Surgical Program

Patient Care Manual

Knowledge is Power
SCCA Patient and Family Education
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Seattle Cancer Care Alliance
Updated 8/7/2017
Maps and Directions

SCCA Clinic
825 Eastlake Avenue East
Seattle, WA 98109-1023
(206) 606-7222

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

The SCCA and the University of Washington Medical Center Garages (Surgery Pavilion and Triangle) offer same day reciprocal parking. Simply bring your receipt from a participating garage to your next appointment and it will be honored.
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 clinic will be on the right. Visitor parking for the SCCA clinic is beneath the clinic building.

To UW Medical Center 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”).
Important Phone Numbers

For questions about clinic visits, your treatments or symptoms, contact the SCCA Clinic.
For scheduling concerns and questions, call your Team Coordinator:
Scheduler Name: ______________________________________
Scheduler Number: ____________________________________

For questions about your treatment, symptoms and prescription needs, call your Clinical Nurse Coordinator:
Nurse Name: _________________________________________
MD Name: ___________________________________________

In the event of an SCCA phone outage, please call (206) 467-4950 or (206) 467-4951.

In the case of severe weather or a natural disaster, please check the SCCA website for any announcements regarding operational hours. If you are unable to travel, please call your scheduler to reschedule your appointment.

<table>
<thead>
<tr>
<th>CALL FOR PROBLEMS</th>
<th>4th Floor</th>
<th>3rd Floor</th>
</tr>
</thead>
<tbody>
<tr>
<td>8am-10pm, Mon.-Fri.</td>
<td>206-606-7400</td>
<td>206-606-7300</td>
</tr>
<tr>
<td>8am-6pm, Sat, Sun</td>
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<tr>
<td>8am-5pm, Holidays</td>
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</tr>
<tr>
<td>10pm-8am, Mon.-Fri.</td>
<td>206-598-6190:</td>
<td>206-598-6190:</td>
</tr>
<tr>
<td>6pm-8am, Sat, Sun</td>
<td>Ask for the Fellow</td>
<td>Ask for the Resident</td>
</tr>
<tr>
<td>5pm-8am, Holidays</td>
<td>On-Call</td>
<td>On-Call</td>
</tr>
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Apheresis (206) 606-2120
Chaplaincy (206) 606-1099
Guest Services (206) 606-6701
Health Information Management/Release of Information (For assistance with obtaining or transferring your medical records.) (206) 606-1114
Infusion (206) 606-7500
Institutional Review Office (206) 667-6567
Interpreter Access Line (855) 670-9798
Living Tobacco-Free (206) 606-7766
Medical Nutrition Therapy (206) 606-1148
Medical Records (206) 606-1114
Patient & Family Education (206) 606-1472
Patient & Family Resource Center (206) 606-2081
Patient Financial Services (206) 606-1113
Patient Relations Office (206) 606-1056
Pharmacy Refills
    M-F 8am - 8pm (206) 606-6500
    Sat & Sun. 8:30am - 5pm (206) 606-6500
Clinical Pharmacists, M-F 8-5
    Anticoagulation Pharmacist (206) 606-6756
    GI or GU (206) 606-2017
    Breast or Gyn Onc (206) 606-1044
    Heme/Melanoma/Renal Cell (206) 606-6788
    Head /Lung/Neck/ (206) 606-6279
    Neuro Onc and Sarcoma (206) 606-7583
Physical Therapy (206) 606-6373
Procedure Suite (206) 606-7200
Radiation Oncology (206) 606-7318
Rain or Shine / Shine Gift Shop (206) 606-8270 or (206) 606-7560
Receptionist 1st floor (206) 606-1000
Regulatory Guidance (206) 616-8222
Security (Lost and Found) (206) 606-1111
Social Work Office (206) 606-1076
Survivorship (206) 606-1024
Volunteer Services (206) 606-1075
UWMC Human Subjects (206) 543-0098
UWMC Patient Data Service (206) 598-4344
UWMC Patient Relations (206) 598-8382
UWMC Pharmacy (206) 598-4363

For questions about clinic visits, treatments or symptoms, contact the SCCA Clinic.
**UWMC Helpful Contacts**
You may find these phone numbers helpful. If you are using a phone inside the hospital, press only the last 4 digits of numbers that have a 598 prefix.

Admitting 206-598-4310
Billing:
Financial counseling 206-598-4320
Doctor fees (UW Physicians) 206-543-8606
UWMC billing 206-598-1950
Emergency Medicine Service (ER) 206-598-4000
Interpreter Services 206-598-4425
TTY 800-833-6384
Lost and Found 206-598-4909
Operating Room 206-598-4270
Patient Relations 206-598-8382
Pavilion Surgery Center 206-598-4214
Pre-Anesthesia Clinic 206-598-5053
Roosevelt Ambulatory Surgery Center 206-598-0900
Social Work and Care Coordination Housing Services: 206-598-4170
Surgical Specialties Center Nurse Advice Line:
Monday to Friday, 8 a.m. to 4 p.m. 206-598-4549
After hours and on weekends and holidays, you can reach your doctor
Through the paging operator: 206-598-6190

**Locations**
• UWMC is at the south end of the University of Washington campus, at 1959 N.E. Pacific St., Seattle.
• UWMC Roosevelt is about 1 mile west of UWMC, at 4245 Roosevelt Way N.E., Seattle.
About Your Surgery Experience

Name_______________________________________________________

Date of surgery________________________________________________

Surgeon______________________________________________________

Clinic Nurse__________________________________________________

Patient Services Specialist (PSS) Name & Phone_______________________

Location and Arrival Time
If your surgery is on a weekday, check in at:

• Pavilion Surgery Center
  2nd Floor, Surgery Pavilion, UWMC
  1959 NE Pacific St, Seattle, WA 98195
  206-598-4214

Or

• Roosevelt Ambulatory Surgery Center
  2nd floor, UWMC-Roosevelt
  4245 Roosevelt Ave NE, Seattle, WA 98105
  206-598-0900

If your surgery is on a Saturday, check in at:

• UWMC Admitting
  3rd floor, UWMC (main floor lobby)
  1959 N.E. Pacific St., Seattle, WA 98195

A staff member from the Pre-Anesthesia Clinic will call you between 2 p.m. and 5 p.m. the day before your surgery. They will verify your arrival location, tell you what time to arrive, and review your pre-surgery instructions. If your surgery is on a Monday, this call will be on the Friday afternoon before. If you have not heard from us by 5 p.m., you are welcome to call 206-598-6334.

Interpreters
UWMC has interpreters to assist you, if needed, before and after surgery. Please tell the patient care coordinator or Pre-Anesthesia Clinic nurse if you would like an interpreter. Or, call Interpreter Services at 206-598-4425 to ask for an interpreter.
Your Pre-Surgery Checklist
Please read and follow these instructions:

- Follow the pre-surgery fasting guidelines.
- Follow the pre-surgery shower and shaving instructions.
- Do not use makeup, deodorant, lotions, hair products, or fragrances on the day of surgery.
- If you are an outpatient and will be going home the same day as your surgery, you must have a responsible adult drive you home. You cannot drive yourself home or take a taxi or bus by yourself.
- Remove all jewelry and body piercings.
- Bring your medical insurance card and photo ID with you.
- Bring your pharmacy insurance card, Labor and Industry (L&I) claim number and card, and your Medicare/Medicaid information, if you have them.
- Bring a list of all the medications that you take and the doses of each one. This includes vitamins, supplements, and anything else you buy without a prescription. Do not bring the actual medicines unless you have been told to do so by the Pre-Anesthesia Clinic nurse.
- Bring a method of payment for any co-pays for medicines needed after surgery.
- Pavilion Surgery Center accepts cash, check, or credit card. Roosevelt Ambulatory Surgery Center accepts VISA or MasterCard only.
- Bring a copy of your health care directive and/or durable power of attorney for health care if you want these placed in your medical record.
- If you have sleep apnea and use a CPAP machine at night to help you breathe, bring it with you.
- Do not bring unattended minors with you. Children age 17 and under must be accompanied by a responsible adult at all times in the waiting room and other areas of the hospital.
- Adjust your medicines:
  Stop taking these__________ days before surgery:
  
  Do NOT take these one the day of the surgery:
  
  Take these on the day of the surgery with 2 ounces (4 tablespoons) of water:

Meeting with Your Surgeon
Before your visit to the Pre-Anesthesia Clinic, you will meet with your surgeon in a UWMC specialty clinic. At this meeting, your surgeon and other care providers will discuss your medical history and home medicines, complete a physical exam, talk with you about the surgery, and have you sign a consent form.
Your Pre-Anesthesia Clinic Visit

We need information about your health before your surgery. At your pre-anesthesia visit, you will be asked to complete a health survey and a home medicine list. When you come to the Pre-Anesthesia Clinic, be sure to bring:

- Bring a list of all the medications that you take and the doses of each one. This includes vitamins, supplements, and anything else you buy without a prescription. Do not bring the actual medicines unless you have been told to do so by the Pre-Anesthesia Clinic nurse.
- The results of tests you have had at any other hospital or clinic, especially heart or lung diagnostic testing such as an electrocardiogram (EKG), stress test, echocardiogram, pulmonary function tests, etc. We will include copies of these records in your surgical information packet. If you need help getting test results from your doctor or clinic, please ask us and we can help you.

Having this information is important. It will help your doctors know about things that may affect your care and recovery. Nurses trained in anesthesia assessment will review your health survey, medical history, and home medicine list. If needed, blood tests, an EKG, and a chest X-ray will be done. Depending on your type of surgery, other tests may also be needed.

You will not meet your anesthesia team at this visit, but will meet them the day of your surgery. Nurses trained in anesthesia assessment will review your health survey, medical history, and home medicine list. If needed, blood tests, an EKG, and a chest X-ray will be done. Depending on your type of surgery, other tests may also be needed.

Medicines Before Surgery

It is important to talk with your surgeon and Pre-Anesthesia Clinic staff about the medicines you are taking. You may need to stop taking some of them for a day or more before your surgery.

Some medicines you may need to stop taking are:
- Oral diabetes medicines and insulin
- Warfarin (Coumadin)
- Aspirin and other over-the-counter medicines that affect blood clotting, such as ibuprofen (Advil, Motrin) and naprosyn (Aleve, Naproxen)
- Certain diet medicines
- Herbal remedies and supplements

A nurse will tell you which of your medicines you can take the morning of surgery.

Anesthesia

A team of anesthesia providers will be with you during your surgery to keep you comfortable and manage your breathing, heart rate, blood pressure, and any medical issues that might arise.

The 3 main types of anesthesia that may be discussed at your pre-surgery visit are:
- General – you are unconscious and have no awareness of the surgery.
• Regional – a numbing medicine is injected into a cluster of nerves, so you do not have sensation (feeling) in a large area of your body. You may also be given medicine to relax you or help you sleep.

