314) 241-1600</td>
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<tr>
<td><a href="http://www.thenccs.org">www.thenccs.org</a></td>
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Diagnostic imaging exams

Type of imaging exam
- CT (computerized tomography)
- PET/CT
- DEXA (dual-energy X-ray absorptiometry)
- Mammogram
- MRI (magnetic resonance imaging)
- MUGA (multi-gated acquisition scan)
- Nuclear medicine bone scan
- Plain X-rays
- Ultrasound

Prior to your exam day

➔ Tell your physician and technologist if there is any chance that you may be pregnant.

• Prior to the day of your exam, please tell your care team if you have an allergy to CT or MR contrast.
• See additional instructions specific to your appointment.
• Check with your care team to see what medications you should or should not take on the day of your imaging exam and any instructions to follow after the test regarding resuming your medications.

At the clinic before your exam

➔ Please arrive 15 minutes prior to your scheduled appointment time to allow for check-in and screening.

• Medical Imaging/Radiology is on the second floor.
• Wear loose-fitting clothing without metal, such as zippers, belts, snaps or buttons.
• Remove all metal objects, such as hairpins, jewelry, eyeglasses, hearing aids, and any removable dental work that may obscure images.
• You may be given a gown to wear during the exam.
• Please turn your cell phones and/or pagers OFF before your exam begins.
Preparing for a CT exam

Food and fluid restrictions

- Do not eat anything for 4 hours before your exam.
- You may continue to drink clear liquids* until your scan.
- Check with your physician or nurse regarding what medications you should or should not take on the day of your imaging procedure.
- CT exams of the abdomen and/or pelvis may require you to drink an oral contrast product during the hour before your scan time.
- If you are given IV contrast, you will be required to remain in the imaging department for at least 30 minutes after the injection of IV contrast.
- If there are concerns about your kidney function, please check with your physician or nurse for special instructions for your exam.
- You may use the restroom any time before your exam unless instructed otherwise.

* Clear liquids are:

- Water
- Clear juices
- Tea
- Black coffee → do not add milk, cream, or sugar
- Clear broth
Preparing for a DEXA exam (dual-energy X-ray absorptiometry)

- Eat normally, but don’t take calcium supplements including TUMS for at least 24 hours before the exam.
- Dress comfortably.
- Wear loose-fitting clothing without metal, such as zippers, belts or snaps & buttons.
- You may be given a gown to wear during the exam.
- Tell your physician and your scheduler if you have recently had a barium exam or have received contrast material for a computed tomography (CT) or radioisotope scan; you may have to wait 7 to 10 days before having a DEXA test.

→ Check with your care team for clarification of these instructions if needed.

→ Tell your physician and X-ray technologist if there is a chance that you may be pregnant.
Preparing for a mammogram

Scheduling

- Schedule your mammogram for the **week after your period, or at least two weeks before** your next period. This is when your breast tissue is less sensitive. If you no longer have periods, any time of the month is fine.
- Before setting a date for a mammogram, talk to your physician about any **new findings or problems** in your breasts. Inform your physician of any past surgeries, hormone use, and family or personal history of breast cancer.
- Tell your physician and technologist if there is any chance you may be **pregnant**.
- **If you have had any prior mammograms**, please have them sent to Breast Imaging. Breast Imaging needs to review previous mammograms 48 hours prior to your exam in order to have them prepared for comparison. Send mammograms to:

  Seattle Cancer Care Alliance  
  825 Eastlake Ave East  
  SCCA Radiology Film Room G2209  
  Seattle, WA 98109

Preparing for the appointment

- **Please arrive 15 minutes before** your scheduled appointment time to allow for check in and screening.
- Please wear a two-piece outfit, as you will be asked to remove all your clothing and jewelry above the waist. You will be given a gown that opens in the front to wear during your exam.

Before your mammogram exam

- Wipe off any deodorant, talcum powder, or lotion under your arms or on your breasts. These can appear on the mammogram as spots. You will be given special wipes at your appointment to cleanse your underarms and breast.
- You will be asked to remove all jewelry and clothing above the waist, and you will be given a gown or loose-fitting material that opens in the front.
- Please turn your cell phones and/or pagers OFF when your exam begins.
- Report any unusual findings, such as a lump, thickening, redness, or swelling, to your physician and the technologist.
- Tell your physician and technologist if there is any chance you may be pregnant.

→ Some women avoid having a mammogram because of anxiety or fear. Remember that having a mammogram is a way for you to stay healthy. The mammogram can catch problems early, which often leads to a complete cure.
MRI screening form
Your physician has ordered an MRI exam for you.

→ Call (206) 606-1434 if you may be pregnant or weigh more than 300 pounds.

→ Review complete “MRI Patient Screening Form” for additional conditions that may affect the exam.
  • In most cases, surgical staples, clips, pins, and screws are not a risk during MRI if they have been in place for more than 4 to 6 weeks. If there is any question of metal fragments in the eye, an X-ray may be done to check for them.
  • To prevent a delay or cancellation of your exam, if you have ANY of the following implanted devices, allergies or may be pregnant (see complete list below) please tell your team coordinator or call 206-606-1434 to review your eligibility for your exam.
    • Pacemaker / defibrillator
    • Cerebral (brain) aneurysm clip*
    • Cochlear implant*
    • Cardiac stents*
    • Implanted or external drug pump (including chemotherapy)
    • Breast tissue expander
    • If pregnant, # of weeks:_______
    • Dialysis or renal failure
    • Allergy to CT contrast or gadolinium
    • Drug or contrast allergies

Please bring the wallet card that identifies the implanted devices.
Preparing for nuclear medicine bone scan or MUGA exam

- Increase your fluid intake before and after the injection. Try to drink 3 to 4 glasses of your preferred drink after the injection. Empty your bladder frequently.
- There are no eating or drinking restrictions.
- If you are unable to remain still for 45 minutes, please speak with your referring physician for pre-medication.
- You will be given a document that states the period of time during which the small amounts of radiation remaining in your body are capable of detection by radiation monitoring equipment. This amount of radiation poses no danger to the public and is allowed by the State of Washington medical use regulations.

→ Women who are pregnant or breast feeding should not have this exam.
Preparing for an ultrasound exam

- If the abdomen will be studied, you must not eat or drink anything for at least 8 hours before your exam.
- Medications may be taken with a small amount of water.
- For pelvic exams, you must drink at least 16 ounces of water before the exam to fill your bladder. Do not go to the bathroom until instructed by the technologist.

→ If you are diabetic, check with your physician or nurse about dietary and medication restrictions.
Participating in research

Clinical missions
In choosing to come to SCCA, you directly benefit 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
Seattle Children’s:
- The principal investigator of your study
- Institutional Review Board: (206) 987-2023
- Children’s general counsel: (206) 987-204
Chapter 2 – Finding Your Way
Treatment at SCCA
Care and treatment is provided in the clinic when possible. This allows you to stay in the comfort of your home.

Your local phone number
We must have your local phone number so we can reach you when needed. The receptionist keeps a current list of local phone numbers to reach patients and family members. Please keep the receptionist informed of your current local phone number and address.

The mail system
Your mail is sorted by the receptionist and kept behind the reception desk on the 6th Floor. Please ask the receptionist to check your mailbox for appointments and messages every day you receive care in the clinic.

Appointments
Your schedule and your donor’s schedule will be coordinated by your team coordinator. Your team coordinator will meet with you to go over the details of the schedule. He or she will keep you informed of all changes and additions to your schedule. Please check in with the receptionist in the waiting area for all clinic appointments. You or a family member must check your mailbox every time you are in the clinic, so you do not miss any appointments.

Chest X-rays
You may be scheduled for a routine chest X-ray in the Radiology department on the 2nd floor of the clinic. Chest X-rays will be scheduled for you as needed.

Radiology
If you are scheduled for certain procedures such as a magnetic resonance, computed tomography or an ultrasound, you will need to go to the 2nd floor of the clinic.

Apheresis unit
The Apheresis unit is in the clinic on the 5th floor where procedures such as stem cell collection and red blood cell depletion are done.

Pharmacy
The Transition Services staff will confirm sources of oral and IV medications. The pharmacy is located on the 5th floor of the clinic and is open from 8 am to 8 pm, Monday through Friday, and 8:30 am to 5 pm on Saturday and Sunday. New medication orders can be picked up anytime the pharmacy is open. All refills must be called in 48 hours before the day that you need your refill medications.

Resources and announcements for families
Notice of clinic activities will be put in your mailbox and posted in key spots throughout the clinic. Family member activity schedules will be communicated via the mailbox system. Other activity information and tickets for special events can be obtained from the Guest Services information desk located on the 1st floor of the clinic.
Release of medical information
Clinic medical information can be obtained from SCCA Health Information Management. You will be asked to sign an authorization form to release your personal health information. There is no charge for records released to you or your physician.

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

- Runny or stuffy nose
- Post nasal drip
- Shortness of breath
- Cough
- Wheezing or chest tightness
- Sore throat
- Sneezing
- Watery eyes
- Ear pain
- Fever
- Diarrhea, nausea or vomiting
- New rash

Please contact your care team if you have any family members, friends or caregivers (who are in regular physical contact with you) who have any of the above symptoms. Even if it is thought that the symptoms are only related to allergies, please contact your team. All respiratory virus infections begin with symptoms that are like allergy symptoms. It is possible to have allergies and a respiratory virus infection at the same time. Your care team will give you further instructions about how to manage the situation. Please remember that a respiratory virus infection with mild symptoms in a person with a healthy immune system can become a more serious infection if passed to a person with a weakened immune system.

Service dogs, therapy dogs, and pets
Healthcare facilities and other places that serve the public must allow people with disabilities to be accompanied by their service dogs. At SCCA, service dogs can accompany handlers in all areas of the clinic, except for in rooms where invasive procedures and imaging take place.

A service dog is a dog that is individually trained for the purpose of assisting or accompanying a disabled person’s sensory, mental, or physical disability. The special training service dogs receive is more than obedience training or positive reinforcements that are given to family pets.

A therapy dog is trained to provide affection and comfort to people. A therapy dog’s primary job is to allow people (who may or may not have disabilities) to make physical contact with it and enjoy that contact. Service dog handlers are protected under the ADA because of the disability the handler experiences. Although the emotional benefits of therapy dogs are significant, physical contact to the dog by many individuals in an infection concern in cancer centers that serve large numbers of patients with severely weakened immune systems. This is one of the reasons why the SCCA does not allow therapy dogs, other therapy animals, or pets. Please do not bring therapy dogs, therapy animals or pets to SCCA.
**Fresh flowers and plants**
Fresh or dried flowers and plants are not allowed in the clinic because of the organisms that grow on them and in their dirt or water, which can cause infections. Latex free balloons and silk flowers are okay. Make sure there is not decorative moss around silk flowers. Only artificial moss is allowed.

**Non-smoking environment**
Smoking is not acceptable at the clinic. People who smoke must leave SCCA’s campus to smoke. Washington law prohibits smoking within 25 feet of all entrances, exits, windows, and ventilation system of public places. Contact the Living Tobacco Free program to sign up for smoking cessation or call the Washington State Quit Line at 1-800-784-8669 (1-800-QUIT NOW) for free treatment or referral to other resources.

**Guest wireless internet access guide**
Seattle Cancer Care Alliance offers free W-Fi to our patients and visitors. For your convenience, connectivity is available throughout the clinic, including in patient rooms and visitor waiting areas. To connect to the Wi-Fi network, follow these steps:

- Enable the wireless feature on your device.
- Connect to the “SCCA-Guest” network.
- Once you are connected, open your web browser. Upon your first attempt to navigate to a website, you will be redirected to the Acceptable Use policy logon Page. You must read and accept the policy, by clicking “I Accept” at the bottom of the page. After accepting the policy, your browser will automatically load the Seattle Cancer Care Alliance homepage.
- You can now browse the web normally.

**SCCA secure email**
To ensure the confidentiality of personal health information that SCCA sends you via email and to comply with Health Insurance Portability and Accountability Act of 1996 (HIPAA) regulations, an email encryption service is used. Encrypted emails, also called secure email or secure messages, help keep your personal health information private. This secure email site requires some extra steps, but we are confident it will allow us to communicate with you safely and efficiently by email. Each email sent will include brief instructions on how to access the secure email site. For more information, please visit the secure email page on our website at www.seattlecca.org/scca-secure-email.cfm.
Inpatient treatment

Inpatient admission
You may be hospitalized during your transplant. 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 BMT-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.

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

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<tr>
<th>Phone number</th>
<th>Dial</th>
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<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>
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<tr>
<td>Or dial “6190” and ask the hospital operator to connect you</td>
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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.

**SCCA Hospital and UWMC 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. The nurse will look at your mouth daily and more often when you are likely to experience mucositis, an inflammation of the mouth.

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

**Chest X-rays**
Chest X-rays are done weekly to check your lungs.
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.

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 of 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 chicken pox 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 because of the risk of theft.
Using the family room
All who use the family room must help to keep it clean. Please 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 each patient’s fluid intake and output. Therefore, never empty a urinal, bedpan, or emesis basin.

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

Release of medical information
Inpatient health record information can be obtained from Health Information Management at UWMC. There is no charge to send copies to your physician.
Chapter 3 – Managing Care at Home

“There are only four kinds of people in this world:
Those who have been caregivers
Those who are currently caregivers
Those who will be caregivers
Those who will need caregivers”
-Quote from Rosalynn Carter’s colleague

Rosalynn Carter’s book Helping Yourself Help Others begins with the above quote. Education and support have been developed to meet the needs of you and your caregivers. Education offerings include weekly group classes, videos, individualized instruction, and written materials. Support is offered by team members including nursing, social work, and spiritual health. Please review the next two sections for details of caregiving.
Suggestions for coping with care at home

- Ask questions. If you are not sure, call using the important phone numbers provided.
- Remember that you are a member of the team, and your input is important. Keep your nurse and physician informed.
- Review the symptom sheets provided and call for help if needed.
- Review hints for self-care.
- Ask your family and friends for help before you are too fatigued. Keep a list of what friends can do, and delegate. For example, one person could drive you to an appointment, another could make a meal, and another could go to the grocery store. Some people have more time than others; this is where your list would be helpful.
- Organize your day into manageable segments. Develop a schedule each day/week with the caregiver who is providing the care. This process allows family members or friends to be in agreement with the goals for the day or week. If everyone is working with the same agenda in mind, the tension within a family usually decreases.
- Remember, the staff at SCCA is here to support you as well. Tell your care team, including your social workers, if you need more support.
- Use websites to keep family and friends informed: www.caringbridge.com or www.carepages.com

Outline of typical caregiver responsibilities

Making arrangements:
- Transportation
- Financial
- Tracking appointments

Giving emotional support:
- Being physically present
- Giving encouragement

Providing physical care:
- Identifying changes in patient’s condition
- Reporting patient’s symptoms to healthcare staff
- Obtaining medical care if needed
- Monitoring patient compliance in self administration of oral medications
- Recording medications taken/administered
- Acquiring and maintaining medical supplies
- Performing tasks such as central line care
- Administering fluids and medications using an intravenous pump

Maintaining the home environment:
- Cleaning
- Food preparation
- Shopping
Patient advocacy:
- Gathering information and assuring that pertinent information is given to medical staff
- Helping with decision-making

Providing assistance/support to others:
- Serving as a communication link with other family members or friends
- Imparting information to children
- Providing child care

Taking care of the caregiver
Caregivers are encouraged to take care of themselves through exercise, proper diet, and adequate sleep. Caregivers can benefit from breaks. You may be at risk to become ill if you do not take care of yourself.

Here are some helpful tips from Rosalynn Carter’s book, Helping Yourself Help Others:
- Listen to your friends. Be open to others’ observations.
- Let go. Know your limits.
- Focus on your loved ones’ strengths.
- Learn relaxation techniques.
- Take care of your health.
- Maintain a life outside your caregiving role.
- Insist on private time.
- Build a caregiving team.
- Rely on your sense of humor.
- Appreciate the benefits of leisure time.
- Help your loved one find a support group.
- Seek professional help.
- Appreciate your own efforts.
- Seek spiritual renewal.

Develop a plan of care
The nursing staff will work with you to develop a unique home care plan. You have a nurse available 24 hours a day to answer questions. You may utilize multiple family members and friends during different stages of transplant. You and your caregiver need to develop a schedule and division of tasks that is satisfactory to both of you. You can participate in self-care, as long as you feel well enough to do so. You both can learn to operate the ambulatory pump. When a different person (including the patient) takes over line care, they should review the steps with a nurse.

The home care plan should meet safety needs. The following recommendations give an idea of the different levels of caregiving needed throughout the transplant and recovery process. Each patient and family organizes their routines different. Some patients and families like to keep a logbook of activities, infusions, and medications. Please see the examples of a home care schedule at the end of the manual.
Recommendations for caregiver support

We hope these recommendations will assist families in anticipating the need for caregiver support. Needs change throughout the transplant process.

Inpatient phase: Patients do not require caregivers but do appreciate and benefit from emotional support from family and friends.

Clinic phases and support levels: Caregivers are very important in providing care when the patient is ambulatory.

- **Consistent support:** Caregiver is present most of the time; breaks should be less than three-four hours. Adult patients, but not children, can be left alone if they have access to the phone, the ability to contact emergency services, operate ambulatory pumps, get to the restroom, and have access to food and fluids. **Criteria for recommending a consistent caregiver for the patient are:**
  - During conditioning (including Dilantin administration), chemotherapy, and radiation therapy
  - First 1 to 2 weeks in the SCCA clinic after initial discharge after transplant
  - Three different IV infusions such as hydration, medications, or parenteral nutrition (PN or TPN) over a 24-hour period
  - Neutropenia (ANC < 500)
  - Altered mental status: drowsy, confused, impaired judgment, poor memory
  - Weakness/limited mobility (cannot walk without assistance)
  - Sliding scale insulin (when starting therapy)

- **Intermittent support:** Does not need a caregiver for most hours within a 24-hour period. A caregiver is available 2-3 times per day to provide assistance with dressing changes, medications, transportation, and processing information provided during conferences or clinic visits.

- **Minimal support:** Patients do not require a caregiver but do benefit from emotional support during clinic visits and conferences.

Patient and caregiver education

Patient and caregiver education is an integral part of treatment and services offered. Informational, educational, and support services are available to patients, family members, and caregivers. You have the right to information regarding health status, disease, treatment options, the treatment process, managing and monitoring health in the home setting, and maintaining health after treatment. The education program has three major components:

- Individual teaching
- Classes
- Videos (online at youtube.com/c/SCCAPatientEducation)

Individual teaching is offered on topics such as care of the central line, medications, blood glucose monitoring, and specific needs that may arise during the treatment and recovery process. Educational classes focus on gaining an understanding about the treatment process and developing the skills needed for the patient’s treatment, and recovery in the home setting.
Class descriptions
Classes are scheduled by the clinical support staff. A personalized list of appointments and scheduled classes is placed in your patient mailbox.

Managing care at home and review of transplant process
This class includes an overview of the bone marrow/stem cell transplant process, review of the patient/caregiver role and resources and how to prevent infection. Content of this class includes managing symptoms (mucositis, dehydration, diarrhea, bleeding, and breathing problems) and adjusting to recovery at home. We will also discuss what to expect at different phases of your transplant.

Food safety class
The content of this lecture and discussion class includes the rationale for food safety, foods to omit, safe food selection, proper food handling techniques including cooking, preparation, and storage.

Long-term recovery class
Information on how to manage care after leaving the SCCA is presented. Content includes immune system recovery, assessing symptoms, treatment of graft-versus-host disease, guidelines for daily living and coping with the common psychological reactions after transplant.

Guidelines for preventing infection
What is an infection?
Infections are caused by germs, which are also called microorganisms or microbes. Germs cause illness by entering the body and multiplying. Typical germs that can infect transplant patients are bacteria, viruses, and fungus (molds and yeast).

During your transplant, your immune system will be weak, so you will be at a higher risk for getting infections. Infections in people who are receiving a transplant can be more serious than in those people who are otherwise healthy. It is critical to limit exposures to that might increase your risk for acquiring an infection, and to seek help when you do develop infectious symptoms. While it is not possible to prevent all infections, there are a number of simple steps that you and your family/caregiver can take to help prevent many common infections. While this section cannot cover all scenarios or possible situations, it includes basic information on how to prevent infections during your transplant.

Clean your hands often
Cleaning your hands is one of the best ways to prevent infections. Hand hygiene is key, especially during the first year after your transplant and/or while taking immunosuppressive medicines (medicine that weakens your immune system).