• Local – a numbing medicine is injected into the skin and tissues near the area of surgery. This numbs only the area of surgery, similar to the local anesthetic given for dental work. You may also be given medicine to relax you or help you sleep.

Please tell your nurse if you would like to discuss special concerns with an anesthesiologist during your visit.

24 Hours before Surgery

Your Arrival-Time Phone Call
A staff member from the Pre-Anesthesia Clinic will call you the afternoon before your surgery day to verify your arrival location, tell you when to arrive, and review your pre-surgery instructions. If your surgery is on a Monday, this call will be on the Friday afternoon before.

• Please make sure we have the correct phone number where you can receive this pre-surgery phone call. If you do not receive this call by 5 p.m., call the Pre-Anesthesia Clinic at 206-598-6334.

Fasting Guidelines
Unless you have instructions from your doctor about bowel cleansing, eat normally and take your usual medicines the day and evening before surgery. But, starting at midnight, you will need to follow special fasting guidelines.

It is very important to follow these guidelines about not eating or drinking before surgery. These guidelines reduce your chance of vomiting and inhaling stomach contents into your lungs. For your safety, if you forget and/or do not follow these fasting guidelines, your surgery may need to be rescheduled for another day.

Some patients may drink liquids after midnight the night before surgery. Other patients, based on their medical condition and type of surgery, will not be able to eat or drink anything after midnight the night before surgery. The Pre-Anesthesia nursing staff will explain the guidelines that you need to follow.

For ALL patients:
• Do NOT eat after midnight.
• Do NOT drink alcohol after midnight.
• Do NOT drink liquids after midnight that are not clear. This includes coffee or tea with cream or milk, lattes, milk, or orange juice.

For patients who are told NOT to drink liquids after midnight:
• Do NOT drink ANY liquids after midnight. The Pre-Anesthesia nurse will tell you if you may have up to 2 ounces (4 tablespoons) of water for taking the medicines you are allowed to take.

For patients who are told they MAY drink liquids after midnight:
  • From midnight until 4 hours before you arrive at the hospital, you may drink an unlimited amount of CLEAR liquid. This means you may have liquids such as water, clear juices (no pulp), carbonated drinks, Gatorade, and clear tea.
  • After this time, do not drink anything before coming to the hospital.

**Shower Instructions**
Use a special soap called Chlorhexidine gluconate (CHG) to shower or bathe, both the night before and the morning of surgery. You can buy CHG at most large drugstores. It comes as a 2% and a 4% solution. Either one is OK. A common brand is Hibiclens, but any brand is OK. Follow the manufacturer's instructions for using it.
  • Use the CHG soap FROM THE NECK DOWN. Wash thoroughly, especially around the area of your surgery.
  • DO NOT use CHG on your face or to wash your hair. (You may use your regular soap and shampoo to wash your face and hair.)
  • Rinse well and repeat.
  • Pat dry with a clean towel. Put on clean clothes.
  • After your morning shower or bath, DO NOT put on makeup, deodorant, lotions, hair products, or fragrances.

**Shaving**
To lower the risk of infection, do not shave any part of your body that you do not already shave every day. If you normally shave near your surgical site, DO NOT shave that area for 2 days (48 hours) before the morning of your surgery.

**Parking and Directions**
Parking at the hospital is validated for a reduced rate. Refer to the map on page 16 for directions to parking areas. For more information on:
  • Campus parking and current fees, call 206-685-1543
  • Hospital parking, call 206-598-5275
  • Driving directions, visit: www.washington.edu/admin/commuterservices/get_to_uw/visitors/index.php

**Your Ride Home**
If you are going home on the same day you have surgery, you must arrange for a responsible adult to take you home. Your ride must be ready within 30 minutes of your discharge. Your surgery may be cancelled if you arrive without a responsible adult to drive you home, get you settled, and make sure you are safe and comfortable. You cannot take a taxi or bus home by yourself.
Leaving for the Hospital
When you come for surgery:
  • Wear loose clothing that will be easy to take off and comfortable to wear home.
  • Please do not bring valuables with you.
  • Remove all jewelry and body piercings.
  • Do not use any makeup, deodorant, lotions, hair products, or fragrances.

Bring With You
  • Bring a list of all the medications that you take and the doses of each one. This includes vitamins, supplements, and anything else you buy without a prescription. Do not bring the actual medicines unless you have been told to do so by the Pre-Anesthesia Clinic nurse.
  • A photo ID, your insurance and pharmacy insurance cards, and co-payment for discharge medicine.
  • A copy of your health care directive and/or durable power of attorney for health care if you want one placed in your medical record.
  • Your L&I claim number, if you have one.
  • Your CPAP machine if you have sleep apnea and use it at night to help you breathe.

On the Day of Your Surgery

Check In
On the day of your surgery, report to your designated location. Most times, we ask you to come in 1½ hours before your surgery. This gives us time to prepare you for your surgery. During this time, you will:
  • Sign admission forms.
  • Be assessed for health status changes.
  • Meet your anesthesiology team.
  • Have your intravenous line (IV) started. An IV is a small needle and thin tube that is used to deliver medicines and fluids to your body.

Bring a book or a project to help pass the time. We will update you about any changes that might affect your surgery start time.

Note: Female patients may receive information about urine pregnancy testing before surgery. Tell your nurse or an anesthesia staff person if you would like to be tested.

Getting Ready for Surgery
The surgery “prep” area has many patients who are being prepared for surgery. In a private space, we will ask you to remove your clothes, including undergarments. You will put on a hospital gown. You will need to remove glasses, contact lenses, and hearing aids. In some cases, you will also be asked to remove dentures. Please bring cases to store these items, if you have them.
You will meet the nurses and anesthesia team who will care for you during your surgery. You will be able to ask them any questions you have about your care.

To reduce your risk of infection, you will be covered with a heating blanket to warm your body while you wait to go into the operating room. Ask for a heating blanket if you do not receive one.

**Your Support Person**
An adult support person is welcome to be with you during your “prep” time. They may be asked to step out of the prep space, if needed.

Your support person may wait in the waiting room when you are transferred to surgery. They may want to bring something to read while they wait, or a laptop computer or other electronic device to use. Wireless Internet access is available in most areas of the hospital.

We cannot provide child care. If you must bring a child age 17 or under to the hospital, please bring an adult to be with them at all times in the waiting room and other areas of the hospital.

**Surgical Site Marking**
We are committed to making sure you receive high-quality and safe care. While you are here, you or your family will be asked such questions as:

- What is your name?
- What is your date of birth?
- What surgery are you having done?

Do not be alarmed by these questions. We know who you are. We routinely ask some or all of these questions over and over again for your own safety.

Your doctor will check your medical record and talk with you or a family member to confirm your surgery or procedure site. Most times when you have surgery or a procedure, your doctor will mark the site in pen to help ensure your safety.

When your site does need to be marked, your surgeon will mark the site with his or her initials. Special care is taken if you are having surgery or a procedure on the right or left side of your body. Please do not mark yourself or write anything on your body.

If your site does not need to be marked, you will be asked to confirm what surgery or procedure you are having.

At right: A surgeon writing his or her initials on the patient’s surgery site.

**Starting Your IV**
After a numbing solution is applied to your skin, an IV will be placed in a vein in your arm or in the back of your hand. Medicine and fluids can be given to you quickly and easily through the IV, and it will be in place for awhile after surgery. Sometimes, you will be given medicine through this IV to help you relax, or even sleep, before going into the operating room.
Recovery

In the Recovery Room
The recovery room is sometimes called the PACU, which stands for "Post-Anesthesia Care Unit." Most patients are in the recovery room for 1 to 2 hours after their surgery.

In most cases, your loved ones will be able to visit you in the PACU, if you wish. This will be after you have received the care you need to ensure your safety as you wake up from anesthesia and have your pain treated, if needed. There is limited space in the PACU area, so you may have only 1 adult visitor at a time.

A nurse will check your breathing, heart rate, and blood pressure often. Your nurse will help you with any nausea or pain you may feel. It is important that you are comfortable.

Be sure to ask your nurse for pain medicine before your pain gets too intense. Your nurse will ask you to rate your pain on a scale of 0 to 10, where 0 is no pain and 10 is the worst pain.

You may receive pain relief by:
- Mouth (pills, capsules, or liquid)
- Medicine put into your IV tube

If you are staying overnight in the hospital, you may also receive pain relief by:
- Medicine given through a small tube in your back (epidural).
- Patient-controlled analgesia (PCA). This is a machine that puts a dose of pain medicine into your IV tube when you push a button. Your doctors will prescribe the correct amount of medicine for your needs. With PCA, you do not have to wait for a nurse. You are in control of your pain relief. You will not become addicted to these medicines if you use the machine as prescribed.

WARNING: Only you should push the button on your PCA. DO NOT let your visitors push the PCA button.

Going Home
If you go home the day of surgery, the person who takes you home must be able to get you into your home, stay with you, and make sure you are comfortable.

You can expect to have some pain and possibly some nausea after surgery. You may also be sleepy for the rest of the day. For your safety, you will need a responsible adult to stay with you for at least 24 hours after surgery.

For 24 hours after anesthesia, DO NOT:
- Drive
- Drink alcohol
• Travel alone
• Use machinery
• Sign any legal papers
• Be responsible for taking care of another person, such as a child

Ask your surgeon how your activity might be limited after surgery and how long these limits will last. Think carefully about what help you will need and arrange for this help before your surgery. Work out things like how you will get to the bathroom, go up and down stairs, prepare your meals, and care for yourself.

Before you leave the hospital, you will receive information about how to care for yourself at home. A follow-up appointment will be made for you, if you do not have one scheduled already.

**Helpful Contacts**
You may find these phone numbers helpful. If you are using a phone inside the hospital, press only the last 4 digits of numbers that have a 598 prefix.

<table>
<thead>
<tr>
<th>Service</th>
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<tr>
<td>Admitting</td>
<td>206-598-4310</td>
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<tr>
<td>Billing:</td>
<td></td>
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<tr>
<td>Financial counseling</td>
<td>206-598-4320</td>
</tr>
<tr>
<td>Doctor fees (UW Physicians)</td>
<td>206-543-8606</td>
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<tr>
<td>UWMC billing</td>
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<td>206-598-4000</td>
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<tr>
<td>Interpreter Services</td>
<td>206-598-4425</td>
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<tr>
<td>TTY</td>
<td>800-833-6384</td>
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<td>Lost and Found</td>
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<td>Patient Relations</td>
<td>206-598-8382</td>
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<td>Pavilion Surgery Center</td>
<td>206-598-4214</td>
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<tr>
<td>Pre-Anesthesia Clinic</td>
<td>206-598-5053</td>
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<tr>
<td>Roosevelt Ambulatory Surgery Center</td>
<td>206-598-0900</td>
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**Social Work and Care Coordination**

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<tr>
<th>Service</th>
<th>Phone Number</th>
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<tr>
<td>Housing Services:</td>
<td>206-598-4170</td>
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Your surgical clinic will also give you phone numbers to call if you have questions or concerns after surgery.
Parking
You may park in the SCCA parking garage. The parking fee is no more than $4 per day with ticket validation. Parking fees will be prorated for shorter visit times at the clinic. The parking garage is open Monday through Friday from 6:30am to 8pm and weekends/holidays from 6:30am-5pm. You must notify the attendant if your car is being left overnight. The height limit in the garage is 6’7”.