You and anyone you come into contact with, including all members of your household, your physicians, and nurses, should clean their hands frequently. Do not be afraid to ask if visitors or any healthcare staff if they cleaned their hands before they meet with you.
There are two options for cleaning your hands. Standard washing with soap and water is a great way to clean your hands. Alcohol hand sanitizer (hand gel such as Purell®) is another good way to reduce the number of germs on your hands. For home use, be sure to select a hand sanitizer that contains at least 60% alcohol. Hand sanitizers are not as effective when hands are visibly dirty or greasy. Also, keep in mind that these hand sanitizers do not prevent some gastrointestinal infections, such as C. diff and norovirus. Persons with these infections and their caregivers should wash their hands with soap and water instead.

Keep your nails short. Germs like to hide under fingernails. Avoid the use of artificial nails.

At the SCCA clinic, Seattle Children’s, SCCA Hospital, and UWMC, hand sanitizer is located in elevator lobbies, waiting rooms, and exam rooms. Please use hand gel frequently.

When should you clean your hands?
It is important to clean your hands frequently throughout the day, particularly when you are in public places (the clinic, restaurants, shopping, common areas/waiting rooms, etc.). Some specific times that are important to make sure you clean your hands:

• Before eating
• Before and after preparing food
• After touching pets or animals
• After sneezing, coughing, or blowing your nose
• After going outdoors
• Before and after any central venous catheter care or intravenous infusions
• Before taking oral medicines
• Before entering and leaving an exam room
• Before entering and leaving the clinic building
• Before and after getting on a shuttle

How to wash your hands with soap and water
It may sound a bit funny, but washing your hands properly is important. Read through the steps and practice them. Make this process a habit.

• Wet your hands with warm water and apply soap.
• Lather your hands by rubbing them together with the soap. Be sure to lather the backs of your hands, between your fingers, and under your nails.
• Scrub your hands for 15 to 20 seconds—about the time it takes to hum the “Happy Birthday” song from beginning to end twice.
• Rinse your hands with water.
• Dry your hands with a clean or disposable towel or air dryer.
• If possible, use a towel to turn off the faucet.

How to apply hand sanitizer (hand gel)

• Apply one to two pumps of hand sanitizer to the palm of one hand.
• Rub your hands together.
• Rub the product over all surfaces of your hands and fingers until your hands are dry. Make sure you get the product between your fingers and on the back of your hands.
Cleaning
At least once a week and as needed, clean the kitchen and bathroom with a bleach solution. Make the solution daily with 1-part bleach to 10 parts water. The solution needs to be made daily to make sure that the bleach solution is effective. You can also buy a pre-made bleach solution, such as “Clean-Up Cleaner with Bleach” spray made by Clorox®. Key kitchen areas to clean are:
- 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

Personal hygiene
Personal hygiene is necessary to help prevent infection. You may shower or bathe daily, as long as you don’t submerge your central venous catheter under water. Details on central line care are provided later in this manual. Cover your line as instructed. Daily cleansing with soap and water is the first line of defense against bacteria on the skin.

Ill family members
You should not be in the same home as an ill family member.

Dental care
To prevent infection, daily oral (mouth) care is needed. Keep your mouth clean by brushing your teeth twice each day with toothpaste. Ask your physician or nurse if it’s okay to gently floss your teeth. Tell them if your gums bleed or if you have new sores in your mouth. Your physician or nurse may give you a special mouthwash to help clean your mouth. Most patients who are going through a transplant see a dental specialist; ask them any questions you have about your dental hardware (dentures, bridges, retainers) or issues you have with oral care.

Safe eating
Both how you prepare your food and what you eat play a role in keeping you healthy. Your physician and dietitian may recommend a special diet to follow depending on your situation. You might need more protein or calories, or you might need to avoid certain foods. Follow that diet and these other tips to prevent infections:
- Do not share cups, glasses, or eating utensils with other people.
- Cook food thoroughly. Leftovers should be stored in small containers and refrigerated within 2 hours of cooking. Reheat leftovers thoroughly.
- Keep food at its proper temperature. Keep hot foods hot and cold foods cold.
- Avoid salad bars, buffets, deli counters, and food in bulk bins (if not cooked).
- Follow recommendations and check the guidelines for dietary restrictions.
- Ask your nutritionist questions if you don’t know if something you are eating is safe.
- Keep foods fresh and buy in small amounts to avoid spoilage and mold contamination if possible.
- Do not eat or drink foods that are beyond their expiration date.
Prevent infections by avoiding high risk activities

- Avoid activities such as gardening, raking, mowing, farming, or direct contact with soil and plants. These activities create plant or soil aerosols which increases exposure to fungi and bacteria. Potted plants should be avoided. You should avoid working in green houses or managing plants at home. Ask friends and visitors to avoid bringing fresh flowers and potted plants as gifts following your transplant.

- **You cannot have plants or flowers in your home.**

- Avoid close contact with people who have respiratory illnesses (cough, cold, etc.). Be especially careful around school-aged children and those that attend daycare, since they are often exposed to other children who are ill.

- You should not be in the same home as someone with a respiratory virus.

- Avoid crowded areas where you are unable to control the distance between you and others, such as at movie theaters or sporting events.

- Avoid construction sites, including homes or buildings that are being repaired or remodeled. These dusty environments increase your exposure to molds.

- 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.

- 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 will disturb dust and mold, causing it to be stirred up in the air (such as vacuum cleaning, dusting, and scrubbing down showers). If cleaning needs to be done, it is best to clean when you are not in the home; use a wet washcloths or wipes as they capture dust. Do not use feather dusters. Once you have the energy, it is not harmful to iron, wash clothes, dry clothes, and wash dishes.

- Avoid the use of a room humidifier due to bacteria that live in water.

- If you like to use air conditioners (AC) and fans during warm weather, they should be cared for properly as they can bring dust and mold into your home. Regular inspection and cleaning of the AC unit is critical. AC Filters should be changed regularly per manufacturer recommendations.

- Avoid swimming in recreational water such as ponds, swimming pools, lakes, whirlpools, and hot tubs.

- Avoid:
  - Changing a baby’s diaper.
  - Touching bird droppings.
  - Cleaning a fish tank.
  - Emptying and cleaning litter boxes.
  - Cleaning up after pets.

- You may feel “safer” wearing a mask when you are outside, but you are not required to wear a mask when you go out. This is a personal choice. If you choose to wear a mask, you should still avoid situations as described above, which might increase your risk of infection.

Prevent infections spread from animals

Wash your hands immediately after petting your animals. It is not necessary to part with your pets. You should delegate the majority of pet care to other family members or friends. It is important to minimize direct contact with animals, especially animals that are ill, and avoid getting any new pets during your transplant. Do not sleep with pets.
If you have a cat, do not place the litter box in kitchens, dining rooms, or other areas where food preparation and eating occur. Have someone else handle the daily litter box cleaning during the first year after transplant and when you are taking immunosuppressive medicines to reduce your risk of acquiring toxoplasmosis, a parasitic disease. Keep your cats inside and do not adopt or handle stray cats.

It is recommended to avoid contact with reptiles (turtles, snakes, lizards), ducklings, or chicks to prevent exposure to a bacterium called Salmonella. If you have other pets, please discuss this with your team.

**Vaccinations**

It is beneficial for family members and household contacts to be vaccinated to prevent exposure to vaccine-preventable diseases. Recommended vaccines help to prevent important diseases such influenza (flu), pertussis (whooping cough), measles, mumps, rubella, chicken pox, tetanus, diphtheria, and pneumococcal. Have your family members, caregivers and close contacts see their physicians to make sure they are up to date on all the recommended adult vaccines. Children should also be up to date on all childhood vaccines.

Some vaccines, such as MMR (measles, mumps, and rubella), varicella (chicken pox), and shingles (Zostavax®) vaccines, are live virus vaccines. It is often safe for persons in your household to receive these but make sure you discuss the timing of these vaccinations for your family members with your team. Some of these live vaccines pose a very small risk of household transmission, so if a family or household member develops a rash after receiving the chicken pox or shingles vaccine; notify your physician or nurse.

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

Recent outbreaks of pertussis have been seen throughout the US, including Washington State. Due to the risk of pertussis (also known as whooping cough) in transplant patients, make sure that your family, caregivers and visitors check with their physician to see if they are up to date on this vaccine (also known as Tdap - tetanus/diphtheria/acellular pertussis).

Be sure to notify your team if you have been exposed to an infection, if your caregiver or family member is ill, or if they have recently been diagnosed with an infection.

**How does the clinic work to prevent infections?**

Infection prevention is a very high priority at the clinic and a cornerstone of preventing major post-transplant complications. All infections cannot be avoided, but here are some of the steps taken to ensure that you receive care in a safe environment:

- All staff cleans their hands while performing patient care. If you would like to confirm that the staff caring for you has cleaned their hands, we encourage you to ask them. Staff know that we all need to work together to prevent infections. By asking, you are helping us maintain a high standard of care.

- In the clinic, isolation precautions are used as a way of stopping the spread of germs from one person to another. You may be placed on isolation if you have an infection that can be transmitted or harmful
to other people. If you are in isolation, staff will take extra precautions to ensure that those germs do not spread. Staff may place you in an exam room right away, clean their hands more often, and wear protective equipment, like gowns, gloves, and masks. If you are in isolation, make sure to remind staff when you arrive at clinic or are admitted to the hospital.

- We take cold and flu season very seriously. When you check-in for your clinic appointments, at certain times of the year you and your family/caregiver may be asked if you have cold or flu symptoms like a cough or runny nose. If you do not have symptoms of cold or flu, you will be given a sticker to wear that indicates that you have been screened. If you have symptoms, you will be given a mask to wear and you will be placed in isolation to prevent the spread of cold and flu viruses.

- You may notice patients wearing masks. Patients with cold and flu symptoms are encouraged to wear a mask while walking through the clinic. This helps to prevent the spread of cold and flu viruses.

- If you have cold or flu symptoms, it is especially important that you avoid riding any of the shuttles. Even if you think it may be only allergies, let your team know and your nurse will give you taxicab vouchers to use until your cold and flu symptoms go away.

- The flu vaccine is provided in the clinic at no charge to caregivers and household members of transplant patients. Information about flu vaccine clinics are posted starting in October each year.

References
Preventing Infections in Cancer Patients. Centers for Disease Control and Prevention (CDC).
www.cdc.gov/cancer/preventinfections

What are the risks of a blood and marrow stem cell transplant? National Heart Lung and Blood Institute
https://www.nhlbi.nih.gov/node/3548

Anemia

Just the facts
Red blood cells carry oxygen to the tissues of the body. Hemoglobin and hematocrit are the tests used to evaluate the red blood cell count. When these measures are low, your body tissues do not get enough oxygen to do their work. If red blood cells are low, this condition is called anemia.

Your goals
- Recognize symptoms early.
- Get professional help when needed.

Important signs and symptoms
Report symptoms to a physician or nurse during clinic hours today.
- Dizziness.
- Shortness of breath.
- Unusually tired or weak.
- Pounding in your head or ringing in your ears.

What you can do at home
- Get plenty of sleep.
- Save your energy by resting between short periods of activity.
- To avoid getting dizzy, move slowly when getting up from a lying position. Sit up for several minutes before standing.

Information adapted from: Pharmacia and Upjohn Company
Anxiety

Just the facts
It is very common for a person to feel anxious when facing a new or stressful situation. We all feel worried at times in our day-to-day lives. You may experience anxiety as nervousness, tension, panic, fear, or feeling like something bad is going to happen. Anxiety can also be experienced as physical symptoms such as upset stomach, sweaty palms, fast heartbeat, shaking or flushed face.

Although it is normal to feel anxious when facing a life-threatening illness and intensive treatment, there are things that may help decrease the feelings of anxiety. The goal is to reduce anxiety, not eliminate all anxiety.

Your goals
• Learn how to cope with anxiety.
• Get professional help when needed.

Important signs and symptoms
Report symptoms to a physician or nurse during clinic hours today.
• Feelings of dread and apprehension for several days.
• Physical symptoms such as sweaty palms, shaking, rapid heartbeat, etc. Keep in mind that these symptoms can be side effects of treatment.
• Wide mood swings that you cannot control.

What you can do at home
Learn how to cope with anxiety.
• Recognize that anxiety during treatment is normal and so is getting help for it.
• Try to understand what thoughts are triggering the anxiety. For example, if you are anxious about a medical procedure, ask yourself what it is about the procedure that is upsetting. Staff may be able to assist and help you find ways to cope with your anxiety.
• Getting the facts can help. For example, if you are worried about pain or discomfort, there is information available on how to manage symptoms and side effects.
• Thinking about doing things that are pleasant and relaxing can help reduce anxiety. Relaxation is a skill that can be used to counteract anxiety.

Get professional help when needed
If anxiety doesn’t improve despite your efforts to reduce it, discuss it with your physician, nurse or social worker.
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.
Body image changes

Just the facts
Treatment can affect your body and your life in ways that may be hard on your self-esteem. Weight loss or gain, loss of stamina, skin reactions, and puffy face—all of these can be distressing if you think of your body as being who you are. Fortunately, most of the side effects of therapy, which affect appearance and stamina, are temporary.

The first step in coping with body changes is to direct your energy and thoughts toward what you can and will do for yourself. Paying attention to skin care, diet, exercise, and positive attitudes are healthy ways to cope with body image changes. Finding ways to express your feelings about the changes is very important.

Your goals
- Maintain a confident and positive self-image.
- Take care of skin.
- Build stamina with exercise.
- Wear attractive and comfortable clothing.
- Get professional help if needed.

Important signs and symptoms
Report symptoms to a physician or nurse during clinic hours today.
- Feeling very sad most of the day, very angry, or losing interest in life because of body changes.
- Not taking care of self (not exercising, dressing, or caring for skin).

What you can do at home
- Maintain a confident and positive self-image.
- Express your feelings to trusted family members, friends, physician, nurse, or social worker.
- Talk with other people who have had similar treatment about what they did and how they coped with changes in body image.
- List your best points, and then list your options on how you would like to try to maintain a good body image.
- Laugh! Humor is a fine way to cope. Treat yourself to funny movies, TV shows, books, or even people.

Consider using a hair alternative
- Buy or borrow a wig. The Patient and Family Resource Center on the 3rd floor of SCCA offers wig fitting appointments and wig resources. Most offices of the American Cancer Society can tell you how to obtain or borrow a wig. Many of them have a “wig bank.”
- Use a headwrap. Making headwraps out of scarves is easy. A headwrap can complement your looks. The emphasis should be on color and texture rather than on complicated tying techniques.
- The book Beauty and Cancer by Diane Doan Noyes and Peggy Mellody, gives instructions on headwraps, skin care, makeup, clothing, nutrition, and exercise.
- Try turbans, scarves, hats, or caps. Head coverings protect against drafts, enhance appearance, and help retain body heat.
- Visit or call the Resource Center to schedule a wig fitting.
Wear attractive and comfortable clothing
- Wear colorful clothing. Chemotherapy and radiation tend to make skin pale, sallow or ruddy. Colors and interesting patterns can decrease the intensity of skin changes.
- If your face becomes very round or puffy, wear a “V” shaped neckline.
- If you have lost a lot of weight, try a round or oval neckline.
- Avoid any garment that might puncture or break the central intravenous line such as front clasping underwire bras or pins. Soft fabrics drape best over catheters.

Take care of skin
- Select skin care products that you like and are inexpensive, fragrance-free, hypoallergenic and alcohol-free.
- Cleanse skin twice a day. Mild soap and water is the most basic cleanser, especially good for oily skin. Cleansing creams are good for dry and normal skin because of their moisturizing effect. All cleansing products should be applied gently to avoid pulling the delicate surface of your skin. Use caution to avoid bruising the skin.
- Use a moisturizer to help skin retain its moisture. Avoid hot water.
- Wear sunscreen or protective clothing when outside.
- Report any skin changes such as rash or inflammation to the physician or nurse.

Build stamina with exercise
- Exercise daily. Exercise is one of the simplest and most effective ways to reduce stress, increase stamina, and impart a feeling of well-being.
- Begin slowly with low intensity exercise, such as walking. Your body will tell you what your limits are. A good rule of thumb is you should never be out of breath. You should be able to talk while exercising.

Get professional help
- Talk with your physician, nurse, or social worker for a referral to a counselor.
Breathing problems

Just the facts
Difficulty breathing may occur during your treatment. Symptoms include shortness of breath, wheezing, and cough. A number of things can cause breathing problems: infection in the lungs, fluid in the lungs, or bleeding. The most common cause is infection. Do everything you can to prevent irritation and infection in the lungs. Exercise and breathing clean air helps the lungs function optimally.

Your goals
- Keep your lungs healthy.
- Call for professional help when needed.

Emergency signs and symptoms
Call 911 immediately if you are:
- Unable to breathe.
- Choking/not able to move air.

Urgent signs and symptoms
Call the clinic or the after-hours clinic now if:
- Trouble breathing/shortness of breath.
- Gets “winded” more easily with normal activity
- Feeling as if you can’t get enough air.
- Troubled breathing when lying flat.
- Wheezing with breaths.
- New or recurrent cough.
- Uncontrollable or continuous cough.
- Tightness or wheezing with each breath.
- Coughing blood or green/yellow sputum.

Important signs and symptoms
Report symptoms to a physician or nurse during clinic hours today:
- New or recurrent cough.
- Gets “winded” more easily with minimal activity.

What you can do at home
Keep lungs healthy:
- Do not smoke or be around smoke.
- Exercise daily. This helps expand the lungs and improves oxygen exchange and blood flow.
- Sitting in an upright position allows the lungs expand and exchange oxygen better. For example, during the day, sitting is better than lying flat. Standing up and moving really let the lungs expand.
- Avoid wearing any clothing that restricts breathing.
- Avoid contact with any person who has signs of respiratory infection (cold, fever, sneezing, runny nose, etc.).

Call for professional help when needed
Call for help right away when you have a problem with breathing. The sooner treatment can be started, the more likely the treatment will work.
Change and uncertainty

Just the facts
The treatment process is one filled with changes and uncertainty. When will this be done or how can I plan ahead? Answers to these questions are difficult because each patient responds differently to treatment. Complications are hard to predict. You can learn to adapt by taking it day by day.

Your goals
- Adapt to change.
- Cope with uncertainty.

Important signs and symptoms
Report symptoms to a physician or nurse during clinic hours today:
- Having feelings of dread and apprehension for several days.
- Physical symptoms such as sweaty palms, shaking, rapid heartbeat, and so on. Keep in mind that these symptoms can also be caused by side effects of treatment.
- Wide mood swings that you cannot control.

What you can do at home
Adapt to change:
- Identify the change that is taking place and any options you have.
- Discuss these changes with family and staff.
- Ask staff for explanations.
- Keep track of questions and information in a notebook.

Cope with uncertainty
- When planning for the future, limit the time span as much as possible.
- If plans need to be made, consider alternative plans.
- Talk about your hopes and disappointments with someone who listens.
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 physician or nurse.

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

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

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

Ask your physician or nurse if you need a laxative.
Dehydration

Just the facts
Dehydration means there is not enough fluid in your body. It occurs when there is not enough fluid intake. The body does not function well without enough fluid. Excessive loss of fluid can result from diarrhea, vomiting, fevers and sweating. Dehydration can cause complications such as increased weakness, dizziness, rapid heartbeat, and confusion.

Your goals
- Fluid intake.
- Call for professional help when needed.

Urgent signs and symptoms
Call the clinic or the after-hours clinic immediately if your child is:
- Dizzy or lightheaded.
- Fainting.
- Confused.

Important signs and symptoms
Report symptoms to a physician or nurse during clinic hours today.
- Decreased urination, dark urine, strong smelling urine.
- Increased weakness.
- Decrease in eating and drinking.
- New or increased vomiting.

What you can do at home
- Drink fluids as recommended by your team.
- Call your team if you detect early signs of dehydration; you may be able to correct the problem by drinking more.
- Limit caffeinated beverages such as: coffee, cola, diet cola, hot or iced tea, and hot chocolate.
- Check with your dietitian or nurse for goals or restrictions.

Get professional help when needed
- Monitor for signs of dehydration such as decreased amounts of urine and dark urine.
- Report symptoms to the physician or nurse promptly.
Depression

Just the facts
Dealing with a life-threatening illness causes a roller coaster of emotions. Most patients experience feelings such as helplessness, despair, and sadness during treatment. Symptoms of depression can also include loss of appetite, changes in sleep patterns, lack of energy, and inability to focus. If you have had symptoms of depression or have been on anti-depressants before in your life, be sure to inform the physician, nurse, or social worker.

Your goals
- Acknowledge that it is normal to have feelings of sadness at times.
- Allow yourself to feel sad at times.
- Identify when you need help with depression.

Important signs and symptoms
Report symptoms to a physician or nurse during clinic hours today.
- Feeling sad most of the time for several days.
- Feelings interfere with your ability to care for yourself.
- You have thoughts about hurting yourself.
- Mood swings that you cannot control.