All University of Washington Medical Center garages and the SCCA garage offer same-day reciprocal parking. Simply bring your receipt from a participating garage to your next appointment at the other location and any remaining paid time will be honored. In and out parking is available. Keep your parking receipt and present it to the attendant.

There is limited metered street parking near all buildings.

At UWMC, parking is available in 3 places at the hospital (see map below):
- Triangle Parking Garage
- Surgery Pavilion Parking Garage
- S-1 Parking Garage

Valet parking service is offered weekdays 8 a.m. to 5 p.m. The valet booth is on the drive to the main hospital entrance. At UWMC Roosevelt, the parking garage is under the building.

Driving Directions to UWMC, 1959 N.E. Pacific St.:
- From Interstate 5: Take Exit 168B (Bellevue, State Route 520) heading east. Take the first exit (Montlake Boulevard) and follow the signs to University of Washington Medical Center.
- From Interstate 405: Take Exit 14 (Seattle via Evergreen Point Bridge, State Route 520) heading west. Take the first exit (Montlake Boulevard) and follow the signs to University of Washington Medical Center.

To UWMC Roosevelt, 4245 Roosevelt Way N.E.:
- From Interstate 5: Take the N.E. 45th St. exit and go east on N.E. 45th St. Turn right heading south on Roosevelt Way N.E. Go 2½ blocks. UWMC Roosevelt is on the right.
Questions?
We want to partner with you to give you our best care. Patients who are involved in their care have better results and fewer problems.

Your questions are important. Ask your doctor or nurse any questions you may have about the care you receive. If you have concerns, tell a staff member or call UWMC’s Patient Relations at 206-598-8382. UWMC clinic staff are also available to help.

Surgical Oncology Post-Operative Instructions

Post-Surgery
You will wake up in the recovery room; you will be very sleepy. You will have:

- An IV in your arm to give you medicine.
- An Epidural Catheter may be in your back to give you pain medications. Your anesthesiologist will decide if you will benefit from this.
- A catheter tube may or may not be placed in your bladder to drain your urine.
- Sequential Compression Devices (SCD’s) that are inflatable stocking for your legs.
Your Incision
- You will have an incision that is closed with surgical clips or stitches. You will be given instructions on how to care for the incision. Inspect your incision daily for signs of infections such as: redness, increased pain, swelling, or foul smelling drainage from your wound.
- Do not lift any heavy items (10-15 pounds) for _______ weeks.
- If you have a stoma or an ostomy bag, you will be taught how to care for this.

Pain Management and Medication
- You may have a pain pump for a few days after your operation that you can use to control your pain.
- Your doctor or anesthesiologist may insert an epidural catheter to control your pain.
- Do not take Aspirin® or Aspirin® products until two days after your operation.

Post-Operative Instructions
- You will be given pain-relieving medication, this may be constipating. Increasing fluid (6-8 glasses/day), fiber and fruits in your diet may be helpful in avoiding this problem.
- Return to your daily activities as tolerated. Use pain as your guide and take frequent rest periods.
- Refer to your handouts regarding care of your incision and/or drains.

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<th>CALL FOR PROBLEMS</th>
<th>Surgical Oncology Clinic</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>4th Floor Patients</td>
</tr>
<tr>
<td>8am-5pm, M-F</td>
<td>206-606-________</td>
</tr>
<tr>
<td>5pm-8am, M-F</td>
<td>206-598-6190</td>
</tr>
<tr>
<td>Weekend and Holidays</td>
<td>Ask for the Resident On-Call for General Surgery</td>
</tr>
</tbody>
</table>
Hibiclens® (Chlorhexidine Gluconate) Antiseptic Antimicrobial Skin Cleanser

Preoperative Surgical Scrub

- Please shower with the special soap provided two times before surgery. This special soap will cleanse your skin and help prevent infection.
- Shower the night before and the day of surgery.
- Use approximately one ounce of antiseptic soap (30 ml), washing below the neck only.
- Rinse well.
- Repeat above steps.
- Use freshly laundered towel to dry off after each shower.
- Put on freshly laundered garments (night clothes, underwear, etc.).

WARNINGS – This soap is for external use only. DO NOT USE ON FACE. Keep soap out of eyes, ears, and mouth. Misuse around eyes could cause serious and permanent eye injury. If soap should contact the eyes or ears, rinse out thoroughly and promptly with water. Notify your physician. Keep this harmful product out of reach of children. NOT for use as a shampoo or douche.
LMX-4

What is LMX-4?
LMX-4 is a brand name for a topical cream that contains an anesthetic called Lidocaine in a nonprescription strength.

What is Lidocaine Used For?
Lidocaine can relieve the pain caused by minor cuts, minor burns, abrasions, sun burns, and insect bites. Lidocaine preparations are also commonly used by physicians and other health care professionals to numb the skin and other areas of the body prior to performing minor skin surgery, insertion of IV lines, obtaining blood specimens, and other such procedures.

When Do I Apply LMX-4?
Apply to site at least 1 hour before the procedure.

What is an Occlusive Dressing?
An occlusive dressing is a bandage of various materials used to cover and protect a specific area. Tegaderm is one type of an occlusive dressing that can be used.

How Do I Use LMX-4 with an Occlusive Dressing?
- Prepare site by washing with mild soap and water. Do not use alcohol or acetone as they will strip the skin of naturally occurring oils that LMX-4 needs to penetrate the skin. The use of a dressing is recommended for children to keep the cream in place and to prevent accidental ingestion.
- Apply a small amount of cream to the treatment area and gently massage it into the skin. Next, squeeze enough cream to completely cover the affected area so that no skin is visible beneath the cream.
- Cover cream with the Tegaderm bandage, seal the edges and make sure there is no leakage. Ordinary plastic wrap or Press-and-Seal wrap may be substituted for the Tegaderm bandage.
- The cream should remain undisturbed for 30 min; however, you or your child may experience a sufficient numbing effect in less time.
- Remove the dressing and cream and wipe the area clean with clean gauze or tissue.
- Wash your hands.

What Precautions Should I Take When Using LMX-4?
- Be careful to avoid injury to the treated area while it is numb and you are not feeling pain.
- LMX-4 should only be used externally.
- Do not put LMX-4 in your mouth or nose. If swallowed, get medical help or contact Poison Control Center right away.
• Be careful not to get any of this medication into your eyes. If any of the medication
does get into your eyes, immediately wash out the eye with water and protect the eye
until sensation returns. Check with your doctor.
• Do not use LMX-4 inside the ear. Do not use large quantities, particularly over raw
surfaces or blistered areas. Application of LMX-4 cream to larger areas or for longer
periods than recommended could result in too much Lidocaine being absorbed into the
skin, resulting in serious adverse effects (see below).

Does LMX-4 Have Any Side Effects?
Although uncommon, side effects may occur. The most common side effects are irritation,
redness, itching, or rash. Although these side effects usually do not require medical attention, if
they continue or are bothersome, report them to your nurse or doctor.

If you notice any adverse or unusual effects such as blurred vision, dizziness, difficulty
breathing, trembling, chest pain, or irregular heartbeats, contact your doctor immediately.

How do I store LMX-4?
Keep out of reach of children. Keep container tightly closed at all times when not in use. Store
at room temperature. Throw away any unused medication
Medicines to Avoid before Surgery
Your doctor wants you to stop taking aspirin, aspirin-like products, or non-steroidal anti-inflammatory agents. Here is a list of specific medicines and supplements to avoid before and after your surgery or procedure.

- Stop taking these products _____ days before your procedure.
- You may resume taking these products _____ days after your procedure.
- You may take acetaminophen (Tylenol) as needed for minor aches and pains.
- Review with your doctor all medicines and supplements that you are taking.

The lists in this handout are not complete. Other products or supplements may also cause bleeding problems. Important note for patients who have had cardiac stents or other heart surgery in the past year: Talk with your cardiologist (heart doctor) before you stop taking any aspirin product or clopidogrel (Plavix).

Products to Avoid
Avoid these products in the days before and after surgery as indicated by your doctor.

Prescription products with aspirin or other salicylates:
- Amigesic
- Ascomp with codeine
- Alor
- Carisoprodol Compound
- Darvon Compound 65
- diflunisal
- Dolobid
- Empirin with codeine
- Fiornal
- Lobac
- Lortab ASA
- Magan
- Magsal
- Mobidin
- Monogesic
- Norgesic
- Novasal
- Orphengesic
- Panasol
- Percodan products
- Roxiprin
- Salflex
- salsalate products
- Salsitab
- Soma products
- Synalgos-DC
- Talwin Compound
- Trilisate
- trisalicylate products
- Zorprin
Prescription products with these nonsteroidal anti-inflammatory agents (brand name in parentheses):

- diclofenac (Voltaren, Cataflam)
- etodolac (Lodine)
- fenoprofen (Nalfon)
- flurbiprofen (Ansaid)
- ibuprofen (Motrin)
- indomethacin (Indocin)
- ketoprofen (Orudis, Oruvail)
- ketorolac (Toradol)
- meclofenamate (Meclomen)
- mefenamic acid (Ponstel)
- nabumetone (Relafen)
- naproxen (Naprosyn, Anaprox)
- oxaprozin (Daypro)
- piroxicam (Feldene)
- sulindac (Clinoril)
- tolmetin (Tolectin)

Other prescription drugs:

- celecoxib (Celebrex)
- cilastozol (Pletal)
- dipyridamole (Persantine)
- dipyridamole/aspirin (Aggrenox)
- valdecoxib (Bextra)
- ticlopidine (Ticlid)

Nonprescription products with aspirin or salicylates:

- Alka-Seltzer products
- Anacin
- Arthropan
- Ascriptin
- Aspergum
- Asprimox
- Bayer products
- Bufferin
- Doans
- Ecotrin
- Empirin
- Excedrin
- Halfprin
- Mobigesic
- Pepto-Bismol
- Saleto
- Vanquish

Nonprescription products with nonsteroidal anti-inflammatory agents:

- Advil products
- Aleve products
- Dristan Sinus
- Haltran
- ibuprofen products
- Menadol
- Midol Extra
- Motrin
- naproxen

**Coumadin (Warfarin)**

Ask your doctor:

- How many days BEFORE your surgery to stop taking this drug.
- If you need bridge (short-term) therapy with an injectable anticoagulant (blood-thinner) such as heparin, or a low molecular weight heparin such as enoxaparin (Lovenox).
Herbal Products and Other Natural Supplements
Stop taking ALL natural products, herbal medicines, vitamins, and other supplements 7 days before your surgery. They may be resumed when your doctor says it is OK. Following are herbs and other supplements that are especially harmful to take if you are having surgery because they can cause extra bleeding:

- agrimony
- alfalfa
- aniseed
- arnica
- artemesia
- asa foetica
- bishop’s weed
- bladderwrack
- bochu
- bogbean
- boldo
- bromelains
- burdock
- capsicum
- cassio
- celery seed
- chamomile
- Chinese wolfberry
- chondroitin
- clove
- cod liver oil
- coltsfoot
- dandelion
- danshen (salvia)
- devil’s claw
- dihydroepiandrosterone (DHEA)
- dong quai (angelica)
- fenugreek
- feverfew
- fish oil
- flax seed
- gamma linoleic acid
- garlic
- ginger
- ginkgo
- ginseng
- glucosamine
- horse chestnut
- horseradish
- licorice
- meadowsweet
- melatonin
- melilot
- nattokinase
- onion
- pantethine
- papain (papaya extract)
- parsley
- passionflower
- policosanol
- poplar
- prickly ash
- quassia
- red clover
- resveratrol
- sea
- buckthorn
- sweet clover
- sweet woodruff
- tonka beans
- turmeric
- vinpocetine
- vitamin E
- wild carrot
- wild lettuce
- willow bark

Questions?
Your questions are important. Call your doctor or nurse if you have questions or concerns.
UWMC
and SCCA clinic staff are also available to help.
• UWMC Outpatient Pharmacy: 206-598-4363
• SCCA Pharmacy: 206-606-6500
Advance Care Planning

A serious illness or accident can happen to anyone at any age. Advance care planning can help you document decisions about your health care in case you become ill or injured and can no longer speak for yourself. Completing your advance directives is one of the best ways to make sure that your family, friends, and doctors know about and follow your health care choices.

An advance directive is a combination of two legal documents (provided to you in this section of the manual), called:

- **Durable Power of Attorney for Health Care (DPOAHC):** This form lets you name a health care agent. A health care agent is someone who can make decisions about your care, including decisions about life support, if you can no longer speak for yourself. If you do not designate your health care agent, Washington law will assign one for you.

- **Health Care Directive:** This form expresses your wishes in writing regarding your medical care, including decisions about life support if you cannot speak for yourself—for instance, if you are in a coma. Having written instructions can help reduce confusion or disagreement among your family members or health care providers. Your family and doctors are required by law to follow the instructions in your health care directive.

You can complete either just the PDOAHC or the combined Health Care Directive/DPOAHC. The combined form takes more time to complete as it lets you name your health care agent and describe what treatment you would want if you have a serious accident or illness and cannot speak for yourself.

Once you have filled out the forms you want, give photocopies of the signed original to your health care agent(s), physician(s), lawyer, family, close friends, clergy, and anyone else who might become involved in your health care.

For your convenience, the SCCA provides complimentary notarization of your advance care planning documents in the Patient and Family Resource Center located on the 3rd floor of the clinic.

If you have questions or need guidance in preparing your advance care planning documents, please call our SCCA Supportive Care services at 206-606-1076 and a staff member will be glad to assist you.
Durable Power of Attorney for Health Care (DPOAHC) Questions and Answers

What is a Durable Power of Attorney for Health Care (DPOAHC)?
The DPOAHC lets you name a health care agent, to make decisions about your medical care. These include decisions about life support if you can no longer speak for yourself.

How should I choose a health care agent?
Be sure the person you appoint as your health care agent understands your wishes, agrees to honor them, and will take responsibility for making medical decisions for you even if others challenge your wishes.

The person you name to be your health care agent:
- Must be at least 18 years old and mentally competent.
- May be a family member or close friend you trust to make serious decisions.
- Does not have to be your spouse, partner, or a member of your biological family.
- Need not live in Washington but would need to be readily available in a medical emergency.

The person you appoint as your health care agent cannot be:
- Your physician or an employee of your physician.
- An owner, operator, administrator, or employee of a health care facility in which you are a patient at the time you sign your DPOAHC.

What happens if I do not choose a health care agent?
If you do not designate a health care agent, Washington law will assign one for you. An agent will be chosen from the list below in the following order:
- A guardian with health decision-making authority, if one has been appointed by a court.
- Your spouse or registered domestic partner (even if you are separated but not legally divorced).
- Your adult children.
- Your parents.
- Your adult siblings.

When there is more than one person given authority, such as your children, parents, or siblings, all must agree.

What if I have a same-sex spouse or registered domestic partner?
Your domestic partner or spouse may not have the right to make your health care decisions or even have access to you in an emergency medical situation outside of Washington. List your domestic partner or spouse as your health care agent on your DPOAHC form if you travel outside of Washington and want him/her to make health care decisions for you.
What if the court appoints a guardian for me?
Washington law does not direct that a health care agent should be the court's first choice for guardian. It makes sense to request that one of your health care agents serve as your guardian, because that is the person you trust. A judge is not required to appoint the person you request, but the court would probably give your wishes serious consideration.

How can I revoke or cancel my DPOAHG?
You may revoke your DPOAHG at any time by doing any one of the following:
- Canceling, defacing, obliterating, burning, tearing, or otherwise physically destroying it or having another person destroy it for you in your presence. All copies should be destroyed.
- Executing a written and dated revocation.
- Orally expressing your intent to revoke it.

Where should I keep my DPOAHG?
Keep the original signed documents in a secure but accessible place that your agent knows about. Copies of your DPOAHG are just as valid as the original. Give photocopies of the signed original to your health care agent(s), physician(s), lawyer, family, close friends, clergy, and anyone else who might become involved in your health care. If you enter a nursing home or hospital, have photocopies of your documents placed in your medical records. To ensure your DPOAHG is accessible, you may want to keep copies in your wallet/purse, car or in a suitcase.

What if I want to make changes?
If you want to make changes to your documents after they have been signed, you should complete a new document. However, updating addresses or phone numbers is permissible. Updates should be initialed and dated.

What if I travel to other states?
If you travel, you may want to take copies of your DPOAHG with you, as other states may honor it. Although they may have specific requirements about notarization or witnessing, most states do not require a specific form or format.

Do I need to have my DPOAHG witnessed or notarized?
Beginning January 1, 2017, the DPOAHG must be either witnessed by 2 witnesses or notarized in order to be legally binding.

The witnesses must be:
- At least 18 years old,
- Not related to you by blood, marriage, or adoption,
- Not your health care agent named in this document,
- As far as they know, not beneficiaries of your will, and no claim against your estate,
- Not directly involved in your health care,
- Not an employee of your physician or a health care facility where you may reside.

DPOAHG completed prior to January 1, 2017, will remain legally valid as long as its version complied with the Washington State law at the time of its completion. In addition, some states do require DPOAHG to be notarized. SCCA provides complimentary notarization of advance care planning documents in our Patient and Family Resource Center located on the 3rd floor of the clinic.
6. **Summary And Signature**
I understand what this document means. If I am ever unable to make my own health care decisions, I am directing my agent to make health care decisions for me. I make this document of my free will, and I believe I have the mental and emotional capacity to do so. I want this document to become effective even if I become incompetent.

Signature [sign only in the presence of two witnesses, if witnessing OR notary, if notarizing]  
Date

Note: You must complete either section 7 (Statement of Witnesses) or section 8 (Notarization) in order for this document to be legally binding.

7. **Statement Of Witnesses** [print your name - not the names of your witnesses – on the line below]

_____________________________ is personally known to me, and I believe him/her to be capable of making health care decisions. I affirm I am at least 18 years old, not related to him/her by blood, marriage, or adoption, and not his/her health care agent named in this document. As far as I know I am not a beneficiary of his/her will or any addition to his/her will, and I have no claim against his/her estate. I am not directly involved in his/her health care, and I am not an employee of his/her physician or a health care facility where the person making this document may reside.

**WITNESS 1**

Signature
Date
Printed Name
Phone
Address

**WITNESS 2**

Signature
Date
Printed Name
Phone
Address

8. **Notarization**
State of Washington, County of ____________________________

I certify that I know or have satisfactory evidence that ____________________ signed this document and acknowledged it to be his/her free and voluntary act for the uses and purposes mentioned in this document.

Dated this __________ day of __________, 20 ______

________________________________________
NOTARY PUBLIC in and for the State of Washington

Residing at _________________________________________

My commission expires ____________________________

Note: SCCA provides complimentary notarization for your DPOAHC in the Patient and Family Resource Center located on the 3rd floor of the clinic.

Page 2

**Photocopies and faxes of this signed document are legal and valid**

[Seattle Cancer Care Alliance logo]

DURABLE POWER OF ATTORNEY FOR HEALTH CARE
Advance Directive Questions and Answers

What is an Advance Directive?
An Advance Directive protects your right to refuse or request treatment, if you are not able to make decisions. Combining the two documents helps you to keep the information in one place. An Advance Directive is a combination of two legal documents, called:

- Health Care Directive
- Durable Power of Attorney for Health Care

What is a Durable Power of Attorney for Health Care?
The Durable Power of Attorney for Health Care lets you name a health care agent. A health care agent is someone who can make decisions about your care, including decisions about life support, if you can no longer speak for yourself.

What is a Health Care Directive?
The Health Care Directive lets you state your wishes if your physician decides that you have developed a terminal condition and can no longer make your own medical decisions. The Health Care Directive also applies to conditions of persistent unconsciousness or vegetative state, and irreversible coma. Another physician must agree with your physician’s decision.

What if I need help with preparing my advance directive?
Consider filling out the Values Worksheet form located on the last two pages of this document. It may help to gather your thoughts and clarify your values about your end-of-life choices. If you feel that it helps to explain your beliefs about your end-of-life wishes, you may choose to include it with your signed advance directive. If you have questions or need guidance in preparing your advance directive, please call our Supportive Care services at 206-288-1076 and a staff member will be glad to assist you.

How should I choose a Health Care Agent?
Be sure your health care agent understands your wishes and agrees to follow them. This person will take responsibility for making your medical decisions, even if others challenge your wishes.

The person you name to be your health care agent:
- Must be at least 18 years old and mentally competent.
- May be a family member or close friend you trust to make serious decisions.
- Does not have to be your spouse, partner, or a member of your biological family.
- Does not need to be in Washington, but needs to be available in a medical emergency.

The person you appoint as your health care agent cannot be:
- Your physician or an employee of your physician.
- An owner, operator, administrator, or employee of a health care facility where you are currently a patient.
What happens if I do not choose a Health Care Agent?
Choosing a health care agent is recommended. If you do not choose a health care agent, Washington law will assign one for you. An agent will be chosen from the list below in the following order:
- A guardian with health decision-making authority, if one has been appointed by a court.
- Your spouse or registered domestic partner (even if you are separated but not legally divorced).
- Your adult children.
- Your parents.
- Your adult siblings.

When there is more than one person given authority, such as your children, parents, or siblings, all must agree.