What you can do at home
- Allow yourself to feel sad at times.
- Talk about these feelings with someone who listens (family member, volunteer).
- Talk with other patients in your situation (ambulatory support groups, phone contact, Internet).
- Use spiritual resources.

Get professional help when needed
Psychiatrist and psychologists can provide:
- Evaluation of cause of depression (sometimes medications can cause depression).
- Medication to manage depression.
- Counseling.

Ask your physician, nurse, or social worker for a referral.
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 physician 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).
- Follow dietary recommendations. Note any food allergies or intolerances and discuss with the physician, nurse or dietitian.
- Prevent infection and irritation.
- Wash hands often with soap and warm water.
- Keep anal area clean with mild soap and water.
- Do not use ointment or creams on the anal area unless directed by the nurse/physician.
- 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.
Exercise and blood value precautions

Platelets are important for blood clotting. Your platelet count must be greater than 20,000 to do any type of strenuous cardiovascular exercise (power walking, running, cycling, dancing, etc.) or strength training with weights (cuff weights, dumbbells, machines, and elastic tubing). If your platelet count is consistently below 100,000, you need to check your blood counts prior to exercise to know whether or not you can do strength training and/or cardiovascular exercise. If your platelet count is less than 20,000, you may have an increased risk of bleeding with certain types of exercise that could become serious and even life threatening.

• **Platelet count 50,000 to 100,000**: cardiovascular exercise and strength training with weights are allowed. If you have any signs of bleeding (i.e. from the nose), you should **not** exercise, and you must notify your physician or care team, even if your platelets are in this range.

• **Platelet count 20,000 to 49,999**: strength training with weights and cardiovascular exercise are ok if you have no signs of bleeding, but both must be performed without strain, such as holding your breath. Strain during any type of exercise can spike your blood pressure and increase your risk for a stroke or major bleed. Massage at platelet counts below 50,000 should be discussed on a case-by-case basis with your physician. Gentle comfort massage is allowed, if the skin is not fragile or prone to easy bruising for other reasons (such as chronic steroid medications) but deep tissue massage is **not** allowed.

• **Platelet count 10,000 to 19,999**: strength training without weights (machines, dumbbells, or elastic tubing) or strain, and cardiovascular exercise without strain, are both ok when you are steady on your feet and have no sign of bleeding.

• **Platelet count less than 10,000**: **NO** strength training or cardiovascular exercise until your platelet count is in a safe range for exercise. Walking around your room, to the bathroom, and with assistance from a caregiver are **OK** as long as you are steady on your feet and have no sign of bleeding.

**Hematocrit (Hct)/hemoglobin (Hgb)** are lab values that reflect the level of red blood cells within your blood. Red blood cells carry oxygen around to your tissues. If your red cell number and oxygen-carrying capacity (Hct and Hgb) are too low and you exercise anyway, you are diverting needed oxygen from your vital organs to your muscles, which may cause micro-damage to your organs. When your Hct or Hgb are too low, you are not allowed to perform strength training or cardiovascular exercise until you’ve had a red blood cell transfusion and we are sure that your red cell numbers have improved to the safe range. It’s always difficult to anticipate how much a transfusion will increase the level of Hct and Hgb – a follow-up blood count is the only way to know for sure.

⇒ If your hematocrit is less than 25% or your hemoglobin is less than 8.0, consultation with your medical provider or a physical therapist is necessary to determine safe exercise options.
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. 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. 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.
- 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 physician 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 the patient has 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 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>
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</thead>
<tbody>
<tr>
<td>96.8</td>
<td>36.0</td>
<td>6.8 to 99.2°F (36.0 to 37.3°C)</td>
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<tr>
<td>97.8</td>
<td>36.6</td>
<td>This is the normal temperature range. Call for chills or shaking chills.</td>
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<tr>
<td>98.0</td>
<td>36.7</td>
<td>98.0 to 98.2°F (36.7 to 37.2°C)</td>
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<td>98.2</td>
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<td>98.4</td>
<td>36.9</td>
<td>98.4°F to 99.4°F (36.9 to 37.3°C)</td>
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<td>98.6</td>
<td>37.0</td>
<td>98.6°F to 99.6°F (37.0 to 37.3°C)</td>
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<td>98.8</td>
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<td>99.0</td>
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Hand-foot syndrome

Just the facts
Hand-foot syndrome (HFS) is a side effect, which can be caused by certain chemotherapy drugs. HFS symptoms may be caused by the breakdown of chemicals that are used in chemotherapy. HFS is a skin reaction which often affects hands and feet, although it can also affect other areas where there is increased pressure or warmth (like the buttocks, groin, armpits or under the breasts).

Your goals
- Avoid tight fitting shoes or gloves.
- Control skin irritations with moisturizers and avoid activities that can make HFS worse.
- Call for professional help when needed, especially if pain becomes a problem.

Important signs and symptoms
Report symptoms to a physician or nurse during clinic hours today:
- Palms or soles of the feet are red or tender.
- Skin of palms and soles peeling.
- Numbness, burning, or tingling sensation.

What you can do at home
Prevent dryness and irritation:
- Before treatment, a pedicure is suggested if you have preexisting buildup of hard skin and calluses on your feet.
- Frequently apply ample moisturizer to hands and feet, especially in the creases. Recommended moisturizers include: Bag Balm®, Udderly Smooth Cream®, Lanolin® creams (unless allergic to wool), Aveeno® cream, Eucerin® cream, and Lubriderm®.
- Avoid heat. Bathe or shower in lukewarm water. Soak hands/feet in basins of cold water for 15 minutes 3 to 4 times per day when possible. Take cool baths and put gel ice packs on affected areas.
- Avoid activities that cause irritation due to even slight rubbing or pressure on the skin. For example, vigorous washing, gripping tools, typing, driving, or playing musical instruments. Do not apply any adhesives or dressings, such as Band-Aids, since adhesive will irritate skin further.
- Sit or lie on padded surfaces of chairs or mattresses. Raise legs whenever possible with cushions.
- Place a pillow between knees or wear pajamas if rubbing of legs occur during sleep.
- Avoid any unnecessary and vigorous exercise.
- Wear loose fitting clothing and shoes with comfortable soles. Do not walk barefoot.

Alleviate symptoms if they start
- Place palms or bottoms of feet on an ice pack or a bag of frozen peas to provide temporary relief from pain and tenderness. Alternate on and off for 15-20 minutes at a time. (May use gel insoles that can be cooled before insertion in shoes).
- Apply moisturizing cream of choice AFTER the area has been cooled for maximum comfort.
- If your physician suggests a steroid cream, apply it after the skin has been cooled and apply emollients over the top of the steroid cream for maximum effectiveness.
- If blistering and ulceration starts, apply gentle moisturizers on your hands and feet and contact your physician or nurse, who may suggest further therapies.
• Talk with your nurse about how to change your activities of daily living (bathing, dressing, etc.) if the HFS is severe.
• Contact your physician regarding other over the counter or prescription options to relieve symptoms of hand-foot syndrome.
Memory and concentration

Just the facts
Changes in memory and concentration are common throughout treatment. The changes may be temporary. Your memory and concentration may improve as your treatment is completed and when you start feeling better. Many factors effect memory.

Memory and concentration problems may be situational and vary from day to day due to stress, pain, medications, menopause, anxiety, aging, depression, and fatigue. Since you may have good and bad days, you may want to use routine strategies to assist you when you are having a bad day. It can be a frustrating and taxing problem.

Your goals
• Learn how to cope with changes in memory and concentration.
• Get professional help when needed. Neuropsychologists evaluate memory.
• Ask your physician to make sure that your medications are not causing the problem.

Urgent signs and symptoms
Call the clinic or the after-hours clinic now if:
• Disoriented
• Confused

Important signs and symptoms
Report symptoms to a physician or nurse during clinic hours today:
• Forgetting things more quickly and more often than usual.
• Harder to read more than a paragraph or a page at a time.
• Hard to keep your mind from wandering.

What you can do at home
Learn how to cope with changes in memory and concentration:
• Write down important information. Keep these notes on a notepad that is small enough to keep with you at all times.
• Establish consistent daily routines.
• Have regular sleep time and eat nutritious snacks and meals.
• Manage your stress.
• Keep distractions to a minimum.
• Ask people to repeat things.
• Keep a list of questions for your physician. Write the answers down.
• Tape record important conversations or conferences.
• Get important information in writing. Ask people to write it down for you.
• Place notes around the house to remind you of things.
• Keep an appointment calendar and one central memory book.
• Use a device to remind you to take your medications such as a watch or cell phone timer that can be programmed to go off at times when medications need to be taken.
• Keep things in a designated place, (for example: always keep your keys in the same place).
• Be understanding and patient with yourself and know that these temporary changes are to be expected.
• Ask your physician to review your medications.

**How can I keep my mind active?**
Below is a list of resources you might want to utilize to enhance your cognitive abilities. Although age takes its toll on most everyone in this area, there are things you can do to regain some of your mental plasticity and prevent any further decline in your cognitive faculties.

- **Puzzle Books:** Crossword puzzles are known to improve mental skills.
- **Sudoku:** Similar to a cross word puzzle, but with numbers instead.
- **Card Games:**
  - Start with a shuffled deck of cards and a stopwatch. Sort the cards into separate piles, one for each suit (diamonds, clubs, spades, hearts). Do this three times daily. A typical young adult can do this in 35 seconds. Keep practicing this task until you can do it in that amount of time!
  - Play and learn other card games such as Bridge, Rummy, Pinochle, Canasta, Cribbage, Black Jack, or Solitaire.
- **Games:** Play stimulating games such as Chess, Checkers, Scrabble, and any other games you enjoy. If you or your child has a Nintendo®, you can get Brain Age, a game developed by neuroscience researchers to improve mental abilities and hand/eye coordination.
- **Hobbies:** Learn a new skill such as knitting or crocheting, or a new sport. Try writing and brushing your teeth with the opposite hand than you usually do.
- **Conversation:** Enjoy a cup of coffee with a friend and discuss world events.
- **Languages:** Learn a new language. Rosetta Stone has CDs that you can purchase in various languages.
- **Read Books:** Join a book club or attend a book reading. A couple of suggestions include:
  - *The Better Brain Book* by David Perlmutter and Carol Colman
  - *Whole Brain Thinking* by Jacquelyn Wonder and Priscilla Donovan
  - *Carved in Sand* by Cathryn Jakobson Ramin (the story of her struggle with early onset memory loss).
- **Website Suggestion:** [www.positscience.com/](http://www.positscience.com/) is a website where you can try out a couple of the exercises from their Brain Fitness Program. This program has been used to help veterans with traumatic brain injuries recover some of their capabilities.

**Get professional help when needed**
If problems persist or affect day-to-day living to a large degree, discuss the symptoms with your physician or nurse. Ask your physician or nurse about a neuropsychological referral and neuro-rehabilitation treatment.
Mucositis (inflammation of mucous membranes)

Just the facts
Mucositis and mouth pain are common physical problems for chemotherapy and radiation patients. Chemotherapy and radiation lead to inflammation of cells of the tongue, lips, mouth, throat and gastrointestinal tract. Saliva usually becomes thicker and more mucous-like. Mouth sores or bleeding in the mouth may occur also. The experience varies from mild discomfort to severe pain, which makes eating, drinking and sleeping difficult.

Your ability to fight infection is temporarily reduced by the therapy (chemotherapy and/or radiation). The inflamed mouth is a possible site of infection. Swelling may make it hard to swallow. If swelling is severe it may become hard to breathe.

Your goals
Call for professional help when needed.
- Prevent infection.
- Control pain.
- Maintain nutrition and fluid intake.

Emergency signs and symptoms
Call 911 immediately if:
- Not breathing
- Severe difficulty breathing.

Urgent signs and symptoms
Call the clinic now if:
- Having difficulty breathing.
- Bright red in the mouth.
- Pain not controlled by medication.
- White patches or sores appear on gums or mouth.
- Difficulty swallowing food or fluid.

Important signs and symptoms
Report symptoms to a physician or nurse during clinic hours today.
- White patches or sores appear on gums or mouth.
- Start to have difficulty eating or drinking.
- Increased sensitivity to foods or significant dryness.

What you can do at home
Prevent infection and irritation:
- Rinse mouth often with salt-water solution every 1 to 2 hours. Recipe: 1 quart water, ½ to ¾ level teaspoon salt. If the salt solution causes stinging or burning this may be relieved by diluting it or adding 1-2 teaspoons of baking soda. Rinsing with salt/soda solutions may also help reduce thickened secretions and should be done before eating, drinking or taking medications by mouth.
- Spit secretions out often and especially before eating, drinking or taking medications by mouth.
• Brush teeth twice a day with a very soft bristle toothbrush as long as you are able. If it becomes too painful or significant bleeding occurs, a child’s toothbrush or toothettes (sponge brushes) can be substituted. Resume using your normal toothbrush as soon as possible as it is more effective at keeping the bacteria under control and causes less trauma.

• Continue to floss daily as long as it is comfortable, and no significant bleeding occurs.

• Avoid using commercial mouthwashes. Many contain alcohol or peroxide, which can dry and irritate your gums and the tissue in your mouth.

Control pain:

• Topical anesthetics such as Lidocaine viscous gel can be used to help control pain. They can be used as a rinse or applied directly to localized areas of soreness. These are prescribed by the physician. They are jelly-like liquids which numb the mouth. These gels can be used full strength or diluted 1:1 or 1:2 if they cause stinging or burning. Fill a small container such as a medicine cup with the solution. Take a small amount (5 to 10 ml) and swish and hold the solution in the mouth for 15 to 30 seconds. Repeat sequence until you have used the entire volume of the cup. Repeat as often as needed. Do not swallow the solution. For single or small areas, try applying the gel with a cotton tip applicator or gauze square once for 15 to 30 seconds then reapply in 30 to 60 second intervals for a total of 3 to 5 minutes. Use the gel at least 15 minutes before or after eating. When used right, the medicine may provide 30 to 45 minutes of pain relief.

• Take pain medication as instructed.

• Tell the physician or nurse if pain medication does not seem to be controlling your pain.

• For chapped lips apply lanolin creams, Chapstick® or Blistex® and lip balms which contain lanolin.

• Place ice packs on painful areas such as cheeks, lips or throat for 10 to 15 minutes every 2 hours.

• Avoid pretzels, chips, tomato juice, and orange juice or hot drinks.

• All oral rinses can be kept in the refrigerator or placed in an ice bath. This can be soothing, help to reduce swelling or control bleeding.

Maintain adequate nutrition and fluid intake:

• Warm fluids: soups, chicken or vegetable broth, tea.

• Cool fluids: smoothies, shakes, iced tea, diluted juices.
Nausea and vomiting

Just the facts
Many patients experience nausea and vomiting at some time during the treatment process. It is one of the side effects of the chemotherapy and radiation. Contrary to what most people think, nausea and vomiting have little to do with your stomach. They are actions controlled by certain centers in your brain and are involuntary. Willpower alone cannot stop nausea and vomiting.

A number of things can trigger nausea and vomiting:
- Chemotherapy agents.
- Radiation.
- Persistent pain.
- Poor kidney and liver function.
- Medications such as some narcotics.
- Infections of the gastrointestinal tract.
- Electrolyte disturbances.
- Graft-versus-host disease.

Thankfully, just as medicine has advanced against cancer, great progress has been made in preventing and treating nausea and vomiting. Some patients have little or no nausea and vomiting and keep eating during most of the treatment process. Anti-nausea (antiemetic) medications are often started before radiation and chemotherapy and then continued on a regular schedule. Even if you do not feel nauseated, you should take the medicine. The fact that you have not vomited means that the medicine is working. Many antiemetics can make you feel tired or sleepy. Some people will feel jittery and restless.

Your goals
- Take anti-nausea medicines.
- Maintain nutrition and fluid intake.
- Call for professional help when needed.

Urgent signs and symptoms
Call the clinic or the after-hours clinic now if:
- Having uncontrolled (constant) nausea and vomiting.
- Blood or “coffee ground” appearing material in the vomit.
- Medicine not kept down because of vomiting.
- Weakness or dizziness, along with nausea/vomiting.
- Severe stomach pain while vomiting.

Important signs and symptoms
Report symptoms to a physician or nurse during clinic hours today if:
- Nausea persists without control from anti-nausea medications.
- Projectile vomiting.
What you can do at home
Prevent nausea and vomiting or manage symptoms well:
  • Take your anti-nausea medicine as instructed before nausea starts.
  • Before chemotherapy, lie down in a quiet place for 15-20 minutes and relax.
  • Wear loose fitting clothes.
  • Use distraction, relaxation, or deep-breathing techniques such as tapes, visualization, or hypnosis techniques. Try breathing through your mouth.
  • Keep your mouth clean. Rinse with water often.
  • Rest in a chair after eating, keeping head elevated.

Take anti-nausea medications
  • Some anti-nausea medicines can cause drowsiness or sleepiness. Do not drive a car or operate any dangerous equipment while you are taking them.
  • Do not drink alcohol while taking anti-nausea medicines.
  • Because anti-nausea medicines can make you drowsy, it is advisable to have your caregiver stay with you throughout this treatment period.

Maintain nutrition and fluid intake
  • Eat small meals during the day so your stomach is not too full.
  • Eat and drink slowly so only small amounts enter your stomach at one time.
  • Avoid eating and drinking one hour before and one hour after chemotherapy.
  • Stay away from sweet, fatty, or fried foods.
  • Drink cool, clear fruit juices.
  • Eat dry foods like toast or crackers to help ease nausea.
  • Avoid odors that bother you. If food smells make you sick, avoid being in the kitchen when food is being prepared.
  • Avoid food served at extreme temperatures.
  • Keep a wide choice of food available.

Call for professional help when needed
  • If you notice that the anti-nausea medicine does not seem to control your nausea, call your physician or nurse. Additional medications may be used to better control your nausea.
  • If the medicines seem to make you nervous, jittery, or cause any unusual sensations, let your physician or nurse know.
  • Do not increase the amount of medicine you take without checking with the physician, nurse, or pharmacist.
  • Do not take any over-the-counter medicines without checking first with your physician or nurse.
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 oncologist and nurse 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 can easily be managed by changing your medication or adding other treatments.

Patient rights and responsibilities
As a patient of the 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.

Assessment of 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, 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**
• 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 medicine.)

**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/opioids, ask your nurse or physician about ways to prevent constipation.
Peripheral neuropathy

Just the facts
Peripheral neuropathy is damage to nerves that can span from your fingers to your toes. Peripheral means nerves beyond the brain and spinal cord. Peripheral nerves take information to the muscles, organs, skin, and joints and then take information back to the brain. “Neuro” means nerves. “Pathy” means abnormal. When this occurs, it can cause pain and numbness, or a sensation that is similar to burning or tingling. In many cases symptoms improve with time. There are many different causes. Some chemotherapy medications can cause this problem. Other causes include: traumatic injury, medical illnesses such as diabetes, infectious conditions, and toxic compounds.

Your goals
- Monitor onset of symptoms.
- Protect your hands and feet.
- Get professional help when needed.

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

Urgent signs and symptoms
Call the clinic or the after-hours clinic now if:
- You are unable to move your legs.
- You have fallen.

Important signs and symptoms
Report symptoms to a physician or nurse during clinic hours today.
- Change in sensation symptoms: numbness, tingling, tremor, burning, loss of sensation, gait imbalance (unstable walking), sensitivity to touch, weakness, tiredness and heaviness.
- Movement symptoms: lack of muscle control, falling, muscle twitching, cramping, foot drop, and muscle atrophy.
- Autonomic symptoms: failure of the nerves to work correctly can result in abnormal blood pressure and digestive problems such as nausea, blurred vision, and dizziness.
- You can meet with a physical therapist if you are having problems with your balance. Ask your team to schedule you for a physical therapy appointment. Home equipment and/or devices to help you walk independently may be recommended for you if you have mobility problems. Discuss with your physician, nurse, and physical therapist safety measures you should put in place.
- Avoid extreme temperatures. Peripheral neuropathy may make areas of your body more sensitive to hot or cold.
- Wear shoes, slippers, gloves, and other clothing to protect your skin from changes.
- Use extra care when using hot, sharp, or potentially harmful objects. You may be more at risk for clumsiness and prone to injury if you have reduced sensations.
- Avoid falls. Review the Fall Prevention symptom sheet in this manual. If you have sensation changes, you are more at risk for falls.
- Check your feet every day, looking carefully at the bottom of your feet and toes for any changes.
For lack of sensation in your hands:
  • Check temperatures with your inner forearms to avoid burns.
  • Always use protective padding for cooking and rubber gloves for cleaning.
  • Keep finger nails short to avoid tearing.
  • Keep hands moisturized to avoid skin breaks from dryness.