What if I have a same sex-spouse or registered domestic partner?
Your domestic partner or spouse may not have the right to make your health care decisions or even have access to you in an emergency medical situation outside of Washington. List your domestic partner or spouse as your health care agent on this form if you travel outside of Washington and want him/her to make health care decisions for you.

What is a POLST form and why is it important?
The POLST form is intended for any adult, 18 years of age or older, with serious health conditions. The form translates your wishes regarding life-sustaining treatments into a physician's orders and requires a physician's signature to be valid. Some physicians may not sign the form if the patient is not the person who has filled it out. Allowing your health care agent to complete a POLST form in your Advance Directive may lessen your physician's concern.

What if I do not want life sustaining treatment for conditions in which my physician is unsure whether I will ever regain consciousness?
In section 5(a) on the Advance Directive form, you can decide the number of weeks you would want life-sustaining treatment to continue if your condition is deemed medically futile. If you prefer to rely on your physician's judgment you can write "Dr.'s judgment" instead.

What if I want temporary life sustaining treatment used?
Sometimes it is hard for physicians to know if using temporary life-sustaining treatment will help a patient recover. You might want life sustaining treatments if there is a good chance of recovery. You might not want life-sustaining treatment; because once treatment has started it might be difficult to have it stopped.

It can be very difficult for doctors and health care agents to give up trying when they know it means a patient will soon die. Stating a time limit will give them permission to stop treatment when there is no reasonable expectation of recovery.

How do I express my wishes regarding comfort care and pain medication?
High doses of pain medication can decrease breathing, sometimes resulting in death. Decreased breathing from pain medication does not cause suffering because the medication causes heavy sedation. Drug dependency in a dying person is not an ethical or legal concern. Developing a tolerance to pain medication is not addiction.

What if a health care institution refuses to honor my wishes?
Catholic or other religiously affiliated health care institutions follow certain religious directives or moral teachings. Because of this, they may not honor your Advance Directive if it conflicts with their institutional values. If you are terminally ill or death is likely, religiously affiliated institutions will usually honor your choices to stop or not start life-sustaining treatment. However, in situations involving pregnancy or persistent vegetative state, they may refuse to honor your wishes. Moving to a different facility is sometimes the best option.
Does my Advance Directive remain in effect after death?
Washington law does not explicitly allow health care directives to remain in effect after death. You can state your intention that the document remains in effect to carry out any procedure you request or consent to, including experimental treatments, organ/tissue donation, autopsy, and medical research or education, on your Advance Directive form.

What if the court appoints a guardian for me?
Washington law does not direct that a health care agent should be the court’s first choice for guardian. It makes sense to request that one of your health care agents serve as your guardian, because that is the person you trust to make a decision to end your life. A judge is not required to appoint the person you request, but the court would probably give your wishes serious consideration.

What if I choose to revoke or cancel my Advance Directive?
You may revoke your Advance Directive at any time by doing any one of the following:
- Canceling, defacing, obliterating, burning, tearing, or otherwise physically destroying it or having another person destroy it for you in your presence. All copies should be destroyed.
- Executing a written and dated revocation.
- Orally expressing your intent to revoke it.

You should notify your health care agent and your physician(s) in writing of your intent to revoke. If you are unable to write, you can have someone else write a statement for you explaining that you are unable to write, but want your Advance Directive revoked.

If possible, destroy copies of your revoked document, or ask those who have revoked copies to destroy them. Keep one copy of your revoked Advance Directive in your records with the word “REVOKED” written across the front. This shows how long you have thought about these issues and could help if it becomes necessary to rely on a new Advance Directive shortly after you prepared the document.

Who can witness the signing of my Advance Directive?
In order to make your directive legally binding, you must sign the document in the presence of two adult witnesses (and a notary if notarizing).

The witnesses cannot be:
- Related to you by blood or marriage.
- Entitled to any portion of your estate through the operation of law or through any will.
- A person who has a claim against your estate.
- Your physician or an employee of your physician.
- An owner, operator, administrator, or employee of a health care facility in which you are a patient at the time you sign your Advance Directive.

Where should I keep my Advance Directive?
Copies of your Advance Directive are just as valid as the original. However, you should keep the original in a secure but accessible place. Do not give the original to your attorney or put it in a safe deposit box or any other security box that would keep others from having access to them in the event of an emergency. Your health care agent(s) or other close family and friends should know where to find your document. To ensure your Advance Directive is accessible, you may want to carry copies in your wallet/purse, car or in a suitcase.
Who should have a copy?
Give copies of the signed originals to your health care agent(s), physician(s), lawyer, family, close friends, clergy, designated agent(s) for funeral arrangements, and anyone else who might become involved in your health care. If you enter a nursing home or hospital, have copies of your documents placed in your medical records.

How do I tell important people my wishes?
It is important to discuss your Advance Directive with people close to you. Discuss your wishes concerning medical treatment with your health care agent(s), physician(s), clergy, family, and friends often, particularly if your medical condition changes. Make clear to other family members that your health care agent(s) will have final authority to act on your behalf.

Will my physician honor my wishes?
When you present your Advance Directive to your physician(s), ask if he or she will honor it. If not, find a physician who will.

What happens if I am offered other health care directive forms when admitted to a health care facility or enrolled in a home-based health care program?
Do not fill out these forms. Give admissions staff a copy of your completed Advance Directive. Most other forms are not as comprehensive or effective and may be interpreted in a conflicting way.

What if I want to make changes?
If you want to make changes after your Advance Directive has been signed and witnessed you should complete a new document. However, updating addresses or phone numbers is permissible. Updates should be initialed and dated. Be sure to review your Advance Directive occasionally to be sure it reflects your current preferences and values. Initial and date it whenever you review it.

Will my Advance Directive be effective in a medical emergency?
No, your Advance Directive will not be effective in the event of a medical emergency. Ambulance personnel are required to provide cardiopulmonary resuscitation (CPR) and other life-sustaining treatments unless a valid Physician Orders for Life-Sustaining Treatment (POLST) form is present.

What if I travel to other states?
If you travel, you may want to take copies of your Advance Directive with you, as other states may honor it. Although they may have specific requirements about notarization or witnessing, most states do not require a specific form or format. Washington State registered domestic partners should be diligent about carrying their Advance Directives when traveling outside of Washington.

Do I need to have my Advance Directive notarized?
Notaries do not normally affirm anything beyond the identity of the person signing the document before them. While Washington State does not require notarization of this advance directive to make it legal, this form includes a notary statement because we believe that notarization eliminates doubt about the validity of your document in the future. Additionally, some states do require advance directives to be notarized. SCCA provides complimentary notarization of advance directives in our Patient and Family Resource Center located on the 3rd floor of the clinic.

Note: Using a notary is not a legal substitution for having your advance directive witnessed. In order to make your advance directive legally binding, you must sign it in the presence of two adult witnesses.
VALUES WORKSHEET

Name

Date

If applicable, name of the person who helped you to fill out this document

The following are questions you may want to consider as you make decisions and prepare documents concerning the kind of health care you want to receive now and in the future. You may want to write down your answers and provide copies to your family members and health care providers, or simply use the questions for discussion. How important are the following items?

<table>
<thead>
<tr>
<th>Item</th>
<th>VERY IMPORTANT</th>
<th>NOT IMPORTANT</th>
</tr>
</thead>
<tbody>
<tr>
<td>Letting nature take its course.</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>Preserving quality of life.</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>Staying true to my spiritual beliefs/traditions.</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>Living as long as possible, regardless of quality of life.</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>Being independent.</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>Being comfortable and as pain free as possible.</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>Leaving good memories for my family and friends.</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>Making a contribution to medical research or teaching.</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>Being able to relate to family and friends.</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>Being free of physical limitations.</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>Being mentally alert and competent.</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>Being able to leave money to family, friends, or charity.</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>Dying in a short while rather than lingering.</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>Avoiding expensive care.</td>
<td>4</td>
<td>3</td>
</tr>
</tbody>
</table>
What will be important to you when you are dying (e.g. physical comfort, no pain, family members present, etc.)?

How do you feel about the use of life-sustaining measures in the face of terminal illness? Permanent coma? Irreversible chronic illness, such as Alzheimer’s disease?

Do you have strong feelings about particular medical procedures? Some procedures to think about include mechanical breathing (respirator), cardiopulmonary resuscitation (CPR), artificial nutrition and hydration, hospital intensive care, pain relief medication, chemo or radiation therapy, and surgery.

What limitations to your physical and mental health would affect the health care decisions you would make?

Would you want to have financial matters taken into account when treatment decisions are made?

Would you want to be placed in a nursing home if your condition warranted?

Would you prefer Hospice care, with the goal of keeping you comfortable in your home during the final period of your life, as an alternative to hospitalization?

In general, do you wish to participate or share in making decisions about your health care and treatment?

Would you always want to know the truth about your condition, treatment options, and the change of success of treatments?
HEALTH CARE DIRECTIVE and DURABLE POWER OF ATTORNEY FOR HEALTH CARE

of: ____________________________________________

(print your name here)

This document states my choices about life-sustaining medical treatment and comfort care. It is meant to inform and guide my agent/guardian and clinicians who will make health care decisions for me if I become unable to speak for myself. I understand that before I sign this directive and durable power of attorney for health care, I can add to, delete from or otherwise change the wording of this directive. I may add to or delete from this directive and durable power of attorney for health care at any time and acknowledge that these changes must be consistent with Washington State law or federal constitutional law to be legally valid. I want this form to replace and cancel all health care powers of attorney and health care directives signed by me in the past.

1. **When I Want This Document To Apply**

I want this document to apply if I become unable to make my own health care decision(s) due to disability or incapacity. I understand that such inability may be temporary. I also understand that if I become unable to make certain decisions, I may still be able to make others. When I can make my own health care decisions, I want to do so. Each section filled out below will cancel and replace any health care directive and durable health care power of attorney signed by me in the past.

**Durable Power of Attorney for Health Care**

2. **My Health Care Agent**

I appoint as my agent: ____________________________________________

Name ____________________________ Name ____________________________

Address ____________________________ Address ____________________________

Telephone ____________________________ Telephone ____________________________

My alternate agent (optional):

3. **The Authority I Give My Health Care Agent**

I grant my agent complete power to make all decisions about my health care. This includes, but is not limited to:

- Consenting to, or refusing/withdrawing consent, for medical treatment recommended by my physician, including life-sustaining treatments;
- Asking for particular medical treatments;
- Accessing my medical records and information;
- Employing and dismissing health care providers;
- Changing my health care insurers;
- Making a Physician Order for Life-Sustaining Treatment (POLST) form for me; and
- Removing me from any health care facility to another facility, a private home, or other place.

This release authority additionally applies to information governed by the Health Insurance Portability and Accounting Act (HIPAA) of 1996 as hereafter amended.

Photocopies and faxes of this signed document are legal and valid.
4. **How To Make My Health Care Decisions**
I want whoever makes my health care decisions to follow the choices I state in this document. If what I would want is not known, then I want decisions to be made in my best interest, based on:
- my values,
- the contents of this document, and
- medical information provided by my health care providers.