Coping with peripheral neuropathy
  • Your physician will try to determine the source of the problem. Ask your physician questions.
  • Let your team know how much the neuropathy impacts your life. There are techniques for coping with pain and discomfort. In many cases, symptoms improve with time.

Websites
www.neuropathy.org
Sexual health

Just the facts
Treatments such as chemotherapy, surgery and/or radiation may cause changes that can affect intimacy and sexuality, including desire and body image. We want to be sure you’re prepared for the physical and emotional changes that you may experience during this time. We encourage you to:

- Discuss any restrictions and questions with your care team.
- Keep an open mind about the possibility of needing to adjust to physical and emotional sexual changes that occur; communicate openly with your partner(s).
- Have a pleasurable experience (free from pain or risk).
- Prevent infection.

PREGNANCY AND CHEMOTHERAPY
Chemotherapy can have harmful effects on pregnancy. If there is a chance you could become pregnant or father a child while undergoing chemotherapy or radiation, talk to your care team about birth control.

If you are sexually active, it is important to prevent infection and pregnancy.

Talk to your care team if you experience:
- Pain, discomfort, or bleeding during or after sex
- Fear about sexual activity
- Lack of desire that is affecting your relationship
- **Women**: vaginal dryness, discharge, pelvic pain, or menopausal symptoms such as hot flushes or loss of menstrual cycle
- **Men**: pain during penetration or ejaculation, abnormal discharge, changes in your ability to get erections or ejaculate

What you can do at home

Optimize positive feelings of intimacy:
- Plan sexual activity for the time of day when you are feeling your best. If you are taking pain medication, take it at an hour when it will be in full effect during sex.
- Talk about expectations and what might feel good, or what to avoid.
- Consider other forms of intimacy—holding hands, snuggling, kissing, self-stimulation and talking can happen at any stage of cancer treatment.
- Find a position or activity that puts as little pressure as possible on the sensitive or painful areas of your body.
- Let your partner know if any kinds of touching causes irritation or pain.
- Use a sexual lubricant to help dry skin areas be slippery.
Prevent infection:
- Wash hands and genitals before and after any type of sexual activity.
- Use a water-based lubricant to keep the vagina or rectum from becoming irritated.
- If you have anal sex, use condoms and a water-based lubricant to help prevent infection and tissue irritation.
- Avoid sexual contact with people who have infectious diseases (colds, flu, cold sores) or sexually transmitted infections.
- If you are not in an exclusive relationship, use a condom or other barrier protection during sexual activity to reduce the risk of infection. This includes oral, anal, and vaginal sex.
- Urinate before and after sex. This rinses out bacteria that may cause infection in the urinary tract.

Common questions about sex during chemotherapy

Is it safe for me to kiss while I’m receiving chemotherapy or after treatment?
To reduce the risk of infection, avoid kissing anyone who has open mouth sores, cold sores, a cold, the flu, or symptoms of a respiratory infection.

When do I need to avoid sexual activity?
- When platelet counts are less than 50,000. This is due to the risk for bleeding.
- When white blood counts are low. Neutrophil (ANC) count should be more than 500 to prevent infection with most sexual activity. An ANC of 1000 or more is needed for anal sex.
- If there is vaginal or rectal bleeding, sores in the mouth, vagina, or rectum.
- When a sexual partner has infectious diseases (colds, flu, cold sores) or sexually transmitted infections.
- Depending on your treatment, traces of chemotherapy may be present in your body fluids during treatment and for a short period of time after. Your care team may recommend that you avoid sexual activity or use safety precautions (condom or other barrier protection) during this time. Contact your care team with questions.

Why don’t I have much sexual desire?
- Lack of desire (also called lack of libido) and fatigue can be a normal response to the stresses of treatment, some medications, and changes in hormone levels.
- Talking to your partner or a counselor may help, and sometimes hormone replacement can be helpful. Talk to your care team so they can help you find what will work for you.

Will I be infertile after treatment?
- Factors that influence fertility include: type and dose of chemotherapy, radiation, and other medications; if you have had a transplant; and, your age at time of treatment.
- Women often stop having periods but resume their menstrual cycle after treatment; some women resume normal menstrual cycles but are still unable to become pregnant due to damage to eggs in the ovary; still, other women may experience complete menopause.
- Men often stop making sperm completely or have very low sperm counts during and for several months after cancer treatment. Not every male will resume normal sperm production and may be infertile.
- Testing of sex hormones, sperm counts, or ovarian function is needed to see if your fertility is intact.
- If you’re interested in preserving fertility, talk with your care team before treatment. This gives you the opportunity to store sperm, eggs, or embryos when appropriate.
Will I be infertile after treatment? (continued)

- A fertility specialist (reproductive endocrinologist) can provide more information about your fertility status and the options available to you before and after treatment.
- Fertility services are not always covered by insurance, but financial assistance may be available. Don’t let fear of cost prevent you from asking what services are possible.

What options do I have to store my eggs or sperm?

- **For men,** sperm banking is the standard approach. Sperm can be collected several different ways, but the simplest is to provide a sample of ejaculated semen. Sperm can be safely frozen for many years.

- **For women,** the standard approach is to collect eggs, which can require hormone therapy and a medical procedure. This process can take up to 2 weeks. Eggs can be frozen individually or fertilized with sperm to create embryos before freezing. Eggs and embryos can be safely frozen for many years.
Sexual health resources

Brochures and books
SCCA’s Patient and Family Resource Center on the 3rd floor of the clinic offers brochures and books that you can check-out. Some titles we suggest include:

- Katz, Anne. **This Should Not Be Happening: Young Adults with Cancer.** First Edition. Pittsburgh, Pennsylvania: Hygeia Media, an imprint of the Oncology Nursing Society, 2014

Websites
Please visit [https://www.seattlecca.org/emotional-and-spiritual-support/medical-support-services/sexuality-resources](https://www.seattlecca.org/emotional-and-spiritual-support/medical-support-services/sexuality-resources) for a list of resources. You can also visit the following websites:

**American Cancer Society**
[www.cancer.org](http://www.cancer.org)

**LIVESTRONG**
[www.livestrong.org/we-can-help/livestrong-fertility](http://www.livestrong.org/we-can-help/livestrong-fertility)

**Look Good Feel Better**
[www.lookgoodfeelbetter.org](http://www.lookgoodfeelbetter.org)

**Save My Fertility & The Oncofertility Consortium**
[www.oncofertility.northwestern.edu/](http://www.oncofertility.northwestern.edu/)
Fertility resources before and after treatment

**University of Washington Reproductive Care**
(206) 598-4225
[www.uwmedicine.org/locations/reproductive-care-uwmc-roosevelt](http://www.uwmedicine.org/locations/reproductive-care-uwmc-roosevelt)

**University of Washington Sperm Cryopreservation Program**
(877) 520-5000

Products
SCCA’s oncology store, Shine, has trained staff to help you identify which products are most appropriate for you. Feel free to call (206) 606-7560 for an appointment and consultation or visit the website at [www.sccashine.org](http://www.sccashine.org).
Sleep problems

Just the facts
People undergoing cancer treatment may experience changes in normal sleep patterns for a number of reasons including: response to medications, discomfort, alteration in normal activity patterns hospital stays and emotional distress. Problems with sleep are associated with fatigue. Up to 50% of patients with cancer have sleep problems.

Your goals
- Prevent insomnia.
- Call for professional help when needed.

Emergency signs and symptoms
Call 911 immediately if patient is unconscious.

Urgent signs and symptoms
Call the clinic or the after-hours number now if you:
- Have not slept in days.

What you can do at home
Promote sleep:
- Keep a regular schedule.
- Create a bedtime routine. Use a preferred relaxation technique such as reading or taking a warm bath or shower.
- Back rubs or massages may be relaxing.
- Avoid alcohol, caffeine, and nicotine before bed.
- Maintain a healthy diet.
- Decrease negative associations with bed time. Do not stay in bed when not sleeping. Do not lie in bed while worrying.
- Do not exercise right before bedtime.
- Avoid electronic devices before sleep such as television and computer.
- Use the bed for sleep and sex only.
- Create a peaceful environment in which to sleep by decreasing noise, dimming lights, adjusting room temperature, and keeping bedding and pillows clean, dry, and wrinkle-free.
- Try not to drink fluid before bed and empty bowel and bladder before bedtime.
- Minimize daytime naps.
- Listen to relaxation tapes and or peaceful music before bed.

Call for professional help when needed
- If you are not sleeping.
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
Overview of medications

Cyclosporine
Cyclosporine is an immune-suppressing drug used to treat or prevent graft versus-host disease (GVHD) in bone marrow transplant patients.

- Cyclosporine comes in 25 mg and 100 mg capsules, and liquid for oral use. It also comes as an IV preparation.
- The concentration of cyclosporine liquid is 100 mg/milliliter (ml). You will be told how many milliliters make up your cyclosporine dose. For example, 250 mg of cyclosporine = 2.5 ml. Know your dose and ask the nurse or pharmacist to show you how to find the dosage mark on the measuring device. It is important to take the correct amount of the drug.
- Blood levels of cyclosporine will be checked at least weekly to make sure that your dose is correct. The goal is to maintain a level that is effective without causing toxicities.
- Cyclosporine can damage kidney function. A high fluid intake helps to flush your kidneys and keep them functioning normally. The level of creatinine in your blood is a measure of kidney function. It increases if kidney function decreases.

Fluid requirements increase while taking cyclosporine.
Goal: _____ cups/day (_____ ml/day)
Your dietitian can provide this information.

Cyclosporine causes magnesium loss from your body. You will probably need to receive magnesium in your intravenous fluid or parenteral nutrition (PN)*. As you are able to eat and drink, your physician will prescribe magnesium pills to be taken several times each day. Magnesium pills cause your bowel movements to become slightly loose or soft. If you develop diarrhea, tell your physician, nurse or dietitian. Most people taking cyclosporine cannot get enough magnesium from food alone; thus, a supplement is still needed. You can get magnesium from these foods:

**Excellent sources:**
- Bran cereals
- Nuts
- Beet greens
- Tofu

**Good sources:**
- Dried apricots
- Brown rice
- Dates
- Soybeans
- Shrimp

*PN is parenteral nutrition, a form of nutritional support given intravenously.

Dose preparation

1. Always wash your hands with warm, soapy water before and after preparing cyclosporine liquid doses.
2. Clean up any drops or spills to protect your family from getting the drug on their skin and to prevent oily stains on clothing or furniture.
3. Measure your cyclosporine liquid dose:
   - A measuring device is provided by the manufacturer. Follow the manufacturer’s instructions for measuring the cyclosporine.
   - Squirt the cyclosporine into the desired diluting liquid. Stir well and drink at once. It is best to use a glass container and rinse it with more liquid to ensure the total dose is taken.
• After use, dry the syringe with a clean paper towel or tissue and replace it in the clear case. To avoid cloudiness, do not rinse the syringe with water or other cleaning agents. If the syringe requires cleaning, it must be completely dry before using it again.

**Cyclosporine blood levels**

On the day you are to have blood levels measured, do not take your morning cyclosporine dose until after the blood draw. Bring the cyclosporine with you to the clinic if you do not plan to return home after blood draw. Your nurse will inform you of your cyclosporine blood draw day.

**Beverage and food recommendations**

- Most people prefer to take the **liquid** format of cyclosporine with a flavored beverage.
- **Oral** cyclosporine should **not** be taken with beverages containing enzyme bergamottin such as grapefruit or grapefruit hybrids such as tangelos or honeybell oranges, Sunny Delight®, Fresca®, Squirt®, or Earl Grey tea.

Please consult your dietitian, pharmacist, or nurse if you have questions about taking oral cyclosporine with other fruit juices or beverages.

**It is good to eat breakfast or a small snack before taking your morning dose of oral cyclosporine.** Some people find that taking cyclosporine by mouth on an empty stomach can result in nausea. If you have eaten dinner within 2 to 3 hours, you may not need to eat again right before taking your evening cyclosporine dose. If cyclosporine continues to cause nausea, talk with your nurse, physician, or dietitian.

**Storage**

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

**Refills**

- Call the SCCA Pharmacy when your supply of cyclosporine gets low. Allow 24 hours for refills.
- Once you are discharged for home, cyclosporine will be prescribed by your local physician. It can be obtained from your local pharmacy. Plan ahead with your physician and pharmacist. Do not wait until you are completely out of medicine to get a refill.

**IV cyclosporine**

- **Rate:** As prescribed. Cyclosporine can cause burning in hands and feet. If this occurs, call the Transplant clinic at (206) 606-7600 or the after-hours clinic at: Adult (206) 598-8902; Pediatric (206) 987-2032
- Cyclosporine must be infused in the white port only. **Do not infuse** in the blood draw side of your central line.
- Keep IV cyclosporine in the refrigerator.
Tacrolimus

- Tacrolimus is an immune-suppressing drug used to treat or prevent graft versus-host disease (GVHD) in bone marrow/stem cell transplant patients.
- Tacrolimus comes in 0.5mg, 1mg, and 5mg capsules for oral use. It also comes as an IV preparation and a liquid form made by the pharmacy.
- Blood levels of tacrolimus will be checked at least weekly to make sure that your dose is correct. The goal is to maintain a level that is effective without being toxic.
- Tacrolimus can damage kidney function. A high fluid intake helps to flush your kidneys and keep them functioning normally. The level of creatinine in your blood is a measure of kidney function. It increases if kidney function decreases.
- **Fluid requirements increase while taking Tacrolimus.** Goal: __cups/day (__ mL/day). Your dietitian can provide this information,
- **Tacrolimus causes magnesium loss from your body.** You will probably need to receive magnesium in your intravenous fluids. As you are able to eat and drink, your physician will prescribe magnesium pills to be taken several times each day. Magnesium pills cause your bowel movements to become slightly loose or soft. If you develop diarrhea, tell your care team. Most people taking tacrolimus cannot get enough magnesium from food alone, thus a supplement is still needed. You can get magnesium from these foods:

  **Excellent sources:**
  - Bran cereals
  - Nuts
  - Beet greens
  - Tofu

  **Good sources:**
  - Dried apricots
  - Brown rice
  - Dates
  - Soybeans
  - Shrimp

**Tacrolimus blood levels**

On the day you are to have blood levels measured, do not take your morning tacrolimus dose until after the blood draw. Bring the tacrolimus with you to the clinic if you do not plan to return home after blood draw. Your nurse will inform you of your tacrolimus blood draw day.

**Beverage and food recommendations**

Oral tacrolimus should **not** be taken with beverages containing the enzyme bergamottin, such as grapefruit or grapefruit hybrids. This includes tangelos or honeybell oranges, Sunny Delight®, Fresca®, Squirt®, or Earl Grey tea. Please consult your dietitian, pharmacist, or nurse if you have questions about taking oral tacrolimus with other fruit juices or beverages.

**It is good to eat breakfast or a small snack before taking your morning dose of oral tacrolimus.** Some people find that taking tacrolimus by mouth on an empty stomach can result in nausea. If you have eaten dinner within 2 to 3 hours, you may not need to eat again right before taking your evening tacrolimus dose. If tacrolimus continues to cause nausea, talk with your nurse, physician, or dietitian.

**Storage**

- Store tacrolimus capsules at room temperature only. Do not store tacrolimus in the refrigerator or freezer or expose it to heat or strong light.
- Keep your tacrolimus with you when you travel.
- Call the SCCA Pharmacy when your supply of tacrolimus gets low. Allow 24 hours for refills.
• Once you are discharged for home, tacrolimus will be prescribed by your local physician. It can be obtained from your local pharmacy. Plan ahead with your physician and pharmacist. Do not wait until you are completely out of medicine to get a refill.

**IV tacrolimus**

• **Rate**: As instructed by your nurse. Tacrolimus can cause burning in hands and feet. If this occurs, call the Transplant clinic at (206) 606-7600 or the after-hours clinic at: (206) 598-8902

• Tacrolimus must be infused in the white port only. **Do not infuse** in the blood draw side of your central line.

• Keep IV tacrolimus in the refrigerator.
Prednisone

- Prednisone is an immune suppressing drug used to treat or prevent graft-versus-host disease (GVHD) in bone marrow and peripheral blood stem cell transplant patients.
- Prednisone comes in several sizes of tablets for oral use. It also comes as an IV preparation.
- You may need to use several different milligram sizes of tablets to take the prescribed total dose. You may also need to cut pills in half to take the prescribed dose.
- Never take oral prednisone on an empty stomach. Take your morning dose of prednisone after breakfast or at least with a glass of milk, or a smoothie. If you have eaten dinner within 2 to 3 hours, you do not need to eat again right before taking your evening prednisone dose.

Nutrition recommendations during prednisone therapy

- **Consume a protein-rich diet while taking prednisone.** You may experience muscle loss while taking prednisone, even if your weight is stable or increasing. A protein-rich diet and regular exercise may help to maintain your muscles. Your dietitian will give you a protein goal.
- **Consume a calcium-rich diet while taking prednisone.** Calcium goal: 1500 mg daily. Prednisone can cause bone loss. Vitamin D and calcium, as well as exercise, can help minimize this loss. Your dietitian will assess your current calcium intake and recommend supplements if needed. Calcium carbonate (such as Tums®) or calcium citrate are recommended supplements.
- **Prednisone may increase your blood glucose (sugar) level, similar to diabetes.** A normal fasting blood glucose level is 60-110 mg/dl. If your fasting blood glucose level is above normal, your nutritionist may advise you to make some diet changes. This may include changing the amount of carbohydrates you eat. Levels of blood glucose usually return to normal when prednisone is stopped.
- **You may need more potassium in your diet while taking prednisone.** Prednisone causes some people to “waste” potassium into their urine. If your blood potassium level is below normal your physician may prescribe a potassium supplement and recommend a high potassium diet. Please ask your care team for the “potassium handout” that includes dietary suggestions.

Prednisone can cause your body to retain fluids. A high salt intake diet can worsen fluid retention. Limit added salt and salty foods such as canned, instant, and frozen soups and entrees, soy sauce, cured meats, and packaged sauces, and seasonings. In general, processed foods contain excess salt. Your dietitian can provide you with more information about diet recommendations during prednisone therapy.
Mycophenolate mofetil (also called MMF or CellCept®)

- MMF is an immune-suppression drug used to treat or prevent graft versus host disease (GVHD) in stem cell transplant patients.
- MMF is available as a 250 mg tablet, 500 mg capsule, liquid suspension, or as a slow infusion through your veins. Swallow the tablet and capsules whole; do not break, crush, chew, or open the capsule or tablet. Do not mix the liquid suspension with any other medicines.
- MMF can cause nausea, vomiting, constipation, abdominal cramps, diarrhea, muscle pain, headache, and/or swelling of the feet or lower legs. Your MMF dosing may be given every 8 or 12 hours.

MMF blood levels

- Some patients may need to have MMF levels drawn. This would require several blood draws over an 8 to 10 hour period on these days.

Beverage and food recommendations

- MMF is absorbed best on an empty stomach. If you are having problems with nausea take the medications with some crackers.
- Do not take within 2 hours of high calcium foods such as cow, almond or fortified soy milk, cheese and yogurt, oral calcium, or oral magnesium supplements.

Storage

- Keep tablets and capsules in a closed container at room temperature away from excessive heat, moisture, and direct sunlight.
- The oral liquid may be stored in the refrigerator but not in the freezer. The oral liquid expires 60 days after you receive it from the pharmacy. Dispose of any unused medication at that time.

Do not refrigerate intravenous infusions of mycophenolate. MMF cannot be mixed with saline flushes. Lines need to be flushed with 50ml of dextrose 5% water before and after the completion of each infusion. Discuss this with your nurse or pharmacist to make sure you understand this instruction.
Sample transplant medication schedule

Bring this sheet to first clinical visit. Include all medications. Indicate those given at home with an “H.”

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<tr>
<th>Medication</th>
<th>Dosage/directions</th>
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<td>Every 4 hours as needed:</td>
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**Suggested medication schedule**

Bring this sheet to first clinical visit. Include all medications. Indicate those given at home with an “H.”

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<th>Medication</th>
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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.