**Health Care Directive**

I make this health care directive to provide clear and convincing proof of my choices and instructions about my treatment.

5. **When I Do Not Want Life-Sustaining Treatment**
If I am in the following condition(s), I would want to be allowed to die: *(initial all that apply)*

- **(a)** If I am unable to think or communicate due to any medical condition (including coma) and this condition is probably permanent or will not improve for __________ week(s).
  `{write number of weeks or “Dr.’s judgment”}`

- **(b)** Total dependence on others for my care because of my physical condition, which is probably permanent.

- **(c)** Pain which cannot be controlled, or can be eliminated only by sedating me so heavily that I cannot communicate.

- **(d)** Dementia such as Alzheimer’s Disease.

- **(e)** Other circumstances in which I would not want life-sustaining treatment (optional):
  *
  *If this space is not sufficient, write: “See attached page.” Any attached page should be signed and witnessed (notary is optional). If you have a potentially life-threatening, chronic condition, discuss specific instructions with your physician.*

6. **Temporary Use Of Life-Sustaining Treatment**
I understand temporary life sustaining treatment might be an option when my physician thinks that my quality of life might improve. If so, then: *(initial one)*

- **(a)** I want life-sustaining treatment, for up to __________ week(s).
  `{insert number of weeks or “Dr.’s judgment”}`

7. Life-Sustaining Treatment I do not want
If I experience a condition I initiated in section 5 or if I experience a quality of life my agent believes I would consider unacceptable, I do not want these life-sustaining treatments started, and, if already in use, I want them stopped (except for temporary use if I authorized that in section 6): \{initial all that you do not want\}

________ Nutrition and hydration other than ordinary food and water delivered by mouth, if I cannot eat and drink enough to sustain myself.

________ All cardiopulmonary resuscitation (CPR) measures to try to restart my heart or breathing, if those stop, including artificial ventilation, stimulants, diuretics, heart regulating drugs, or any other treatment for heart failure.

________ Blood dialysis or filtration to clean life-threatening substances from my blood, if my kidneys do not work normally.

________ Transfusion of blood, plasma, blood products, or other fluids to replace lost or diseased blood.

8. My Wishes Concerning Comfort Care And Pain Medication
If I appear to be in pain, experiencing breathlessness or otherwise uncomfortable, and am unable to communicate my wishes, I want vigorous treatment to relieve my pain and symptoms and to make me comfortable, even if my physicians or other medical providers believe this might make me unconscious or lead to my death: \{initial one\}

________ Yes  _________ No

Furthermore, use my POLST form (if completed) to learn about my other preferences.

9. Regarding A Health Care Institution Refusing To Honor My Wishes
If I am a patient in a health care institution whose policies or religious beliefs are in conflict with this Advance Directive, my admission does not give implied consent to procedures or courses of treatment in conflict with this Advance Directive. Furthermore, if the health care institution in which I am a patient does not follow my wishes as stated in the Advance Directive, I want to be transferred in a timely manner to a hospital, nursing home, or other institution which will agree to honor the instructions set forth in this advance directive.

10. My Wishes Concerning Other Matters
I want this directive to remain in effect after my death for autopsy, organ donation, use of my body for research, and for my agent to make arrangements for my remains if I authorize it below. \{initial all that apply\}

   YES  NO

   a. I consent to medical treatments that are experimental.
   ______  ______

   b. I want to donate organs/tissues.
   ______  ______

   c. I consent to an autopsy.
   ______  ______

   d. I consent to use of all or part of my body for medical education or research.
   ______  ______

Photocopies and faxes of this signed document are legal and valid
I have named the following individual as my designated agent for funeral arrangements: {initial one}.
If you do not use this section, cross it out.

My alternate agent for funeral arrangements:

Name __________________________
Address _________________________
Telephone _______________________

I want my remains to be disposed of as follows:
If you have left instructions in a property will or have made arrangements with a funeral home or People’s Memorial Association, there is no need to complete this part. If you do not use this section cross it out.

11. If A Court Appoints A Guardian For Me
If I have named a health care agent, I want my agent to be my guardian. If he/she cannot serve, then I want my alternate agent to be my guardian. If the court decides to appoint someone else, I ask that the court require the guardian to consult with my agent (or alternate) concerning all health care decisions that would require my consent if I were acting for myself.

12. How This Document Can Be Revoked Or Canceled
This health care directive and durable power of attorney for health care can be revoked by a written statement to that effect, or by any other expression of intention to revoke. However, if I express disagreement with a particular decision made for me, that disagreement alone is not a revocation of this document.

13. Summary And Signature {sign only in the presence of two witnesses}
I understand what this document means. If I am ever unable to make my own health care decisions, I am directing whoever makes them for me to do as I have said here. This includes withholding and/or withdrawing life-sustaining medical treatment, which might result in my death occurring sooner than if everything medically possible were done. I make this document of my free will, and I believe I have the mental and emotional capacity to do so. I want this document to become effective even if I become incompetent.

Signature ________________________ Date ________________________

Photocopies and faxes of this signed document are legal and valid

Seattle Cancer Care Alliance
Fred Hutchinson Children’s NHM Medicine

HEALTH CARE DIRECTIVE and DURABLE POWER OF ATTORNEY FOR HEALTH CARE
14. Statement Of Witnesses {print your name - not the names of your witnesses - on the line below}

__________________________ is personally known to me, and I believe him/her to be capable of making health care decisions. I affirm I am at least 18 years old, not related to him/her by blood, marriage, or adoption, and not his/her health care agent named in this document. As far as I know I am not a beneficiary of his/her will or any addition to his/her will, and I have no claim against his/her estate. I am not directly involved in his/her health care, and I am not an employee of his/her physician or a health care facility where the person making this document may reside.

WITNESS 1

Signature ___________________________ Date __________

Printed Name ________________________ Phone __________

Address ______________________________

WITNESS 2

Signature ___________________________ Date __________

Printed Name ________________________ Phone __________

Address ______________________________

15. Notarization {optional if used in State of Washington}

__________________________ __________________________
Signature {sign only in the presence of a notary} Date

State of Washington, County of _______________________

I certify that I know or have satisfactory evidence that __________________________ signed this document and acknowledged it to be his/her free and voluntary act for the uses and purposes mentioned in this document.

Dated this __________ day of _________________, 20________

__________________________ __________________________
NOTARY PUBLIC in and for the State of Washington
Residing at __________________________

My commission expires ____________________

Note: Notarization of Advance Directives is optional in Washington State. This form includes notary statement because we believe that notarization eliminates doubt about the validity of your document. Additionally, some states do require advance directives to be notarized. SCCA provides complimentary notarization of advance directives in our Patient and Family Resource Center located on the 3rd floor of the clinic.
Managing Symptoms at Home

In the next section, you will find information on the following symptoms. Please talk with your doctor or nurse if you have questions.

- Anemia
- Anxiety
- Bleeding
- Body Image Changes
- Breathing Problems
- Change and Uncertainty
- Constipation
- Dehydration
- Depression
- Diarrhea
- Fall Prevention
- Fatigue
- Fever
- Lymphedema
- Memory and Concentration
- Mouth Pain/Mucositis
- Nausea and Vomiting
- Pain
- Peripheral Neuropathy
- Sexuality
- Sleep Disturbances
- White Blood Cells
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 doctor 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.
- Add green leafy vegetables and liver to your diet when possible.

Information taken 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 the 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 doctor 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. Then ask yourself how you would change the procedure so it doesn’t make you so anxious. Staff may be able to help make those changes so talk with them about it.
- Getting the facts can help. For example, if you are worried about pain or discomfort, there is information available on how to manage.
- 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 doctor, 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 doctor 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 doctor, nurse or pharmacist. Certain medications can increase your risk of bleeding. Do not take aspirin, ibuprofen, amproxin (Aleve®), Alka-Seltzer®, or cold remedies containing these drugs. Please talk to your doctor 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 doctor.
- 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 or Outpatient Department.
- 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, 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 doctor 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, doctor, 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. 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. 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.

Wear Attractive and Comfortable Clothing
- Wear colorful clothing. Chemotherapy and radiation tends to make skin pale, sallow or ruddy. Colors and interesting patterns can decrease the intensity of the 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 alcohol-based products.
- Avoid hot water.
- Wear sunscreen or protective clothing when outside.
- Report any skin changes such as rash or inflammation to the doctor 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.

Get Professional Help
- Talk with your doctor, nurse or social worker for a referral to a counselor.
Breathing Problems

Just the Facts
Difficulty breathing may occur during your treatment. The symptoms include feeling 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 the lungs healthy.
- Call for professional help when needed.

Emergency Signs and Symptoms
Call 911 IMMEDIATELY if:
- 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 doctor 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.
- Daily exercise. This helps expand the lungs and improves oxygen exchange and blood flow.
- Upright position lets 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 doctor 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 result in the colon being less sensitive to its intrinsic reflexes, so always discuss use of laxatives with your doctor or nurse.

Your Goals
- Prevent constipation and recognize symptoms early.
- Get professional help when needed.

Important Signs and Symptoms
Report symptoms to a doctor or nurse during clinic hours today:
- Distended abdomen and/or abdominal pain.
- No bowel movement for more than 2–3 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 fluid. Try to drink at least 8 cups of liquid daily. Drinking hot water upon rising in the morning can stimulate the bowels.
- Eat food high in fiber when possible. Fiber includes: fruits, figs, dates, prunes or prune juice, vegetables, and grains. Ask your nurse if you would like consultation with the dietitian.
- If you are taking pain medication ask your doctor or nurse about the use of laxatives and stool softeners.
- Keep physically active as possible.

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

Just the Facts
Dehydration means there is not enough fluid in the body. The body does not function well without enough fluid. Dehydration can occur if there is not enough fluid intake. This can be due to the excessive loss of fluid from diarrhea, vomiting, fevers and sweating. Dehydration can also 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:
• Dizzy or lightheaded.
• Fainting.
• Confused.

Important Signs and Symptoms
Report symptoms to a doctor 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
• Promote fluid intake.
• Drink as many liquids as possible. If you detect early signs of dehydration, you may be able to correct the problem by drinking more.
• Avoid 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 doctor 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 doctor, 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 doctor 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 doctor, 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. Report diarrhea because it can lead to dehydration and loss of electrolytes. It is not always possible to prevent diarrhea.

Your Goals
• Prevent dehydration.
• Prevent infection.
• Call for professional help when needed.

Urgent Signs and Symptoms
Call the Clinic or the After Hours Clinic NOW if you are experiencing:
• Constant or uncontrolled diarrhea.
• New onset of diarrhea.
• Fever and abdominal stomach cramping.
• Whole pills passed in stool.
• More than 5 bowel movements a day.
• Stool that is bloody, burgundy or black.
• Abdominal cramping.