All hematopoietic cell transplant patients are 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>Eggs, egg dishes, and casseroles</td>
<td></td>
</tr>
<tr>
<td>Eggs</td>
<td>Cook until yolk and white are firm</td>
</tr>
<tr>
<td>Casseroles, foods containing eggs, custards and egg sauces</td>
<td>160°F</td>
</tr>
<tr>
<td>Veal, beef, pork, lamb, rabbit, goat, game</td>
<td></td>
</tr>
<tr>
<td>Whole pieces meat</td>
<td>160°F</td>
</tr>
<tr>
<td>Ground veal, beef, lamb, pork, rabbit, goat, game</td>
<td>160°F</td>
</tr>
<tr>
<td>Poultry (chicken, turkey, duck, goose)</td>
<td></td>
</tr>
<tr>
<td>Chicken and turkey: whole bird and dark meat (leg, thigh, wing)</td>
<td>180°F</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 container outside of bird)</td>
<td>165°F</td>
</tr>
<tr>
<td>Ham</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>Seafood</td>
<td></td>
</tr>
<tr>
<td>Fin fish (such as salmon, cod, halibut, snapper, sole, bass, trout)</td>
<td>Cook until opaque and flakes easily with a fork</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 <em>(may be high risk food for people with low white count or immunosuppressed)</em></td>
</tr>
<tr>
<td>Leftovers, hot dogs and luncheon meats</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.
Additional guidelines for general oncology patients with low white blood count* and all stem hematopoietic transplant patients

*Low white blood cell count refers to a neutrophil count less than 1000/mm$^3$ or when chemotherapy is held due to low neutrophil count.

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 Camembert, blue-veined, Stilton. Feta, brie, goad and Mexican-style cheese (queso fresco) are OK if heated to steaming.
- 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 one minute. 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:
  - Reverse osmosis treated
  - Distillation
  - Filtered through an absolute 1 micron or smaller filter (NSF Standard #53 for cyst removal)

To be sure that a specific brand of bottled water has undergone one of the above processes, contact the International Bottled Water Association (IBWA) at 1-800-928-3711, or visit their home page at 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”).
Diet guidelines for immunosuppressed patients

Overview
You may have decreased immune function because of chemotherapy and/or radiation therapy or from taking medications to suppress your immune system. This means that you are at increased risk of developing a food-related infection. The purpose of this diet is to help you avoid specific foods that are more likely to contain infection-causing organisms while allowing maximum healthy food choices. Choose foods from the “May Eat” column. Do not eat foods in the “Do Not Eat” column. You may want to discuss the safety of these or other foods with your dietitian.

This diet should be followed before and after all conditioning therapy (chemotherapy and/or radiation) and while on immunosuppressive medications. Your health care provider and dietitian will let you know when the diet is no longer required. In general, we recommend the following:

- **For autologous transplant patients undergoing chemotherapy treatment only:** follow this diet during the first three months after chemotherapy or transplant.

- **For allogeneic transplant patients:** follow the diet until you are off all immunosuppressive therapy such as cyclosporine, prednisone, Tacrolimus®, Myfortic®, sirolimus, or MMF.

Before end of these time periods, you and your caregiver should talk to your health care provider and dietitian regarding whether or not to continue any part of the diet.

<table>
<thead>
<tr>
<th>Food groups</th>
<th>May eat</th>
<th>Do not eat</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dairy</td>
<td>All pasteurized, grade “A” milk and milk products including eggnog, yogurt, ice cream, frozen yogurt, sherbet, ice cream bars, milkshakes, processed cheese slices and spreads, cream cheese, cottage cheese and ricotta cheese</td>
<td>Non-pasteurized or raw milk and milk products made from non-pasteurized or raw milk</td>
</tr>
<tr>
<td></td>
<td>Dry, refrigerated, or frozen pasteurized whipped topping</td>
<td>Cheeses from delicatessens</td>
</tr>
<tr>
<td></td>
<td>Commercially packaged hard and semi-soft cheeses such as cheddar, mozzarella, parmesan, Swiss, Monterey Jack, etc.</td>
<td>Cheese containing chili peppers or other uncooked vegetables</td>
</tr>
<tr>
<td></td>
<td>Cooked and pasteurized soft cheeses such as brie, goat, camembert, feta, farmer’s cheese. Though not completely risk free, the risk of contracting food borne illness from COOKED soft cheeses is low</td>
<td>Cheeses with molds (such as blue, Stilton, Roquefort, gorgonzola)</td>
</tr>
<tr>
<td></td>
<td>Commercially sterile ready-to-feed and liquid-concentrate infant formulas (avoid powdered infant formulas if a ready-to-feed or liquid concentrate alternative is available)</td>
<td>Mexican-style soft cheese such as queso fresco, queso blanco (unless made with pasteurized milk and cooked)</td>
</tr>
<tr>
<td>Food groups</td>
<td>May eat</td>
<td>Do not eat</td>
</tr>
<tr>
<td>-----------------------------</td>
<td>--------------------------------------------------------------------------</td>
<td>-----------------------------------------------------------------------------</td>
</tr>
</tbody>
</table>
| **Meat and meat substitutes** | • All meats cooked to well done (see temperature guide attached) or canned meats (beef, pork, lamb, poultry, fish, shellfish, game, ham, bacon, sausage, hot dogs)  
  • Eggs cooked until both white and yolk are firm  
  • Pasteurized eggs and egg substitutes (such as Egg Beaters®), and powdered egg white (all can be used uncooked)  
  • Commercially-packaged salami, bologna, hot dogs, ham and other luncheon meats, heated until steaming  
  • Canned and shelf-stable\(^1\) smoked fish (refrigerate after opening)  
  • Pasteurized or cooked tofu\(^2\)  
  • Refrigerated smoked seafood such as salmon or trout if cooked to 160°F or contained in a cooked dish or casserole | • Raw or undercooked meat, poultry, fish, game, tofu\(^2\)  
  • Raw or undercooked eggs and non-pasteurized egg substitutes; no eggs over easy, soft-boiled eggs, or poached eggs  
  • Meats and cold cuts from delicatessens  
  • Hard cured salami in natural wrap  
  • Uncooked refrigerated smoked, seafood such as salmon or trout labeled as “nova-style,” “lox,” “kippered,” “smoked” or “jerky”  
  • Pickled fish  
  • Tempe (tempeh) products |
| **Fruits and nuts**          | • Well washed\(^3\) raw and frozen fruit; foods containing well washed raw fruits  
  • Cooked, canned and frozen fruit  
  • Pasteurized juices and frozen juice concentrates  
  • Dried fruits  
  • Canned or bottled roasted nuts  
  • Shelled, roasted nuts and nuts in baked products  
  • Commercially-packaged nut butters (such as peanut butter, almond butter, soybean butter) | • Unwashed raw fruits  
  • Unroasted raw nuts  
  • Roasted nuts in the shell  
  • Non-pasteurized fruit and vegetable juices  
  • Fresh fruit salsa found in the grocery refrigerator case  
  • Non-pasteurized items containing raw fruits found in the grocery refrigerator case |

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

\(^2\) Aseptically packaged, shelf-stable tofu and pasteurized tofu do not need to be boiled. Unpasteurized tofu must be cut into 1-inch cubes or smaller and boiled a minimum of five minutes in water or broth before eating or using in recipes.

\(^3\) Rinse under clean, running water before use, including produce that is to be cooked or peeled (such as bananas, oranges and melon).
<table>
<thead>
<tr>
<th>Food groups</th>
<th>May eat</th>
<th>Do not eat</th>
</tr>
</thead>
<tbody>
<tr>
<td>Entrees, soups</td>
<td>• All cooked entrees and soups</td>
<td>• All miso products (such as miso soup and miso paste)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Vegetables</td>
<td>• Well washed[^3] raw and frozen vegetables</td>
<td>• Unwashed raw vegetables or herbs</td>
</tr>
<tr>
<td></td>
<td>• All cooked fresh, frozen or canned vegetables, including potatoes</td>
<td>• Fermented vegetables such as kimchi or sauerkraut</td>
</tr>
<tr>
<td></td>
<td>• Shelf-stable[^1] bottled salsa (refrigerate after opening)</td>
<td>• Fresh, non-pasteurized vegetable salsa found in the</td>
</tr>
<tr>
<td></td>
<td>• Cooked vegetable sprouts (such as mung bean sprouts)</td>
<td>grocery refrigerator case</td>
</tr>
<tr>
<td></td>
<td>• Fresh, well washed[^3] herbs and dried herbs and spices (added to raw</td>
<td>• Non-pasteurized items containing raw vegetables</td>
</tr>
<tr>
<td></td>
<td>or cooked foods)</td>
<td>found in the grocery refrigerator case</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• All raw vegetable sprouts (alfalfa sprouts, clover</td>
</tr>
<tr>
<td></td>
<td></td>
<td>sprouts, mung bean sprouts, all others)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Salads from delisatessens and restaurants</td>
</tr>
<tr>
<td>Bread, grain, and cereal</td>
<td>• All breads, bagels, rolls, English muffins, muffins,</td>
<td>• Raw (not baked or cooked) grain products (such as</td>
</tr>
<tr>
<td>products</td>
<td>pancakes, sweet rolls, waffles, French toast</td>
<td>raw oats)</td>
</tr>
<tr>
<td></td>
<td>• Potato chips, corn chips, tortilla chips, pretzels, popcorn</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Cooked grains and grain products, including pasta and rice</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• All cereals, cooked and ready-to-eat</td>
<td></td>
</tr>
<tr>
<td>Food groups</td>
<td>May eat</td>
<td>Do not eat</td>
</tr>
<tr>
<td>-------------</td>
<td>---------</td>
<td>-----------</td>
</tr>
</tbody>
</table>
| **Beverages** | • Boiled well water\(^4\)  
• Tap water and ice made from tap water\(^5\)  
• Commercially-bottled distilled, spring and natural waters\(^6\)  
• All canned, bottled and powdered beverages  
• Instant and brewed coffee and tea; cold brewed tea made with boiling water  
• Herbal teas brewed from commercially-packaged tea bags  
• Commercial nutritional supplements, both liquid and powdered  
• Commercially sterile ready-to-feed and liquid-concentrate infant formulas (avoid powdered infant formulas if a ready-to-feed or liquid concentrate alternative is available) | • Unboiled well water  
• Cold-brewed tea made with warm or cold water  
• Non-pasteurized fruit and vegetable juices  
• Mate’ tea  
• Kombucha  
• Wine, unpasteurized beer  
• (Note: All alcoholic beverages should only be consumed following health care provider approval) |
| **Desserts** | • Refrigerated commercial and homemade cakes, pies, pastries and pudding  
• Refrigerated cream-filled pastries  
• Cookies, both homemade and commercially prepared  
• Shelf-stable\(^3\) cream-filled cupcakes (such as Twinkies\(^®\), Ding Dongs\(^®\)) and fruit pies (such as Pop-Tarts\(^®\) and Hostess\(^®\) fruit pies)  
• Canned and refrigerated puddings  
• Ices, popsicles and similar products  
• Candy, gum | • Unrefrigerated cream-filled pastry products (not shelf-stable\(^3\)) |
| **Fats** | • Vegetable oils and shortening  
• Refrigerated lard, margarine, butter  
• Commercial, shelf-stable\(^3\) mayonnaise and salad dressings including blue cheese and other cheese-based salad dressings (refrigerate after opening)  
• Cooked gravy and sauces | • Fresh salad dressings (stored in the grocer’s refrigerated case) containing raw eggs or cheeses listed as “Do Not Eat” under “Dairy” |

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\(^4\) Bring tap water to a rolling boil and boil for 15-20 minutes. Store boiled water in the refrigerator. Discard water not used within 48 hours (2 days).

\(^5\) Recommend using boiled or bottled water if using a water service other than city water service. Please see *Water Safety Guidelines* in “Food Safety Guidelines”.

\(^6\) See *Water Safety Guidelines* in “Food Safety Guidelines” for approved bottled water treatments.
<table>
<thead>
<tr>
<th>Food groups</th>
<th>May eat</th>
<th>Do not eat</th>
</tr>
</thead>
</table>
| Other       | • Commercial pasteurized Grade A honey<sup>7</sup>  
• Salt, granulated sugar, brown sugar  
• Jam, jelly, syrups (refrigerate after opening)  
• Catsup, mustard, BBQ sauce, soy sauce, other condiments (refrigerate after opening)  
• Pickles, pickle relish, olives (refrigerate after opening)  
• Vinegar | • Raw honey; honey in the comb  
• Herbal and nutrient supplement preparations (refer to Guidelines for Use of Herbal and Nutrient Supplements in Patient & Caregiver Resource Manual)  
• Brewer’s yeast, if uncooked |

<sup>7</sup> Honey products are not allowed for any child less than one year of age and not allowed for children with SCIDS until 9 months posttransplant.

This education resource is intended to be given as a part of a nutrition consult by an SCCA dietitian. Questions? Ask an SCCA dietitian at nutrition@seattlecca.org
More nutrition tips

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

- Keep in mind that your calorie needs are higher during your transplant. Keep your body nourished even during the times you do not feel like eating.
- You will be using some medications that can be hard on your kidneys, so it is important to drink lots of fluids. Fluids include all beverages, smoothies, yogurt, ice cream, and soups. Your dietitian will give you a goal for daily fluid intake.
- Protein is needed for repair, growth, and fluid balance. Regularly include high protein foods such as eggs, milk/dairy products, meat/poultry/fish, beans, nuts, or high protein smoothies.
- Eat smaller, more frequent meals; snack often, and keep beverages handy at all times. Use a water bottle to keep beverages close all day long.
- Foods will probably taste differently for a while. This will pass, but you may need to make some adjustments to the way you eat. Drink beverages with meals or snacks if your mouth is dry. And remember, what does not taste good today might taste good tomorrow.
- Tell your physician or nurse if you are having nausea, vomiting, diarrhea, constipation, heartburn, or mouth and throat pain.
- A dietitian can answer questions you might have or help you find the foods that will work for you.
Shopping list
Below are some foods that may be easier to tolerate during and after chemotherapy. Circle the items you enjoy and bring the list with you to the grocery store. If you have high blood sugar (hyperglycemia), check with your dietitian or physician to see which foods are right for you.

Beverages
- Carnation Instant Breakfast® drink*
- Milk*
- Chocolate milk*
- Soda pop – caffeine free
- Sports drinks
- Kool-Aid
- Tang*
- Hawaiian Punch*
- Seltzers
- Assorted juices
- Cocoa
- Hot apple cider

Cereals and breads
- Cream of Wheat®
- Cream of Rice®
- Cold cereals
- Muffins

Cool treats
- Jell-O®
- Popsicles
- Sherbet/ice cream*
- Yogurt*
- Pudding*

Dairy/Meats
- Eggs*
- Cottage cheese*
- Cream cheese*
- Thin sliced luncheon meats*
- Assorted hard cheeses*

Fruits
- Canned fruits
- Fresh melons
- Applesauce

Miscellaneous
- Mashed potatoes
- Macaroni and cheese*
- Noodles*
- Gravy

Snacks
- Cheesecake*
- Soft cookies
- Ritz® crackers
- Saltines
- Canned or instant soups
- Graham crackers
- Dinner rolls

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

Some foods to try:

<table>
<thead>
<tr>
<th>Beverages and liquids</th>
<th>Proteins</th>
</tr>
</thead>
<tbody>
<tr>
<td>Seltzer water, diluted nectars and juices</td>
<td>Moist, cooked fish and chicken</td>
</tr>
<tr>
<td>Thinned fruit smoothies</td>
<td>Thin, broth-based soups</td>
</tr>
<tr>
<td>Tea with lemon</td>
<td></td>
</tr>
<tr>
<td>Clear broth</td>
<td></td>
</tr>
<tr>
<td>Sugar-free lemon drops, sour candies</td>
<td></td>
</tr>
<tr>
<td>Breads and cereals</td>
<td>Fruit and vegetables</td>
</tr>
<tr>
<td>Hot cereals thinned with milk or water</td>
<td>Blended fruits or vegetables diluted to a</td>
</tr>
<tr>
<td></td>
<td>thin consistency</td>
</tr>
<tr>
<td></td>
<td>High moisture fruits such as melon</td>
</tr>
</tbody>
</table>
**Tips on eating if your mouth and throat are sore:**
- A soft, bland diet will cause less irritation.
- Avoid rough, acidic, and spicy foods.
- Popsicles and slushies (frozen beverages) may help to soothe your mouth and throat and quench your thirst.
- Try smaller bites of foods that don’t take much chewing.
- Avoid extreme hot and cold food temperatures.
- Canned fruits are usually softer than fresh, raw fruits and cause less discomfort.

**Some foods to try:**

<table>
<thead>
<tr>
<th>Beverages and seasonings</th>
<th>Proteins</th>
</tr>
</thead>
<tbody>
<tr>
<td>Herbal teas</td>
<td>Blended meats and casseroles</td>
</tr>
<tr>
<td>Diluted juices</td>
<td>Bland entrees: macaroni and cheese, soufflés, bland quiches, creamed chicken, spaghetti with cream sauce</td>
</tr>
<tr>
<td>Smoothies/shakes</td>
<td>Pureed foods</td>
</tr>
<tr>
<td>Popsicles</td>
<td>Milk</td>
</tr>
<tr>
<td>Low-salt homemade or canned soups (can be put in the blender to change texture)</td>
<td>Eggnog</td>
</tr>
<tr>
<td>Herbs for seasoning: thyme, basil, oregano, bay leaf</td>
<td>Cottage cheese, yogurt, cream cheese</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Breads and cereals</th>
<th>Fruit and vegetables</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hot cereal; may be thinned with milk</td>
<td>Cool fruits, especially watermelon, honeydew, grapes, papaya</td>
</tr>
<tr>
<td>Dry cereals soaked in milk</td>
<td>Canned fruits, blended if needed</td>
</tr>
<tr>
<td>Plain cooked pasta</td>
<td>Pureed fruits</td>
</tr>
<tr>
<td>Mashed potatoes with butter</td>
<td>Diluted fruit nectars</td>
</tr>
<tr>
<td></td>
<td>Cold blended homemade soups: cucumber, avocado, potato</td>
</tr>
</tbody>
</table>
Tips on eating if your mouth is dry:

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

Some foods to try:

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

<table>
<thead>
<tr>
<th>Breads and cereals</th>
<th>Fruit and vegetables</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cooked cereals</td>
<td>Vegetables with sauces</td>
</tr>
<tr>
<td>Dry cereals soaked in milk</td>
<td>Melon, peaches</td>
</tr>
<tr>
<td></td>
<td>Canned fruits</td>
</tr>
<tr>
<td></td>
<td>Fruit juices and nectars</td>
</tr>
</tbody>
</table>
**Calorie and protein guide**
For calorie and protein information, ask your nutritionist for the booklet, “A Guide to Good Nutrition.”

**Food records**
Follow these steps:
- Use a new food record sheet each day (you can ask for more records from your dietitian).
- Record your name and date.
- Do not write in the “Code” columns.
- Write down the time you eat or drink each food.
- Note if the food is vomited up and what time.
- Turn the food record over and answer the questions on the back.
- Bring your completed food record sheet to each nutrition appointment, every time you come for a blood draw, and for every clinic appointment.

How to record fluids on your food record:
- Include water, juice, milk, soup, ice cream, sherbet, Jell-O®, Kool-Aid®, soda, and yogurt.
- Record fluids as cups, ounces (oz.), or milliliters (mL).
- Describe drinks clearly, such as: 2% milk, or whole milk.
- Specify how much sugar you add when sweetening tea or other drinks.
- List each ingredient of special drinks (such as homemade milkshakes).

How to record solids on your food record:
- Cereal: Measure with a measuring cup. Include the amounts of milk and sugar added. State if milk is used in the preparation of cooked cereals.
- Condiments and Snacks: Include these, as they are important sources of calories. Please write them out on your record! Be specific about the amount you use (1 teaspoon, 2 tablespoons, etc.). Examples are:
  - Butter or margarine (on toast, sandwiches, potatoes, oatmeal, etc.)
  - Mayonnaise or salad dressing
  - Syrup, jam, or honey
  - Olives or pickles
  - Nuts or sunflower seeds
  - Potato chips or other kinds of chips
- Fruits and vegetables: State whether fresh or canned. Measure cooked ones with a measuring cup or state number (such as 3 French fries). Estimate raw foods, such as “one medium tomato” or “3 carrot sticks” or “½ large banana.”
- Meat, cheese, and eggs: State how meat or eggs are prepared (fried, roasted, broiled, etc.). State whether you eat the skin of poultry.
- List portion size by the dimension or cup: 1 hamburger patty, 3" diameter x 1/2" thick; 1/4 cup grated cheddar cheese.
- Some foods can be listed by the piece: 1 scrambled egg, 1 small chicken thigh without skin, 5 potato chips.
How to record soups:
  • State whether homemade, canned, or dehydrated. State if creamed soups are made with milk or water.

How to record mixed items:
  • List recipes for casseroles, pasta dishes, sandwich ingredients, and contents of tacos, pizzas, hamburgers, and hotdogs.

How to record special products, frozen dinners, etc.:
  • Tape onto your food record the nutrient information from TV dinners, protein powders, canned foods, or other products with which we may not be familiar.