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

What You Can Do at Home
Prevent dehydration:
• Drink fluids (in suggested amounts).
• Follow dietary recommendations. Note any food allergies or intolerances and discuss with the doctor, nurse or dietitian.
• Prevent infection and irritation.
• Wash hands often, with warm water and soap.
• Keep anal area clean with mild soap and water.
• Do not use ointment or creams on the anal area unless directed by the nurse or doctor.
• Use white, non-perfumed toilet paper.
Call For Professional Help When Needed

- Describe the type of diarrhea to health care staff by including frequency, consistency, color and presence of cramping.
Fall Prevention

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

If you have a history of confusion with any medications for nausea or pain control please let your doctor or nurse know. We want to prevent falls both in the clinic and at home. Please review this information with your family members and friends who are a 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. You might hurt yourself trying to get up.

Important Signs and Symptoms
- Report symptoms to your doctor 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) please tell staff right away.

**Call for Professional Help When Needed**

- If you are groggy, dizzy, or feeling faint.
- If you fall, please let staff know RIGHT AWAY by yelling or asking anyone around you to help.
- Do NOT attempt to get up alone. You might hurt yourself trying to get up.

**What You Can Do at Home**

- Think about the shoes that 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 or shoes without backs and flip-flops. Wear sturdy, non-skid shoes such as tennis shoes. Please wear both 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 providers 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 doctor about seeing a physical therapist for mobility aid and balance and strengthening. Practice approved exercises regularly to improve your strength, balance and coordination.
• If you live alone, consider getting an emergency system that you can wear around your wrist or neck to alert help immediately if you fall.

References:
Fatigue

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

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

Emergency Signs and Symptoms
Call 911 IMMEDIATELY if:
- If you are the caregiver and cannot wake your patient.

Urgent Signs and Symptoms
Call the Clinic or the After Hours Clinic NOW if:
- Dizzy.
- Too tired to get out of bed or walk to the bathroom.

Important Signs and Symptoms
Report symptoms to a doctor or nurse during clinic hours today:
- Fatigue is getting worse.
- Staying in bed all day.
- Other symptoms occur with increased fatigue.
- Increased weakness or exhaustion.
- Drowsiness or confusion.
- Loss of balance.
- Catching your breath.
What You Can Do at Home

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

Conserve Energy

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

Just the Facts
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 the blood counts are low. Act promptly when a fever occurs because the patient cannot fight infection when the 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 38-38.2°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.
• Fever greater than 1 degree above usual when the patient is on Prednisone or steroids.
• Shaking chills (temperature may be normal).
• Cold symptoms (runny nose, watery eyes, sneezing, coughing).

Important Signs and Symptoms
Report symptoms to a doctor 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.

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 SCCA Clinic before trying measures to bring down the fever.
- Do not give Tylenol® (unless directed by the doctor or nurse).
- When transporting a patient with chills to the SCCA 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 the image below. If you have any questions, please ask your doctor or nurse.
Lymphedema

What Every Person Facing Cancer Surgery Should Know About Lymphedema

If you have been treated surgically for cancer, you may be at risk for developing lymphedema of the arm, leg, trunk or groin. Most people who have had cancer surgery will not develop this side effect. This information describes what lymphedema is, the steps you can take to lower your risk, and what signs to look for. It is not possible to completely predict who will get lymphedema, but recognizing it early and treating it promptly is the best way to manage it.

What is Lymphedema?

Our bodies have a network of lymph nodes and lymph vessels that carry and remove lymph fluid, similar to the way blood vessels circulate blood to all parts of the body. The lymph fluid contains white blood cells, which help us fight infection. During surgery for cancer, the doctor sometimes removes some of the lymph nodes from the underarm, elbow, neck, abdomen, groin, or behind the knee to see if the cancer has spread. Some lymph vessels that carry fluid to the rest of the body are removed also, because they are intertwined with the nodes.

The removal of lymph nodes and vessels changes the way the lymph fluid flows within the treated extremity. This change makes it more difficult for fluid in that extremity to circulate to other parts of the body. If the remaining lymph vessels cannot remove enough of the lymph fluid in the area, the excess fluid can build up and cause swelling, or lymphedema. People who have many lymph nodes removed and radiation therapy may have higher risk of developing lymphedema. Radiation treatment also can damage lymph nodes, thus affecting the flow of lymph fluid in the extremity in the same way, putting you at increased risk of lymphedema.

Lymphedema usually develops slowly. The swelling can range from mild to severe. It can develop immediately after surgery or radiation treatment, or many months, or even many years, later. It is not fully understood why some patients are more likely to develop lymphedema. Although much remains to be learned about this condition, there are lifelong ways that you can care for the extremity to reduce your chances of having future problems.

How to Watch for Lymphedema

If you have had lymph nodes removed or radiation treatment, you should daily examine that area in front of a mirror and compare the size of the surgical side to the non-surgical side. If you note swelling on the treated side, call your doctor or nurse.
Signs of Lymphedema
The signs of lymphedema may include:
- The extremity feels full or heavy
- Swelling
- Skin feels tight
- Less movement or flexibility in the hand, wrist, elbow, shoulder, ankle, knee, leg, or hip
- Difficulty fitting the arm into jacket or shirt sleeves or the leg into pants/socks/shoes
- Ring, watch, and/or bracelet feels tight but you have not gained weight
- Burning, tingling, or feeling as if the limb is bruised

Practical Considerations for Prevention of Lymphedema in the Treated Limb
Avoid injury and infection:
- Keep your skin clean. Wash the arm or leg at least once a day. Avoid using a loofah.
- Use lotion daily. Dry your hands and toes thoroughly and use lotion to keep your skin from getting dry and cracked.
- Use an electric razor only for shaving. NO straight razors.
- Avoid scratches from pets, wear gloves.
- Wear sunscreen SPF 30 or greater.
- Wear insect repellent when appropriate outdoors.
- Maintain good nail care; push cuticles back, do not cut them. If you get a manicure/pedicure, ensure that they use an autoclave to sterilize their instruments.
- Avoid needles (shots, vaccinations, blood draws, IV fluid administration) into the treated extremity.
- Use the opposite extremity to test temperature of water to avoid burns.
- Clean breaks in skin with soap and water right away, then use an antibacterial ointment and monitor healing.
- Use caution with tape/band aids on skin and with tape removal.
- For patients who have had an abdominal, groin or leg lymph node dissection, wear long pants, socks and good shoes when gardening or hiking. Avoid going barefoot.
- For arms- avoid injury and infection of the hand and arm:
  - Use rubber gloves for housework when using cleaning products.
  - Wear oven mitts or use hot pads when cooking.
  - Wear cloth or leather gloves and long sleeves when gardening or hiking.
  - Carry briefcases, backpacks, bags, purses with the opposite arm (use a fanny pack instead if you’ve had bilateral lymph node removal).
  - Use a thimble when sewing.
Avoid Constrictive Pressure on the Affected Extremity

- Wear loose jewelry and clothes without constricting bands. Avoid crossing your legs.
- Do not use a blood pressure cuff on the arm or leg that had lymph nodes removed. If you have had lymph nodes removed from under both arms, then you may have blood pressure/shots only in your legs. If you have had lymph nodes removed from each groin, then you should have BP/shots only in your arms. Discuss with your doctor.
- Do not use constrictive ace-wraps on that arm or leg.
- Watch daily for signs of infection, e.g., pink/redness (of the arm/chest wall or leg/abdomen/groin), pain, heat, swelling or fever. Call your doctor immediately for prompt antibiotics if signs of infection occur. Consult your doctor about rashes should they occur.
- Avoid prolonged and strenuous work; rebuild your strength gradually. Avoid straining by not lifting a weight that you have not built up to. We recommend that you use good judgment and that you take note of what activities, if any, you feel bother the extremity.
- Keep regular follow-up appointments with your doctor.
- Eat a well-balanced, protein-rich, low-fat, low-salt diet. People who are overweight are at higher risk for getting lymphedema.
- Drink plenty of water.
- Avoid hot baths, hot tubs/Jacuzzis, and saunas.
- Get regular exercise. Walk, swim or bike at least 3-5 times a week. Start out with a few minutes and build up gradually to 30-60 minutes each time. A physical therapist can teach you specific light massage and/or drainage-promoting exercises that you can do regularly.
- Discuss with your therapist the need to wear a compression garment during air travel or exercise.

This list describes things to be careful about, though there may be situations that require you or your doctor to override these precautions to perform a necessary procedure, or achieve a necessary task. It is very important to remember that precautions are things to be careful about, not things that are absolutely forbidden at all cost. The onset of lymphedema is unpredictable as each body reacts differently to lymph node removal and/or radiation. Also, lymphedema, in and of itself, is not a life-threatening condition. It is never advisable to adhere to a lymphedema precaution if it means refusing a possibly life-saving treatment.

Treatment
Lymphedema cannot be cured, but prompt treatment may minimize the swelling. Please consult your doctor to discuss treatment options. Treatment may include:

- Physical Therapy
- Occupational Therapy
- Decongestive therapy including manual lymph drainage (MLD- a type of massage performed by a trained therapist), wrapping of the limb, exercising of the wrapped limb, self-MLD massage and meticulous skin care, which the patient is taught to do at home.
- Use of a compression sleeve/garment
For More Information
For more information about lymphedema contact the following organizations:

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

National Cancer Institute Cancer Information Service
1-800-4 CANCER (1-800-422-6237); www.nci.nih.gov

National Lymphedema Network
1-800-541-3259; www.lymphnet.org

Seattle Cancer Care Alliance, Physical Therapy Department
206-606-6373; www.seattlecca.org/physical-therapists.cfm

Information adapted from: American Cancer Society, Indiana American Cancer Society, Cancer Lifeline, UW Cancer Center
The Lymphatic System

Image from Anatomy of the lymph system, Women to Women 2006
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 complete 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 is 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 doctor 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 doctor 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 times 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 doctor. 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 doctor to review your medications.

How Can I Keep My Mind Active?
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. Below is a list of resources you might want to utilize to enhance your cognitive abilities.

• Puzzle Books: Cross- word 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, Gin Rummy, Pinochle, Canasta, Cribbage, Black Jack, or Solitaire.
• Games: Play stimulating games such as Chess, Checkers, Scrabble and any other games you enjoy. If your kids have a Nintendo Playstation, 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 CD’s 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/ 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 doctor or nurse. Ask your doctor or nurse about a Neuropsychological referral and Neuro-Rehabilitation Treatment.
Mouth Pain/Mucositis

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 patient’s experience varies from mild discomfort to severe pain, which makes eating, drinking and sleeping difficult.