How to record brand names foods:
Include these, as the brand name can be helpful. Examples are:
  • ¾ McDonald's Big Mac®
  • 1.6 oz Butterfinger® candy bar

How to record food when eating out:
  • State fast food or restaurant names and the foods and beverages you eat.
Herbal and nutrient supplements

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 effects 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
- Borage
- Chaparral
- Chinese herbs
- Coltsfoot
- Comfrey
- DHEA
- Dieter’s Tea (senna, aloe, rhubarb root, buckthorn, cascara, castor oil)
- Ephedra or MaHuange
- Groundsel or Life Root
- Heliotrope or Valerian
- Kava kava
- Laetrile (apricot pits)
- Licorice root
- L-tryptophan
- Lobelia
- Maté tea
- Pau d’arco
- Pennyroyal
- Sassafras
- St. John’s Wort
- Yohimbe and Yohimbine
Vitamin and mineral supplements and antioxidants

You will be prescribed a multiple vitamin and mineral supplement that provides nutrients at levels approximately those of the Dietary Reference Intakes (DRI). In some instances, you may wish to take higher doses of specific vitamins, minerals, or antioxidants. While higher doses are not suggested, the following is a list outlining the DRI and maximum amounts of supplements recommended. Higher doses may be toxic or interact with other medications.

<table>
<thead>
<tr>
<th>Micronutrient</th>
<th>Dietary Reference Intakes</th>
<th>Safe upper limits</th>
</tr>
</thead>
<tbody>
<tr>
<td>Vitamin A</td>
<td>2700 to 3000 IU/800 to 1000 RE or mcg</td>
<td>No more than 10,000 IU or 3,000 mcg.</td>
</tr>
<tr>
<td>Vitamin C</td>
<td>120 mg</td>
<td>No more than 500 mg.</td>
</tr>
<tr>
<td>(ascorbic acid)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Vitamin D</td>
<td>200 to 600 IU or 5 to 15 mcg</td>
<td>No more than 2000 IU or 50 mcg.</td>
</tr>
<tr>
<td>(calciferol)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Vitamin E</td>
<td>8 to 10 mg or IU</td>
<td>No more than 100 mg or IU while on anticoagulant therapy.</td>
</tr>
<tr>
<td>(tocopherol)</td>
<td></td>
<td>No more than 800 mg or IU.</td>
</tr>
<tr>
<td>ß-carotene</td>
<td>No DRI</td>
<td>No more than 25,000 IU or 15 mg.</td>
</tr>
<tr>
<td>Folic acid (folate)</td>
<td>400 mcg</td>
<td>No more than 1000 mcg or 1 mg.</td>
</tr>
<tr>
<td>Vitamin B₁ (thiamin)</td>
<td>1.1 to 1.2 mg</td>
<td>While high intakes of B-vitamins may not be toxic, talk with your dietitian to discuss your particular needs.</td>
</tr>
<tr>
<td>Vitamin B₂ (riboflavin)</td>
<td>1.1 to 1.3 mg</td>
<td></td>
</tr>
<tr>
<td>Niacin (mg of niacin equivalents)</td>
<td>14 to 16 mg</td>
<td>No more than 35 mg.</td>
</tr>
<tr>
<td>Vitamin B₆ (pyridoxine)</td>
<td>1.3 to 1.7 mg</td>
<td>No more than 100 mg.</td>
</tr>
<tr>
<td>Vitamin B₁₂ (cobalamin)</td>
<td>2.4 mg</td>
<td>While high intakes of B-vitamins may not be toxic, talk with your dietitian to discuss your particular needs.</td>
</tr>
<tr>
<td>Biotin</td>
<td>30 mcg</td>
<td></td>
</tr>
<tr>
<td>Pantothenic acid</td>
<td>5 mg</td>
<td>Iron supplementation is not recommended post-transplant.</td>
</tr>
<tr>
<td>Iron</td>
<td>12 to 15 mg</td>
<td></td>
</tr>
<tr>
<td>Selenium</td>
<td>40 to 70 mcg</td>
<td>No more than 200 mcg.</td>
</tr>
<tr>
<td>Calcium</td>
<td>1000 to 1200 mg</td>
<td>No more than 2500 mg.</td>
</tr>
</tbody>
</table>
Recommended vitamin brands
Note: vitamin brands that contain Iron and/or extra C are not recommended.
• One-a-Day 50 Plus®
• Nature Made Mature Balance®

Antioxidants
A high intake of some antioxidants (vitamin C, vitamin E, and ß-carotene) may protect against the development of certain types of cancer. However, taking antioxidant supplements during radiation and chemotherapy may reduce the effectiveness of these treatments in destroying diseased cells. Therefore, you should stop antioxidant supplementation before chemotherapy and radiation. Antioxidants may be inappropriate post-transplant because of interactions with medications, immunosuppressive therapy, or other vitamins and minerals in your body.

B vitamins
The B vitamins (thiamin, niacin, riboflavin, pyridoxine (B₆), folate, cobalamin (B₁₂), biotin, and pantothenic acid, are water-soluble nutrients that assist in energy production. High levels of supplementation may not be toxic. However, it is important to maintain a balance among these B-vitamins. High doses of one may have a negative effect.

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

Allogeneic transplantation
You are at risk for infections until all immunosuppressive medications have been stopped and are free of active chronic GVHD (graft versus host disease). Immunosuppressive medications include cyclosporine, tacrolimus (FK-506®), prednisone, thalidomide, Imuran®, Rapamycin®, mycophenolate mofetil (MMF, CellCept®) and interferon.
Central line care

What is a central venous catheter?
A central venous catheter is a small flexible tube inserted into a large vein in your chest. It is used to give you fluid, nutrients, medicine, and blood products. It may also be used to get blood samples. A central venous catheter is also called a central line, tunneled catheter, central venous line, or Hickman line. In this section, it is called a “central line”. There are many types of central lines.

How is the central line placed?
Inserting the central line is a minor surgical procedure. It is done in a procedure suite or an operating room and takes about 1 hour. Your doctor will use local anesthesia to numb your neck and chest. You may also be sedated.

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

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

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

What instructions should I follow after my procedure?
- Do not take over-the-counter (non-prescription) pain medications such as acetaminophen (Tylenol®) and ibuprofen (Advil®) without checking with your care team first.

- Secure the line by wearing a tight-fitting tank top/undershirt or sports bra for at least 1 night after placement.

- Do not lift anything heavier than 5 pounds for 3 days after your surgery. Do not participate in activities that use your chest muscles such as vacuuming, bowling, weight lifting, tennis or golf while you have the central line. You may have sex, but do not pull on the catheter. If you have any questions about your activities, please ask your care team.
How do I care for my central line?
The day after your surgery, you will have an appointment to get your dressing changed for the first time. Your central line will need ongoing care. This care is described in the rest of this packet.

Parts of your central line

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

<table>
<thead>
<tr>
<th>Central line care</th>
<th>How often</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clean central line</td>
<td></td>
</tr>
<tr>
<td>• Use alcohol wipes</td>
<td>Daily</td>
</tr>
<tr>
<td>• Change tape tabs, if using</td>
<td></td>
</tr>
<tr>
<td>Flush lumens</td>
<td>Daily or with each use</td>
</tr>
<tr>
<td>Protect line from water:</td>
<td></td>
</tr>
<tr>
<td>• Put Parafilm® on end caps</td>
<td>When bathing/showering</td>
</tr>
<tr>
<td>• Put AquaGuard® or Press’n Seal®</td>
<td></td>
</tr>
<tr>
<td>over dressing</td>
<td></td>
</tr>
<tr>
<td>Change dressing</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Every 7 days for Tegaderm® CHG</td>
</tr>
<tr>
<td></td>
<td>or other clear dressing</td>
</tr>
<tr>
<td></td>
<td>Every 1-2 days for gauze and</td>
</tr>
<tr>
<td></td>
<td>tape dressing</td>
</tr>
</tbody>
</table>
Important notes on central line care

Keep your line safe

• Keep your bulldog clamp with you at all times. The bulldog clamp is a safety clamp. If the central line leaks, gets cut, or breaks, clamp the central line close to your chest and call the clinic immediately.

• Secure your central line **one** of the below ways to prevent accidental removal of the line:
  - Place central line ends in a clean cloth pouch and secure the pouch with a bulldog clamp to clothing or a lanyard. Pouches are for one-day use and should be washed daily; OR
  - Place plastic tape tabs between clamp and cap on the central line and change daily. Use the plastic tape tabs and bulldog clamp to secure the central line to clothing or a lanyard.

• Always place central line clamp on the thick reinforced area of the line.

Protect your line from water

• Always cover your central line dressing with a plastic covering such as AquaGuard or Press’n Seal to prevent water from entering the dressing and exit site. The uncovered dressing and exit site should never come in contact with water.

• Always securely wrap your central line end caps with Parafilm to prevent water from entering the cap top or into the connection to the central line. If you notice moisture under the Parafilm, ask to have your end caps changed in the clinic.

Clean your line

• Clean your lumens once a day with alcohol wipes after your bath or shower. If using plastic tape tabs to secure your line, replace tape tabs each day.

• Your care team will tell you how often to change your dressing and if you will change it yourself or have it changed in the clinic.

• If your dressing starts to come off, gets wet, or if there is moisture underneath it, it needs to be changed. Ask to have your dressing changed in the clinic. You may change it yourself if you have been taught how to do this and have the correct supplies at home.

***

Do not

• Do not remove the end caps from your central line.
• Do not let end caps, central line or dressing go under your bath water.
• Do not go into swimming pools and hot tubs.
• Do not store central line supplies in a moist (humid) area, such as the bathroom or kitchen.
• **Do not use scissors near your central line.**
**Antibiotic infusions**
If you are receiving antibiotics, your physician will recommend that you alternate infusing your antibiotic doses between lines of your catheter.

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

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

**Instructions**
1. If using tape tabs, remove plastic tape tabs. If not using tape tabs, go to step 2.

2. Use 2 alcohol wipes, 1 to hold the line and 1 to clean it. Start where the line exits the dressing and wipe towards the end cap. Using the same alcohol wipes, clean the clamps.

3. If using plastic tape tabs, replace them. Fold about ½ inch of tape over at each end to make the tab easier to remove.

4. Repeat this for each lumen.
Flushing your central line
Flush your central line with saline and heparin at least once a day or at the end of an infusion. Heparin helps prevent a clot within the central line. The daily heparin flush is still required even if you are on any oral or injectable blood thinners to prevent or treat a blood clot.

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

How to flush your central line
Gather your supplies and then follow steps 1 through 16 below.

Supplies
• 2, 10 ml saline syringes*
• 2, 5 ml heparin syringes*
• 2 alcohol wipes
• 1 pair of gloves

*You need a prescription for saline and heparin syringes.

Instructions

1. Wash your hands.

2. Place all supplies on a clean surface. Remove syringes from their packages by peeling the plastic downward.
3. Put on gloves. Vigorously scrub the central line end cap with an alcohol wipe for 15 seconds (count one one-thousand, two one thousand, etc.) using a twisting motion as if you were juicing an orange. **Take special care to clean the tip of the cap.** Allow the cap to dry completely (at least 5 seconds).

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

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

6. Unclamp the central line.

7. Push the plunger on the saline syringe with **alternating pressure and release** (starting and stopping to create turbulence) to inject the fluid into the central line. This keeps clots from forming in the central line. Leave ½ ml of saline in the syringe.
How to flush your central line, continued

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

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

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

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

12. Unclamp the central line.
How to flush your central line, continued

13. Push the plunger on the heparin syringe with **alternating pressure and release** (starting and stopping to create turbulence) to inject the fluid into the central line. This keeps clots from forming in the central line. Leave 2 ml of heparin in the syringe.

14. Clamp the catheter (leaving 2 ml of heparin in the syringe) while keeping your thumb on end of the plunger of the syringe.

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

16. Repeat steps for each lumen.
Changing your dressing
In most cases, your dressing will be changed in the clinic. You may be taught how to change your dressing at home. If so, please follow the instructions below. While you have your central line, please:

- Look at your dressing and exit site every day. Report any redness, drainage, or pain to your care team.

- Talk to your nurse if your skin is sensitive to the dressing.

If you have a Tegaderm CHG dressing:
- It should be changed every 7 days.

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

If you have a gauze and tape dressing:
- It should be changed every 24 to 48 hours.
How to change your Tegaderm CHG dressing

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

Instructions
1. Wash your hands with soap and water and put your supplies on a clean work surface.
2. Put on clean gloves.
3. If present, remove plastic tape near central line end caps.
4. Remove existing dressing.

   If you have a Tegaderm CHG dressing:

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

   If you have a gauze and tape dressing and are switching to Tegaderm CHG: Remove the old gauze and tape dressing and throw away. Do not use scissors.
5. Report to your nurse if there is:
   - Bleeding or drainage at the central line site.
   - Redness or swelling at the central line site.
   - Pain or discomfort at the central line site.

6. Remove gloves.

7. **Wash your hands again.**

8. Put on pair of clean gloves.

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

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

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

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

   - **Alternate cleaning procedure for chlorhexidine AND povidone-iodine allergies:** Use a 70% alcohol swab to clean the exit site in circular motion, starting at the central line exit site and moving outward away from the exit site. Repeat with the other two povidine-iodine swabs, for a total of 3 cleanings at the exit site. Allow to air dry and do not wipe off.
How to change Tegaderm CHG dressing, continued

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

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

13. Apply new dressing.

   o Apply Tegaderm CHG transparent dressing by peeling the liner from the dressing, exposing the adhesive surface.

   o Center the dressing and gel pad over the central line exit site and **press gently** to make it adhere. Make sure the central line comes out of the dressing edge at a notch.

   o Slowly remove the paper frame from the dressing while smoothing down the dressing edge.

   o Smooth the entire dressing from the center towards the edge using firm pressure to enhance adhesion. If your gloves stick to the dressing, you may remove them.

   o Remove tape “wings” from frame, lift central line, and apply wing across opening of dressing underneath the central line, creating a little hole where the central line comes through. This helps keep the central line secure.

   o Paint border (outside edges) of transparent dressing with Cavilon No-Sting Barrier Film to create a seal between the transparent dressing and the skin.
How to change your gauze and tape dressing

Supplies

- 2 packages 2x2 gauze or 2 packages 2x2 split gauze
- 4 alcohol pads for cleaning line (use 2 per lumen)
- 1, 10 ml saline syringe
- 1 sterile gauze pad
- Skin Prep
- Paper tape
- 1 ChloraPrep One-Step applicator, also called chlorhexidine
- 2 pairs of clean gloves
- Plastic tape (if using to make tape tabs)

Instructions

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

2. Put on clean gloves.

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

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

5. Tell your nurse if there is any of the following at the central line site:
   - Bleeding or drainage
   - Redness or swelling
   - Pain or discomfort

6. Remove gloves.

7. Wash your hands again.

8. Put on pair of clean gloves.

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

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

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

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

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

13. Apply dressing.

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

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

- Place the second 2x2 over the line and gauze.

- Secure gauze to skin with paper tape.

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

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

- Place plastic tape tabs between clamp and cap on the central line and change daily. Use the plastic tape tabs and bulldog clamp to secure the central line to clothing or a lanyard.
<table>
<thead>
<tr>
<th>Problem</th>
<th>Solutions</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Line does not flush.</strong></td>
<td>1. Check to see if central line is clamped or kinked.</td>
</tr>
<tr>
<td></td>
<td>2. Call the SCCA clinic or after-hours numbers for instructions.</td>
</tr>
<tr>
<td><strong>Fluid is leaking from the central line.</strong></td>
<td>1. Immediately place a bulldog clamp on the central line as close to the chest as possible.</td>
</tr>
<tr>
<td>Central line may be cut accidentally if dressing is removed with scissors.</td>
<td>2. Wash hands and put on gloves</td>
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<tr>
<td></td>
<td>3. Check the central line to find the break. It can be as small as a pinhole.</td>
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<tr>
<td></td>
<td>4. Clean the break with an alcohol wipe.</td>
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<tr>
<td></td>
<td>5. Wrap a sterile 2x2 gauze or an alcohol wipe around the break in the central line and tape it in place.</td>
</tr>
<tr>
<td></td>
<td>6. Call the SCCA clinic or after-hours numbers for instructions.</td>
</tr>
<tr>
<td><strong>Central line end cap comes off.</strong></td>
<td>1. Immediately clamp central line — DO NOT REPLACE CAP.</td>
</tr>
<tr>
<td></td>
<td>2. Wash hands and put on gloves</td>
</tr>
<tr>
<td></td>
<td>3. Scrub central line end with alcohol for 15 seconds and let dry 5 seconds.</td>
</tr>
<tr>
<td></td>
<td>4. Place sterile saline syringe on end of central line — DO NOT FLUSH.</td>
</tr>
<tr>
<td></td>
<td>5. Call the SCCA clinic or after-hours numbers for instructions.</td>
</tr>
<tr>
<td><strong>Swelling around the exit site or fluid leaking from exit site.</strong></td>
<td>1. Stop any fluids running into the central line.</td>
</tr>
<tr>
<td>Swimming of the neck and face can be a sign that the central line is out of place.</td>
<td>2. Place an ice pack on the swollen area; do not apply directly to bare skin.</td>
</tr>
<tr>
<td></td>
<td>3. Call the SCCA clinic or after-hours numbers for instructions.</td>
</tr>
<tr>
<td><strong>Air in the central line, you ARE NOT short of breath.</strong></td>
<td>1. Check the clamp to make sure that it is closed.</td>
</tr>
<tr>
<td>This could be caused by air being accidentally injected into the central line or the end cap falling off when the line is not clamped.</td>
<td>2. Wash hands and put on gloves.</td>
</tr>
<tr>
<td></td>
<td>3. Open 2 saline syringes and 1 heparin solution flush syringe.</td>
</tr>
<tr>
<td></td>
<td>4. Scrub the end of the central line cap with alcohol wipe for 15 seconds and let dry 5 seconds.</td>
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<tr>
<td></td>
<td>5. Attach one of the saline syringes.</td>
</tr>
<tr>
<td></td>
<td>6. Unclamp the line.</td>
</tr>
<tr>
<td></td>
<td>7. Pull back on the syringe until blood appears.</td>
</tr>
<tr>
<td></td>
<td>8. Clamp the line and discard the syringe.</td>
</tr>
<tr>
<td></td>
<td>9. Scrub the end of the central line cap with alcohol for 15 seconds and let dry for 5 seconds.</td>
</tr>
<tr>
<td></td>
<td>10. Flush the central line as usual, making sure to close the clamp at the end of the flush.</td>
</tr>
<tr>
<td></td>
<td>11. Call clinic if central line end cap is off.</td>
</tr>
<tr>
<td></td>
<td>12. <strong>If you become short of breath, call 911.</strong></td>
</tr>
<tr>
<td><strong>Air in the central line and you SUDDENLY become SHORT OF BREATH, DIZZY, OR CONFUSED.</strong></td>
<td>1. Lie down on your left side so that your right hip is lifted above the level of the heart while checking the clamps on the central line to be sure they are closed.</td>
</tr>
<tr>
<td></td>
<td>2. Call 911 for emergency assistance.</td>
</tr>
<tr>
<td></td>
<td>3. Tell the medics to take you to University of Washington Medical Center emergency room (or Seattle Children’s, if pediatrics).</td>
</tr>
</tbody>
</table>
When your physician prescribes an antibiotic

What is an antibiotic?
An antibiotic is a drug. It is used to treat some infections. It may also be used to prevent an infection. Antibiotics can save lives. But, they are powerful drugs and should be used only when needed. They must also be taken exactly as your physician prescribed.

Why do I need an antibiotic?
Your care team thinks that you might:
• Have an infection, or
• Be at risk for an infection

What else do I need to know?
• We may run tests before you start taking your antibiotic. These tests will help us know which antibiotic will most likely work best for you.
• We may run more tests while you are taking the drug. These tests will help us watch for any side effects. Based on your test results, your physician may:
  o Change your antibiotic
  o Stop your antibiotic if it is no longer needed
  o Important: Take all of your antibiotic pills as your physician has prescribed.

While you are in the hospital, you may receive your antibiotic through an intravenous (IV) line
Are there side effects?
You may have side effects from your antibiotic. Some may be mild, but others can be more serious. Taking antibiotics can increase your risk for two serious problems: *Clostridium difficile* infections and antibiotic-resistant infections.

*Clostridium difficile* infections
*Clostridium difficile* (*C. diff*) is a type of bacteria. When you take antibiotics, some of the good germs in your gut are destroyed. This allows the *C. diff* bacteria to grow. Diarrhea is one sign of *C. diff* infection. Tell your care team right away if you have new diarrhea:

- While you are taking an antibiotic, or,
- Within a few weeks after stopping an antibiotic.

Antibiotic-resistant infections
This type of infection is harder to treat with antibiotics. Taking antibiotics may increase your risk of getting this type of infection in the future. Your care team will watch you for any signs of antibiotic resistance. To help prevent antibiotic-resistant infections:

- Take antibiotics only when needed, when prescribed by your physician.
- If your physician prescribes an antibiotic, finish taking all of the pills as instructed.

Questions or concerns
Your questions are important. If you have any questions or concerns about antibiotics or possible side effects, please talk with your care team.

*Important*: Take all of your antibiotic pills as your physician has prescribed.

Adapted from "When your physician prescribes an antibiotic" © 05/2017, by University of Washington Medical Center, Seattle, WA.
Chapter 4 – Long Term Recovery

“The actual BMT in the hospital was doable, the recovery is the hard part.”
-BMT survivor
How to take care of yourself in the first year

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

-BMT Survivor

The long-term recovery phase may take a year or longer. This is the time to reestablish your life after transplant. What does reestablishing your life entail? It means gradually getting back to your life patterns at work, school or at home, and making adjustments in relationships with your family and friends. It may also mean learning to adjust to the therapy needed for chronic or long-term complications. Former patients have noted that the interruption of life plans, the adjustment in relationships and preparing to re-enter work and family life can be difficult adjustments to make. You may experience a sense of loss or discouragement. Some people become involved in the quest for deeper meaning in their lives. You may want to seek therapy to help you cope with chronic health issues and emotional responses to the challenges of treatment and recovery. You may find that you will benefit from counseling to gain tools for coping with issues of chronic illness or feelings of loss, anxiety, stress, worry and depression.

Reestablishing your life may vary from difficult and rough to easy and smooth. During their recovery some patients express a positive view caused by achieving a redirected life, greater compassion for others and improved family relations. The majority of survivors report that their quality of life is now the same or better than before transplant. On the other hand, some patients struggle and become discouraged as they cope with the various life changes. Despite the intensity of the transplant experience, most patients make effective adjustments in their life and maintain an optimistic outlook for the future.

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

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

Transition to home
The Long-Term Follow-Up (LTFU) department offers telephone consultation services to you and your primary physician when you return home. Call your local physician for everyday concerns. Call your oncologist for treatment related issues. LTFU consultation is available at SCCA if you or your physician is concerned about transplant-related side effects or complications. It is a real possibility that you may be readmitted to a hospital during your first year after transplant.
Self-care steps
You can play a proactive role in your own recovery by taking responsibility for the following self-care steps.

Physician’s visits
These include physical exams, as well as labs and tests (such as blood counts and kidney and liver function tests). Our standard recommendations are:
- Weekly visits for the first month and every other week for the next 2 months. Then go once every 3 to 4 weeks, depending on your progress. Your physician will help you decide.
- A one-year follow-up evaluation is necessary to assess disease status, late complications and to receive vaccinations. Call (206) 667-4415 to make your one-year follow-up appointment.

Skin care
Note any of the following changes in skin, and report them to your physician:
- Color changes
- Rash
- Lesions
- Scaly skin
- Texture changes and thickening
- Stiff or tight skin around joints

It is important to protect yourself from UVA (Ultraviolet and UVB Radiation) and UVB rays for two reasons: exposure can cause sun-activated, chronic graft-versus-host disease (GVHD) of the skin and also add to the increased risk of skin cancer. Take the following steps to protect yourself from harmful rays.
- Protect your lips with SPF (Sun Protection Factor) 30 Chapstick®
- Use sunscreen: SPF 30 or greater is recommended for everyone, reapply every hour while outdoors
- Wear clothing with SPF protectant manufactured into the fabric such as Columbia®, Solumbra® and ExOfficio®
- Avoid long (over 1 hour) exposure to sun
- Apply sunblock or wear SPF clothing even on cloudy days, as they still result in exposure to ultraviolet radiation.

If dry skin is a problem, it is not necessary to bathe daily.
- Use oil in bath water
- Use lotion
- Try natural soap for sensitive skin

Nail care
You should not have manicure and pedicures if your immune system is still recovering and on antibiotics. Avoid fake nails and cutting your cuticles. If your ANC (absolute neutrophil count) is greater than 1,500, without need for transfusions and you are off high dose steroids (greater than 1mg/kg.), you can have a manicure or pedicure. Make sure a single basin is used, and equipment is sterilized after each person. Check your facility for licenses at: https://fortress.wa.gov/dol/dolprod/bpdLicenseQuery/ Choose “Cosmetologist, Barber, Manicurist, Esthetician”.

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Eye care
See your eye physician (ophthalmologist) for any of the following changes:
  - “Gritty” feeling
  - Discharge
  - Changes in vision
  - Continual redness
  - Continual dryness without relief from eye drops
  - Pain or sensitivity to light
  - Sensitivity to wind
  - Burning
  - Excessive tears

Of the patients who receive total body irradiation pre-transplant, 20% develop cataracts within 1 to 5 years after transplantation. Cataracts are also more common in patients who receive long-term steroids. Cataracts can be removed surgically, and the lenses will be replaced. Many patients who develop chronic GVHD will experience eye problems which can be severe. Adequate management of GVHD of the eyes is necessary to avoid severe complications (see chronic GVHD section). Discuss with your eye physician if it is appropriate to change the prescription for your glasses. You may wait until you are receiving less medication such as prednisone that can affect eyesight.

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

Dental visits
See your dentist six months after you return home for an exam to monitor for tooth decay and overall oral care. Routine dental cleaning and dental work should be postponed for at least 12 months after transplant, longer if you are still on an immunosuppressant. Your dentist should also monitor for oral cancer every six months. If dental work is necessary and you are still receiving immunosuppressant medication you will need an antibiotic based on recommendations from the American Heart Association. If urgent dental care is needed in the first year or while you are still on drugs that affect your immune system (those that help prevent or treat graft-versus-host disease), you should take oral antibiotics prescribed by your physician, before dental work is done.

Dry mouth
See a dentist if you have extreme problems with decay. However, fluoride and excellent oral hygiene can minimize or prevent this. Daily home use of fluoride brush-on gels or custom fluoride trays is recommended. Follow guidelines provided by the Oral Medicine department. Saline rinses or other non-prescription products, such as Biotene®, can help to relieve dryness.

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

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

Cognitive changes
The issue of cognitive changes is receiving more research attention. Cancer causes biochemical changes that are now suspected of contributing to cognitive changes, even before any treatment. High-dose chemotherapy and radiation affect cognitive function. Studies show varying incidences of “chemo brain” among transplant patients. However, research indicates that the decrease in memory, multi-tasking ability and attention which characterize post-treatment cognitive changes resolve for a majority of people after about a year. People can return to their pre-transplant cognitive functioning anywhere from one to five years post-transplant. Some people will continue to have memory or fine motor difficulties. If you are still having difficulties with cognitive changes after one year, ask your physician for a referral for neuropsychological testing so you know what your deficits are and what you can do about them. Review the symptom sheet in this manual. In the meantime, help your memory by keeping a notebook where you put the things you want to remember. Make sticky notes about what you do not want to forget, like taking a medication before you go to bed. Put the sticky note by something you always remember, like brushing your teeth. Keep a basket by the door for the things you need to take with you like keys or glasses.

Sleep
Most people have difficulty with sleep at some point during and after transplant. It can be hard to get on a regular cycle of sleep and worry tends to increase as people lie in bed awake. Medication should be a short-term solution, not a lifetime aid. Tips that help include keeping the bedroom dark and cool, and going to bed and getting up at the same time each day. Get out of bed and do a relaxing activity like reading if you do not sleep after 30 minutes of trying. Learn relaxation skills to help your body and mind to relax while you are lying in bed.

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

You may continue to experience significant distress following your transplant. Sometimes, this can lead to feelings of sadness or depression and associated symptoms such as worry, anger, and fatigue. Distress can also lead to changes in sleep and eating patterns. Even post-traumatic stress can happen. We recommend making time and saving energy to participate in activities that you enjoy, so life is not entirely about your health. Spend time with friends and family. If these symptoms continue for more than a couple of weeks, it is important to discuss them with your physician or nurse. Some people find that talking to a therapist after transplant is very helpful. There is so much that most people have been through and have to cope with after treatment. Talking with a therapist can help you reclaim your life and make sense of what you have gone through.
**Fatigue, weight, and exercise**

“Some problems such as fatigue can begin during therapy and may continue indefinitely, though the duration and severity differs greatly between individuals.”

-Rabiya Tuma, PhD, *Treatment Aftershocks*

Many people report increased fatigue after transplant. Exercise is an effective way to decrease this fatigue over time. We recommend a program of daily moderate exercise, such as walking. Increase the distance and pace as your strength and stamina increase. It is also important to rebuild muscle through a program of gradually increasing weight training. Couple this with stretching, yoga and/or gentle fitness classes. See if a YMCA near you a low-cost cancer survivorship has program, or ask for a physical therapy referral to get an exercise plan from someone who has experience with exercise after cancer treatment. If you exercise at a moderate level and have rebuilt muscle, but your fatigue continues or if your fatigue increases, talk to your physician about other possible causes of fatigue. The best exercise is the one that you do regularly! Follow the advice of the nutrition staff. Eat healthy foods.

**Osteoporosis for allogeneic transplant recipients**

Osteoporosis or bone loss may happen in some patients. It is related to irradiation, use of steroids, inactivity and low hormone levels. Weight bearing exercise is recommended to help prevent or stabilize osteoporosis. You may need calcium and vitamin D supplements, or bone rebuilding medications. You can discuss this with your local physician.
**Immune system recovery**

Adequate immune function takes approximately 1 year after transplantation to recover. Adequate immune function may take longer if you have chronic GVHD or are taking medications that suppress your immune system. During this time, you are still vulnerable to infections. Symptoms such as fever, chills, coughing, difficulty breathing, severe diarrhea or vomiting should be promptly reported to your physician.

**Cytomegalovirus (CMV) monitoring**

You may need weekly CMV monitoring after treatment. At discharge you will receive specific recommendations to take to your local physician.

**Exposure to others**

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

**Hand washing**

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

**Temperature**

Take your temperature if you are feeling ill, shaking chills or suspect that you have a fever. Note time and circumstances. Notify your physician promptly if you have a:

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

**Rash**

Notify your physician promptly if any rash develops.

**Animals and plants**

Avoid contact with body excretions of all animals and do not sleep with pets. Do not bring new pets into the home during the first year or thereafter if you are taking immunosuppressant medications. Established household pets and plants may remain in the home. Gardening is not recommended while on drugs that suppress the immune system.

**Sexual activity**

Limiting the number of sexual partners is advised. Use condoms for protection against Sexually Transmitted Infections (STI). Normal cleanliness should be observed. Use birth control as necessary to prevent pregnancy, as you may not be sterile. Discuss with your physician and nurse. If dryness is a problem, a lubricant may be helpful. Drugs used for impotence should be avoided while you are on an immunosuppressant and should not be used without a cardiac evaluation.
Swimming
Swimming may expose you to microorganisms capable of causing infections. You should measure the benefits of swimming against the potential risks of these infections. If swimming or water aerobics is the preferred or recommended method of exercise, it should be done in a well-maintained pool with adequate chlorination. Your face should not be submerged under the water. Never swim with a central line in place. Also, do not swim for the first 6 months after the transplant or if on drugs that treat GVHD within the first year. Hot tubs should not be used for the first 6 months after transplant or if you are on drugs that treat GVHD.

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

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

Take a copy of critical medical records with you.
- Seek medical care promptly for new symptoms.
- Control your environment by avoiding crowds and maintaining infection precautions.
- If you fly, ask to be moved if you are seated near someone with respiratory symptoms. Carry hand sanitizer and wipes.

Other reminders
- **Minimize** exposure to dirt and aerosolized material
- **Minimize** sun exposure, use sunscreen (SPF greater than 30)
- **Use** hat, long-sleeve shirts and long pants if outside for long period of time
- **Avoid** construction sites
- **Avoid** contact with people that:
  - Have cold and flu symptoms like coughing and sneezing.
  - Display symptoms of other types of infections such as vomiting or skin rashes.
Immunizations

Patients generally receive post-transplant immunizations starting at one year. These killed-virus and killed-bacterial immunizations include:

- Tetanus
- Diphtheria
- Pertussis
- Meningococcal
- Inactivated polio
- Influenza
- Pneumonia
- Haemophilus influenza type B
- Hepatitis B
- Hepatitis A
- Human papilloma virus (HPV) (ages 9-26)

If you do not return for your one-year follow up, ask your physician to contact the Long-Term Follow-Up department about immunizations. If a household member receives the varicella (chickenpox) vaccine, you should be taking acyclovir. If a household member develops lesions (or pox), you need to be isolated while their lesions are present.
Graft-versus-host disease (GVHD)

One form of GVHD which may occur around day 80 or later is called chronic graft-versus-host disease. Approximately 50% of patients who receive allogeneic transplants are diagnosed with chronic GVHD, with variation in the incidence related to characteristics of the donor and the source of the stem cells. GVHD can affect any organ. Unfortunately, 15% of the patients develop severe chronic GVHD that goes on for many years and may lead to disability. The range of medical issues caused by GVHD can be mild to severe.

You might notice your skin becoming dry, scaly and discolored with patches of thickened or hardened underlying tissue. The surface of the eyes and mouth can become dry. Mouth lesions may develop. Sometimes the esophagus, gastrointestinal tract or liver are affected. Weight loss due to poor absorption of food or GVHD increased catabolism (burning more calories despite adequate eating) can occur. Bacterial infections are common. Treatment protocols have been developed for GVHD and the Long-Term Follow Up team is available to you and your physician if you develop symptoms after going home. Having GVHD may not be all bad. Patients with GVHD have a lower risk of the cancer returning after transplantation than patients who do not develop GVHD.

Report any of the following changes to your physician. Make sure your physician is watching for possible changes in your liver and kidney function test results as well.

- **Skin:** Rash, thickness, discoloration, tightness, texture changes, shining, itching
- **Hair:** Thinning or coarse
- **Nails:** Texture changes, brittleness, ridges
- **Eyes:** Dryness, grittiness, irritation, burning, blurring, discharge, tears, sensitivity to light or wind
- **Mouth:** Dryness, pain, sensitivity to hot/cold foods or toothpaste, ulcers, white lacy changes on gums and cheeks
- **Vagina:** Dryness, irritation, tightening
- **Penis:** Irritation
- **Digestive System:** Nausea, vomiting, diarrhea, loss of appetite, unexplained weight loss
- **Lungs:** Chronic dry cough, wheezing, shortness of breath
- **Liver:** Jaundice and elevated liver test numbers
- **Joints:** Unable to fully extend fingers, wrists, elbows, ankles or knees, joint pain, or stiffness
- **Energy Level:** Increased fatigue
- **Temperature sensitivity:** Cold intolerance, inability to sweat

**Treatment of GVHD**

The duration for treatment of chronic GVHD with immunosuppressants varies between two to three years after the initial diagnosis of this complication. Approximately 10% of patients require treatment for seven years or longer for chronic GVHD. Eventually the graft will develop tolerance to the new body and the GVHD will resolve without the need of treatment.
Therapies most commonly used for chronic GVHD are prednisone, cyclosporine, tacrolimus, rapamycin, mycophenolate mofetil, and others. All immunosuppressive drugs have some side effects. The most common toxicities of drugs used for the treatment of GVHD are listed below.

- **Prednisone**: Osteoporosis, deterioration of joints that can require joint replacement, increased risk of infections, diabetes, cataracts and emotional variance, changes in body habitus (weight gain, moon face).
- **Cyclosporine**: Kidney function issues, wasting of magnesium, tremors, headaches, seizures, nausea, increased blood pressure.
- **Tacrolimus (Prograf®)**: Similar to cyclosporine.
- **Mycophenolate mofetil (MMF or CellCept®)**: Nausea, vomiting, diarrhea, bleeding, decreasing white blood cell count, anemia.
- **Rapamycin, Sirolimus (Rapamune®)**: Decreased white cells or platelets, increased triglyceride level, edema, and others.

Despite the side effects of medications used to treat chronic GVHD, adherence to the treatment schedules and doses is of the utmost importance in the long term. Damage from untreated or undertreated chronic GVHD to the eyes, lungs and skin cannot be reversed. It is worse than the side effects of the medications used to treat it.

**Medications**

Your medications are important to help you maintain your general health. Please take them as prescribed.

- **Bactrim® (sulfamethoxazole-trimethoprim)**: This is a broad-spectrum antibiotic specifically for the prevention of pneumocystis pneumonia and for prevention of certain types of bacterial infections (Streptococcus pneumonia and Haemophilus influenza).
  - Take this medication if prescribed for at least 6 months after transplant, or longer if continued on immunosuppression medications.
  - **Always take Bactrim® (or an alternate drug) when taking immune suppression medications.**
  - **If on tapering doses of immunosuppression medications**, take Bactrim® until 6 months after treatment of chronic GVHD.
- **Acyclovir or valacyclovir**: These drugs are antiviral agents used to prevent varicella zoster (shingles). If one of these is prescribed, it should be taken for the entire first year, and should be given concurrently while on immunosuppression and for six months after completion of taper.
- **Hormones**: Hormones may be prescribed for women in premature menopause due to the effects of conditioning therapy.
- **Immunosuppression**: Keep accurate records of dates when stopping or restarting immunosuppressive medications (prednisone, cyclosporine, MMF, tacrolimus, rapamycin). Immunosuppressive medications may require your blood levels to be checked.
Secondary cancers

There is an increased risk of getting a different cancer in long term survivors after transplantation. The risk starts to increase at five years after transplantation. Skin, mouth, thyroid and breast are the most common sites of secondary cancers after transplant. Cancer screening evaluation is recommended and includes: complete skin examination, oral exams, breast exam and mammograms (woman), prostate exam (men), colonoscopy (according to age and history), and others as needed. Original disease restaging is also recommended at periodic intervals depending on diagnosis. For patients transplanted for CML or acute lymphocytic leukemia PH+, blood monitoring for the BCR/ABL by PCR test is recommended periodically.
Reconnecting with life and survivorship

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

-BMT Survivor

It is normal to feel vulnerable after returning home. These feelings are valid, but don’t push the panic button every time someone sneezes! It’s important for you to see your friends and return to normal activities too. Just use common sense—“when in doubt, don’t.” Some patients, especially those who had a stormy transplant course, find it hard to plan for the future. Make a specific detailed plan for something you want to do. This helps you to feel like you are moving toward something, not just marking time while you recover.

Helpful hints to remember

- It is healthy to find a “silver lining” in your situation. It doesn’t mean that you forget the clouds, it’s just that the clouds are not the whole story.
- You are your own best friend. Take care of yourself. Get enough rest, exercise and good nutrition. Be patient with yourself and others.
- Watch for changes in your body, hair, nails, eyes, skin, mouth and joints. Tell your physician of any changes.
- Try to take one day at a time; focus on your goals for today, particularly after you first return home. Make sure you include something you enjoy in each day.
- It is normal to feel alone at times; it’s true that no one else has been down your road and really knows what it is like for you. Make it a goal to connect with people and do activities you enjoy so that you start to feel like part of your community, even if at first you don’t feel like it.
- Remember that your caregiver and family have also been through a major challenge. Check in with them weekly to let each person describe what they are experiencing. You don’t need to fix each other’s concerns; just use this as a time to listen and reflect upon what each person is feeling. Ask if there is anything that would make things better.
- Do not be afraid to ask for professional guidance; you deserve it! Almost everyone receives some kind of help.
- Check with your employer to see if you have access to an Employee Assistance Program.
- SCCA suggests that you return one year following your transplant for re-evaluation.

Relationships

It may be difficult to resume relationships as they were before your BMT because your experience has changed your perspective on life. Your illness may have affected the feelings and perspectives of the people around you. It may have produced role changes that can affect relationships. People report that these changes can be very positive, but they also can take some time to sort out. Make sure each person in your family has a chance to describe their fears and concerns. Even if it is hard, try to give each person time to describe what is going on in their lives and thoughts. Caregivers may be used to taking care of you and home tasks. These role changes can take time to get back to normal. You can help them along by discussing a weekly plan of who will do what. As you are ready for more responsibility, make this clear to your caregiver. With friends, it might help to discuss what is different in your life and how much the friendship means to you. Sometimes you may have to reach out to friends rather than waiting for them to come to you.
Returning to work or school
Returning to work or school is very complicated. You need to be ready both physically and emotionally. We suggest that you wait 6-12 months after transplant to return to work or school, but home tutoring or work in a home office can precede these dates. You may be eligible for social security benefits because of your inadequate immune system. This will be the case for at least one year and possibly longer if you are on immunosuppressive medication for GVHD. There are many organizations that assist cancer and transplant survivors with employment issues. For more information on your employment rights, see the Resources section at the end of this chapter.

The Department of Vocational Rehabilitation offers counseling to for emotional or physical disabilities. Some people are eligible for social security. See below for additional information:

- Department of Vocational Rehabilitation  [www.dshs.wa.gov/dvr/](http://www.dshs.wa.gov/dvr/)
- Americans with Disability Act  [www.ada.gov/](http://www.ada.gov/)
- Cancer and Careers  [www.cancerandcareers.org](http://www.cancerandcareers.org)

Financial concerns
Many people report insurance and financial concerns. We recommend that you look into social security and private disability insurance. Look online and at the Resources at the end of this chapter for more information on BMT financial concerns.

Young adults
The road to independence and maturity is more difficult for young adults who have been ill. Feelings may fluctuate, sometimes viewing parents as being overly concerned and involved, and at other times feeling insecure and wanting more parental guidance and reassurance. Many young adults report that starting to date and sexual activity can bring uncertainty. An excellent resource for young adults experiencing this is [myplanet.planetcancer.org/](http://myplanet.planetcancer.org/)

Sexuality
“Nobody wants to talk about it. It becomes a self-propelling problem, in that, the longer time goes by, people then also become kind of less connected with that part of themselves.”

- Sharon Bober, PhD

Most men and women notice a drop in sexual desire during the first year. Make time for intimacy so that you begin to re-awaken those feelings. You may have a low energy level or feel unattractive due to the changes that your body has undergone. Partners often hesitate to make sexual advances out of concern for your health. Women can have vaginal changes and men may have erection problems. Medications can be the cause of some of these changes; problems may disappear over time or after stopping the drugs. Hormones can change for men and women after transplant. For men, it often takes a full year for testosterone levels to return to normal, affecting both erections and desire. It’s important for both partners to talk about their feelings and to be patient with one another. Begin to set aside “date” time to be romantic, include touching in your intimate time together. Start trying sexual activity even if your desire is not back to its previous level. If dryness or irritation is a problem, a silicone-based lubricant can be helpful. Water-based lubricants are also safe, but won’t last as long. If graft versus host disease or sensitivity is a problem, ask to see a sexuality-after-cancer specialist or look online at BMT websites on sexuality to learn more about what can be done for these problems. After cardiac evaluation, drugs used for erectile problems can be helpful for some men.
**Survivor syndrome**

“Little studied, survivor guilt brings with it a host of issues that can cause depression, anger and self-blame that may even compromise health.”

-Kathy Latour, *Getting Through Survivor Guilt*

You may have feelings of guilt because you are alive when others did not survive. You may also have a strong sense of grief and loss. Even though you are glad to be alive, it is normal to feel that you have lost things that you will never again be able to regain. Discussion with a counselor, minister, priest or rabbi can help put this in perspective. If you aren’t sure what you want to do, or feel like you want a change, give yourself time to recover while you discover what you want most. Some people re-evaluate what they want to do for the rest of their life. Having survived this adventure, you might decide to try another new one!

**Survivorship clinic**

Cancer and its treatment can result in some potentially long-lasting or late-onset effects. The SCCA Survivorship Clinic addresses various problems cancer survivors may face after therapy ends. These include pain, fatigue, and fear of recurrence, living with uncertainty, neuropathy, lymphedema, bone loss, sexual dysfunction, cardiovascular disease, memory issues, and future cancer risk. At the survivorship clinic, our medical staff will talk with you about how to assess and manage late complications or issues you may be experiencing and develop a plan to support your future health.

As part of your appointment in the Survivorship Clinic you will receive an individualized [Treatment Summary and Survivorship Care Plan](#). This includes an evaluation and information on the prevention of the late effects of your cancer and cancer treatment, recommendations and resources for dealing with long-term effects, and suggestions for healthy lifestyle behaviors. Copies of the treatment summary, survivorship care plan, and any recommendations made during the appointment are shared with your health care team, including your oncologist and primary care physician. We will work in partnership with these physicians to make sure your survivorship needs are being met. We do not provide testing for recurrence of your cancer; this care will continue to be provided by your oncologist. To schedule an appointment in the SCCA Survivorship Clinic please call (206) 606-1024. Visit the Survivorship Clinic website at [www.fredhutch.org/en/treatment/survivorship/survivorship-clinic.html](http://www.fredhutch.org/en/treatment/survivorship/survivorship-clinic.html)

Transitional Transplant clinic (TTC) is a clinic for patients with complex conditions such as GVHD that is not well controlled, serious infections, or other complex conditions that require extensive ongoing management. Talk with your nurse if this is right for you.
Sample letter for returning home

To my family and friends:

I am recovering from a bone marrow transplant. I am able to return home; however, my recovery from this procedure can take months. The following is a list of some of the ways you can help with my recovery.

My risk for infection continues
It will take at least ____ months for my immune system to recover. It’s possible that it could take even longer, depending on what medications I will need or what complications I might experience. I am at a higher risk for infection and will need to pick activities that will minimize my risk of infection. Family and friends need to be up to date with their vaccinations. Please see the vaccination recommendations in the Preparing for Transplant booklet.

Hand washing etiquette
Hand washing is the most effective way to prevent infection from spreading. I was taught to wash my hands frequently. My family, friends and visitors will be asked to do the same when in my company. Please don’t be offended if I remind you to wash your hands.

Time to eat
I have to follow a special diet while my immune system recovers. If you wish to help by providing meals, I would be happy to give you a list of what I can and cannot eat.

Fatigue
I will have good days and bad days. I would like to see you; however, short visits will be better for me. Some days I might not be up to visitors, long conversations or involved activities. Exercise can help with fatigue so please offer to walk with me.

Memory and concentration
The treatment and medications I take can affect my memory and ability to concentrate.

My caregiver
______________ had a lot of responsibility while we were in Seattle. Now that we are home,______________ will still have caregiver responsibilities along with all the usual home and work routines. If you would like to help, please see the list of suggestions below:

• Drive me to and from appointments.
• Run errands for my caregiver or visit with me so my caregiver can have a break.
• Take my children out for an activity.
• Help with household chores and/or yard work.
• Remember my caregiver with a phone call or offer to do something fun.
• Join me for a walk!
• Walk the dog.

And please remember, all of your help and phone calls are appreciated as I move forward with my “post-transplant” life! The support of family and friends is an integral part of this transition. Thank you so much for your support.

Sincerely,
Survivorship resources and websites

Post-transplant networks
Blood and Marrow Transplant Information Network
www.bmtinfonet.org

Be the Match
Bethematch.org

BMT-TALK Bone Marrow Transplant Forum. Email listserv@listserv.acor.org to subscribe. In the message body, write “SUBSCRIBE BMT-TALK” and your first and last name.

Emotional Support for Transplant Patients Cancer Survivors Network
http://csn.cancer.org/

Recommended tests and procedures
Center for International Blood & Marrow Transplant Research
www.cibmtr.org

Fertility
Resolve Support Group for infertile couples:
www.resolve.org

Help with post-transplant medication costs
Patient Access Network Foundation
www.panfoundation.org/

Hospitals and clinics
Seattle Cancer Care Alliance
www.seattlecca.org

Fred Hutchinson Cancer Research Center
www.fredhutch.org

SCCA Hospital and University of Washington Medical Center
www.uwmedicine.org/patient-care/locations/uwmc/Pages/default.aspx

Seattle Children’s
www.seattlechildrens.org

Insurance and employment rights
Cancer Advocacy Now
www.canceradvocacynow.org
Employment Rights Cancer and the Americans with Disabilities Act
www.eeoc.gov/facts/cancer.html

The Job Accommodation Network
http://askjan.org

Fair Employment for Cancer Patients and Survivors
http://csn.cancer.org/node/161348

National organizations
National Bone Marrow Transport Link
www.nbmtlink.org/resources_support/support.htm

National Cancer Institute

National Marrow Donor Program- Search Post-Transplant Care
http://marrow.org/Physicians/Post-Transplant_Care/Post-Transplant_Care.aspx

National LGBT Cancer Network
www.cancer-network.org

American Cancer Society
www.cancer.org

National Coalition for Cancer Survivorship
www.canceradvocacy.org

Men’s health
Men’s Health Network
www.menshealthnetwork.org

Pediatric
American Childhood Cancer Organization
www.acco.org

Children’s Oncology Group
www.survivorshipguidelines.org

Human Growth Foundation
Hgfound.org

Skin care
Skin Cancer
www.skincancer.org
Sun Safety
www.fda.gov, search “Sun Safety”

Sun Precautions Clothing
www.sunprecautions.com or Phone number 1-800-882-7860

Women’s health
North American Menopause Society
www.menopause.org

National Women’s Health Network
http://nwhn.org/

Health Insurance Pamphlet ACS

Young adult
My Planet
http://myplanet.planetcancer.org/

The Long-Term Follow-Up Department
Please contact your local physician for medical needs or emergencies. If you have transplant-related questions that your physician cannot answer, or to schedule your long-term follow-up appointment, leave a voice mail message and one of the long-term follow-up staff members will return your call. Please leave the spelling of your name in addition to your question. We will attempt to return your call within 24 to 48 hours during weekdays. Your call will be reviewed, and an experienced transplant nurse will return your call within 24 to 48 hours.

Long-Term Follow-Up Physician Program Guidelines:

Fred Hutch Long Term Follow Up:
Click on “Information for Patients” in the left hand navigation column.

Contact information for LTFU
Phone number: (206) 667-4415
Toll Free Fax: (206) 376-8197
Fax: (206) 667-5619
Email: LTFU@seattlecca.org
Common infection control questions

<table>
<thead>
<tr>
<th>Questions often asked</th>
<th>Time after transplant</th>
</tr>
</thead>
<tbody>
<tr>
<td>All patients post-transplant</td>
<td>Not receiving immunosuppression</td>
</tr>
<tr>
<td>From 3 to 6 months</td>
<td>Receiving immunosuppression</td>
</tr>
<tr>
<td>From 6 months to 1 year</td>
<td>Receiving immunosuppression</td>
</tr>
</tbody>
</table>

**Patients:** Discuss with your physician when restrictions may continue to apply to your care after one-year post-transplant.

### Animals, birds, reptiles, fish

<table>
<thead>
<tr>
<th>Small cage rodents (gerbils, rabbits, hamsters, guinea pigs, hedgehogs, prairie dogs, ferrets, others)</th>
<th>Do not handle</th>
<th>No</th>
<th>Ok</th>
<th>Ok</th>
<th>Ok</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reptiles and amphibians (snakes, turtles, frogs, lizards, and iguanas)</td>
<td>Do not handle</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Farm animals (pigs, horses, cows, llamas, others)</td>
<td>Do not handle; stay out of barns full of hay</td>
<td>No</td>
<td>Ok</td>
<td>Ok</td>
<td>Ok</td>
</tr>
<tr>
<td>Exotic, wild, and game animals (deer, elk, squirrels, bear, and monkeys)</td>
<td>Do not handle</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Zoos and petting zoos</td>
<td></td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Aquariums (3)</td>
<td>Do not touch marine life in handling tanks</td>
<td>No</td>
<td>Ok (3)</td>
<td>Ok (3)</td>
<td>Ok (3)</td>
</tr>
<tr>
<td>Animal trophy mounts in the house</td>
<td></td>
<td>Ok</td>
<td>Ok</td>
<td>Ok</td>
<td>Ok</td>
</tr>
<tr>
<td>Fishing (fresh and salt water)</td>
<td></td>
<td>Ok</td>
<td>Ok</td>
<td>Ok</td>
<td>Ok</td>
</tr>
<tr>
<td>Hunting (wild game and birds) and sport shooting (2)</td>
<td></td>
<td>No</td>
<td>Ok (2)</td>
<td>Ok (2)</td>
<td>Ok (2)</td>
</tr>
<tr>
<td>Horseback riding</td>
<td></td>
<td>No</td>
<td>Ok</td>
<td>Ok</td>
<td>Ok</td>
</tr>
<tr>
<td>Cats/dogs</td>
<td></td>
<td>Ok</td>
<td>Ok</td>
<td>Ok</td>
<td>Ok</td>
</tr>
<tr>
<td>Do not sleep, feed, bathe, or groom pets</td>
<td></td>
<td>Ok</td>
<td>Ok</td>
<td>Ok</td>
<td>Ok</td>
</tr>
<tr>
<td>New pets in patient’s household</td>
<td></td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Cleaning feces, litter boxes, utensils, cages, and tanks</td>
<td></td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Domestic birds (parakeets, parrots, others)</td>
<td></td>
<td>No</td>
<td>Ok</td>
<td>Ok</td>
<td>Ok</td>
</tr>
<tr>
<td>Not if you have respiratory problems</td>
<td></td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Poultry and wild birds (pigeons, baby chicks, chickens, ducks, geese, and other wild birds)</td>
<td></td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
</tr>
</tbody>
</table>
### Other activities

<table>
<thead>
<tr>
<th>Activity</th>
<th>(1)</th>
<th>(2)</th>
<th>(3)</th>
<th>(4)</th>
<th>(5)</th>
<th>(6)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Golfing</strong> (2)</td>
<td>No</td>
<td>Ok</td>
<td>Ok</td>
<td>Ok</td>
<td>Ok</td>
<td>Ok</td>
</tr>
<tr>
<td>Sun protection required; without venous catheter device</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Spectator events and crowds</strong></td>
<td>No</td>
<td>Ok</td>
<td>Ok</td>
<td>Ok</td>
<td>Ok</td>
<td>Ok</td>
</tr>
<tr>
<td><strong>No hand shaking</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sexual activity</td>
<td>Ok</td>
<td>Ok</td>
<td>Ok</td>
<td>Ok</td>
<td>Ok</td>
<td>Ok</td>
</tr>
<tr>
<td>Working with mechanical equipment (oil changes, working on cars and engines)</td>
<td>Ok</td>
<td>Ok</td>
<td>Ok</td>
<td>Ok</td>
<td>Ok</td>
<td>Ok</td>
</tr>
<tr>
<td>Camping and hiking</td>
<td>Ok</td>
<td>Ok</td>
<td>Ok</td>
<td>Ok</td>
<td>Ok</td>
<td>Ok</td>
</tr>
<tr>
<td>Down comforters (with cover)</td>
<td>Ok</td>
<td>Ok</td>
<td>Ok</td>
<td>Ok</td>
<td>Ok</td>
<td>Ok</td>
</tr>
<tr>
<td>School</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>Ok</td>
<td>Ok</td>
<td>Ok</td>
</tr>
<tr>
<td>Hot tubs</td>
<td>No</td>
<td>Ok</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Avoid all public hot tubs (6)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Swimming (1)</td>
<td>No</td>
<td>Ok</td>
<td>No</td>
<td>Ok</td>
<td>Ok</td>
<td>Ok</td>
</tr>
<tr>
<td>Without venous catheter device, avoid head submersion and diving, use sun screen</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gardening (digging in soil); mowing the lawn; raking leaves</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Having plants in the home</td>
<td>Ok</td>
<td>Ok</td>
<td>Ok</td>
<td>Ok</td>
<td>Ok</td>
<td>Ok</td>
</tr>
<tr>
<td>Do not handle (4)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Making/kneading yeast breads (5)</td>
<td>No</td>
<td>Ok</td>
<td>Ok</td>
<td>Ok</td>
<td>Ok</td>
<td>Ok</td>
</tr>
<tr>
<td>Carpenter work</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Occasional woodworking (sawdust)</td>
<td>No</td>
<td>Ok</td>
<td>Ok</td>
<td>Ok</td>
<td>Ok</td>
<td>Ok</td>
</tr>
</tbody>
</table>

**Key:**

1. No swimming if venous access device still in place (i.e., catheter) or patient history of sinusitis. Swim in chlorinated and well-maintained pools. Uncertain water conditions of lakes, rivers and the ocean for swimming are Ok if water is tested routinely for safety by local state and health departments; avoid small bodies of standing water (lakes and ponds). Swimming in pools used by non-toilet trained babies and children not recommended. Water aerobics Ok.

2. Shooting rifles/shotguns & golfing is not recommended if venous access devise still in place (such as a catheter).

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

4. Real Christmas trees: in the water reservoir of the tree stand, use water solution of 1-part chlorine solution (Clorox®) in 10-parts water.

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

6. Avoid all public hot tubs.
Chapter 5 – Appendix
Overview
Fred Hutch, Seattle Children’s, and University of Washington Medicine have integrated their adult and pediatric oncology-related patient care services into a separate, jointly governed Seattle Cancer Care Alliance (SCCA). SCCA creates a highly integrated approach to cancer research and treatment. 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.

SCCA purpose and principles
The Alliance 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 care, regionally and beyond.
• Collaboration across the care delivery system.

Inpatient services
Pediatric inpatients receive care at Seattle Children’s, and adult inpatient services are provided at SCCA Hospital or a specialized unit of UWMC.

Outpatient services
Outpatient services are located at the SCCA clinic, in the South Lake Union neighborhood at 825 Eastlake Avenue East. If you have any questions regarding the Alliance, feel free to ask your physician or nurse.

SCCA patient rights and responsibilities
SCCA respects the rights of all our patients equally and individually.

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. 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 online at www.jointcommission.org, or by e-mailing your concerns to complaint@jointcommission.org.

Medicare and Medicaid patients may also make complaints to Livanta LLC BFCC-QIO Program, 9090 Junction Drive, Suite 10, Annapolis Junction, MD 20701. Phone: 1-877-588-1123, Fax (appeals): 1-855-694-2929, Fax (all other types): 1-844-420-6672

Personal valuables
SCCA 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 Hutch, UW Medical Center, SCCA Hospital, 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 before entering the clinic.
Maps and directions

To SCCA from I-5 north or southbound:
1. Take Exit 167 Seattle Center/Mercer St.
2. Move to the far-right lane and turn right at Fairview Ave. N.
3. Turn right at Aloha St and go 2 blocks.
4. SCCA will be on the right. Visitor parking is beneath the clinic building.

To UW Medical Center and SCCA Hospital from SCCA:
1. Travel north on Fairview Ave N or Eastlake Ave E (street becomes 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 Surgical Pavilion:
On Pacific Street, turn left at turning lane toward the Surgical Pavilion. Veer left into the Pavilion Parking Garage. Take garage elevator up to third floor. (garage height restriction is 6’ 8”)

To UWMC 8SE:
From main entrance, follow signs for the “Cascade Elevators”. Take elevators to 8th floor (8SE). Turn right from elevators and check in at the 8SE Reception Desk (parking can be validated here).

To UWMC Triangle Garage:
Access from NE Pacific Place off of Pacific Street, across the street from the Medical Center via a pedestrian tunnel under NE Pacific (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

Seattle Children’s Hospital
4800 Sandpoint Way NE
Seattle, WA 98105
(206) 987-2000

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

SCCA clinic, 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.
# Charts and records

## Blood counts

<table>
<thead>
<tr>
<th>Day</th>
<th>Date</th>
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| WBC | 4 - 10 |
| ANC | 3.2 - 4 |
| Polys | 2 - 7.5 |
| Bands | 0 - 1 |
| Lymphs | 1 - 4.5 |
| Monos | 0 - 1.4 |
| Eophils | |
| Basophil | 0 - 0.3 |
| Metamyelocyte | 0 |
| Myelocyte | 0 |
| Platelet | 150 - 400 |
| SGOT | <50 / 78 |
| Creatinine | 0.7 - 1.5 |
| BUN | 4 - 22 |
| Bilirubin | <1.2 / 0.3 |
| Cyclosporine | 300-1200 |

| RBC | 4 - 5.3 |
| HGB | 12 - 15 |
| HCT | 36 - 45 |
| MCV | 81 - 100 |
| MCH | 27 - 35 |
| MCHC | 32 - 37 |
| RDW | 0 - 15.1 |
| Magnesium | 1.5 - 2 |
| Sodium | 136 - 145 |
| Potassium | 3.5 - 5.5 |
| Chloride | 95 - 110 |
| CO₂ | 23 - 31 |
| Glucose | 60 - 110 |
### Daily food intake sheet

<table>
<thead>
<tr>
<th>Time</th>
<th>Served (ml)</th>
<th>Eaten (ml)</th>
<th>Code</th>
<th><strong>Liquids</strong></th>
<th>Time</th>
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**Bowel movement record**

Please answer these questions at the end of the day.

Date ______________
- How many bowel movements (stools) did you have today? ______________
- How many times did you vomit today? ______________

Please circle the number which best depicts your bowel movements today.
1. Watery
2. Liquid, creamy
3. Very loose, mushy, semi-liquid
4. Loose, soft
5. Formed with some liquid
6. Soft, formed
7. Normal, formed
8. Hard
9. Hard, dry