The patient’s 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 doctor 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 1-2 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 doctor. 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 (5-10 ml) and swish and hold the solution in the mouth for 15 – 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 15-30 seconds then reapply in 30-60 second intervals for a total of 3-5 minutes. Use the gel at least 15 minutes before or after eating. When used right, the medicine may provide 30-45 minutes of pain relief.
- Take pain medication as instructed.
- Tell the doctor 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 10-15 minutes every 2 hours.
- 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 Nutrition and Fluid Intake

- Warm fluids - try: chicken noodle soup, chicken broth, tea.
- Cool fluids - try: popsicles, slushies, sports drinks and Kool-Aid®
Nausea & 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 itself, 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
Prevent nausea and vomiting or manage the symptoms well:
- 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 doctor or nurse during clinic hours today:

- 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.
- Prior to 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

- If you notice that the anti-nausea medicine does not seem to be controlling your nausea let your doctor or nurse know. Different medicine may be used to better control the nausea.
- Do not increase the amount of medicine you take without checking with the doctor, nurse or pharmacist.
- Do not take any over-the-counter medicines without checking first with your doctor or nurse.
- 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.
- If the medicines seem to make you nervous, jittery, or cause any unusual sensations, let your doctor or nurse know.
- Since 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 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 be controlling your nausea, call your doctor or nurse. Additional medications may be used to better control the nausea.
- If the medicines seem to make you nervous, jittery, or cause any unusual sensations, let your doctor or nurse know.
- Do not increase the amount of medicine you take without checking with the doctor, nurse or pharmacist.

Do not take any additional over the counter medications without checking first with your doctor, nurse or pharmacist.
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 doctor may ask a doctor 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 your pain medication is used the way your doctor prescribes it, it is very rare 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 health care providers 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 doctor 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 doctor 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 doctor 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? (e.g. burning, radiating, throbbing, stabbing)

It is the goal of the staff at the SCCA 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 doctor 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 (called 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 doctor.
- 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. Such activities may help you notice less pain or discomfort.
- Before taking pain medication/opioids, ask your nurse or doctor 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:
• If you are the caregiver and can not 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 doctor 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.

What You Can Do at Home
• 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 doctor, 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 - please review the Fall Prevention Handout. 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 doctor will try to determine the source of the problem. Ask your doctor questions.
- Let your team know how much the neuropathy is impacting your life. There are techniques for coping with pain and discomfort. In many cases, symptoms improve with time.

**Websites**

[www.neuropathy.org](http://www.neuropathy.org)
Sexuality

Just the Facts
Chemotherapy, surgery and/or radiation may cause physical and emotional changes that can affect sexuality. Treatment can affect sexual desire and erections in men. In women, chemotherapy may cause early menopause and vaginal dryness. Both men and women often lose interest in sex during treatment. Many people have concerns about their body image. Use birth control when undergoing chemotherapy or radiation as directed. Please discuss the time frame for the use of birth control with your doctor or nurse.

Your Goals
- Prevent pain during sexual activity.
- Prevent infection.
- Keep an open mind about ways to feel sexual pleasure.
- Get professional help when needed.
- Discuss any restrictions with your doctor or nurse.
- Prevent unwanted pregnancy.

Important Signs and Symptoms
Report symptoms to your doctor or nurse during clinic hours.
- Women: dry vagina, vaginal discharge, hot flashes, pain, discomfort or bleeding after or during intercourse.
- Men: genital pain, pain during ejaculation.
- Fearfulness about sexual activity.

What You Can Do at Home
Strive for good communication with your partner and your doctor. Ask questions. Although you may feel reluctant, try to be open and ask your doctor or nurse about sexual activity. Let your doctor or nurse know if you are having pain during sexual activity. Medical treatments can often be helpful. Do not let embarrassment get in the way of your medical care or quality of life.

Prevent Pain During Intercourse
- Plan sexual activity for the time of day when you are feeling the best. If you are taking pain medication, take it at an hour when it will be in full effect during sex.
- Find a position for touching or intercourse that puts as little pressure as possible on the sensitive or painful areas of your body.
- Empty your bladder before touching or intercourse. Feelings of fullness can interfere with feelings of sexual relaxation and pleasure.
- Let your partner know if any kinds of touching cause pain. Show your partner ways to caress or positions that aren’t painful.
Women

- Use a water-soluble, bacteriostatic lubricating gel, such as K-Y® Jelly or Astroglide® on the external genitalia for pleasuring, and in the vagina and on your partner for ease of penetration.
- Make sure you feel adequately aroused before you start intercourse. When you are aroused the vagina expands to its fullest length and width.
- Learn to relax vaginal muscles during intercourse. Kegels help you learn to relax these muscles. Ask for instruction if you haven’t learned these exercises before. Kegel exercises also strengthen some of the muscles that control the flow of urine.

Prevent Infection

- Wash hands before and after sexual activity.
- Urinate after sex. This rinses out bacteria that may cause infection in the urinary tract.
- Avoid sexual contact with people who have infectious diseases (colds, flu, cold sores) or sexually transmitted infections.

Cope Creatively with Changes in Appearance.

- Focus on the positive. Positive thoughts can make a sexual experience good.
- Create a healthy illusion -- disguising the changes treatment has made and drawing attention to your best points.
- Consider wearing a wig, scarf, turban, or hat. Discuss this with your partner. There is no right or wrong decision.
- Contact your local American Cancer Society or call 1-800-395-LOOK for information on the “Look Good . . . Feel Better” program.
- Review the American Cancer Society booklet: Sexuality and Cancer for Men or Women.

Keep an open mind about ways to feel sexual pleasure.

- Intimacy ideas such as holding hands, massaging, kissing, and sharing your fantasies.
- Learn new ways to give and receive sexual pleasure. There may be times when intercourse is not possible. Help each other reach orgasm through touching and stroking. At times just cuddling and being physically close can be pleasure enough.
- Enjoy self-stimulation. No matter what kind of treatment you have had, the ability to feel pleasure from touching almost always remains.

Call for Professional Help When Needed

Women: Talk with your doctor or nurse if you notice signs of premature menopause, hot flashes, irritability, headaches, vaginal dryness, or less interest in sex. You may benefit from hormone replacement therapy (HRT) or a change in the dose or type of HRT you are using.

Men: Talk with your doctor or nurse if you experience loss of sexual desire, erection problems, trouble reaching orgasm, premature ejaculation, or pain. Your doctor will work with you to
determine the cause (physical, hormone changes, or anxiety) and get you started on a therapeutic plan. Ask your doctor or nurse about medications.

**Special Note for Transplant Patients**

Married or committed couples who are mutually monogamous do not need to use condoms, but it is fine to do so. Condoms are definitely recommended in situations where couples are not mutually monogamous to minimize transmission of sexually transmitted infection (STI). If the partner has or is suspected to have a sexually transmitted infection, a condom is not a sufficient barrier. That means no sexual activity is best at this time. If an STI is diagnosed, it must first be treated and resolved before resuming sexual activity.

**Common Questions:**

*Is it safe for me to kiss while I’m getting chemotherapy or after treatment?*

Kissing is a wonderful way to maintain closeness with those you love and is usually okay. However, because chemotherapy can be found in the saliva, you should avoid open-mouth kissing where saliva is exchanged for a short period of time during and after chemotherapy. Ask your doctor or nurse how long you need to avoid open-mouth kissing, because it depends on what type of chemotherapy you receive. Also, to reduce the risk of infection, avoid kissing anyone who has open mouth sores, cold sores or symptoms of an infection such as a cold or the flu.

*What restrictions prevent me from resuming sexual activity?*

- Sexual intercourse is restricted at times when platelet counts are less than 50,000. Sexual activity is also restricted when white blood counts are low (neutropenic- neutrophil count less than 500).
- Sexual activity is restricted when there is vaginal or rectal bleeding.
- If your partner has a sexually transmitted infection.*

*A Sexually Transmitted Infection (STI) is any contagious infection that can be spread by sexual contact such as chlamydia or herpes. You can get a sexually transmitted infection from sexual activity that involves the mouth, anus, vagina, or penis.

*Why don’t I have much sexual desire?*

- Lack of desire (also called lack of libido) can be a normal response to the stresses of treatment and not feeling well.
- Some medications can interfere with sexual desire. There can be physical reasons that desire is lacking. Chemotherapy and radiation often affect hormones. In some instances this can be treated with hormone supplementation or other medications. Talk to your doctor or nurse if lack of desire is a problem. They can evaluate if further medical testing is necessary and what treatments or counseling may be available.
Is there anything I can do about my fatigue?
Fatigue can be a long lasting problem after treatment. Try to plan sex for the part of the day when you feel the most energetic. Remember that sexual pleasure doesn’t always need to involve penetration. Talk to your partner about other ways you can give each other pleasure, like touching, cuddling or kissing.

Do we need to use a condom during sex?
Condoms or other barrier protection should always be worn if you are not in a mutually monogamous relationship to reduce the risk of exposure to sexually transmitted infections. This includes all types of sexual intercourse, including oral, anal and vaginal sex.

- Latex condoms should be worn.
- Pregnancy must be avoided while you are receiving treatment and post treatment. Some of the medications used during and after treatment have been linked to birth defects. It is extremely important that birth control be used after treatment if there is a chance you could become pregnant or father a child.
- Condoms should be worn during anal sex to reduce the risk of infection during or after treatment.
- If your partner has a suspected or known Sexually Transmitted Infection, a condom may not be a sufficient barrier during and after treatment. You may need to refrain from having sex for a period of time.
- Talk to your doctor or nurse about how long you need to wear a condom after chemotherapy because the time recommendations can vary depending upon the drugs you receive.

Why is sex painful? What can I do?
Women: Treatment can make it more difficult to become aroused for sex, which can lead to pain because the vaginal walls are not relaxed. Take time to allow yourself to get in the mood with stroking, relaxation or imagery. Women can also experience vaginal dryness due to premature menopause from chemotherapy and radiation. Use a water soluble lubricant during sexual activity to help with dryness. Hormone supplementation may be helpful. Talk to your doctor or nurse if you notice these symptoms as they can often be improved with medications, topical creams and/or vaginal dilators. These symptoms should not be ignored because they can worsen if not treated.

Men: Some men have reported temporary pain with ejaculation after treatment. It is thought that this may be related to inflammation of the urethra from radiation and/or chemotherapy. You should report this symptom to your doctor so that it can be further evaluated to ensure that another problem, such as an infection, is not also a factor. Any unusual tightness, penile curvature, or pain with erection or ejaculation should also be discussed with your doctor or nurse.

I’m having difficulty with erections. What can I do about this?
Difficulty with erections after transplant can occur for different reasons. Sometimes, it’s harder to become and stay aroused because of stress and fatigue. Chemotherapy and radiation to the brain and testicles can also affect hormones involved in arousal and erection. Hormone supplementation
such as testosterone or medications to treat erectile dysfunction can be helpful. Your doctor will decide if medications will be helpful for you.

Is oral sex okay?
- Oral sex is acceptable with certain precautions. It should be avoided while chemotherapy may be in body fluids.
- Talk to your doctor or nurse about how long this is a concern.
- It should also be avoided if your platelet or neutrophil counts are low. There should be no open sores in the mouth or on the genitals.
- To reduce the risk of infection, genitals should be cleansed before and after oral sex. Avoid contact with the rectal area.

Is anal sex okay?
- Anal sex should be avoided if you or your partner’s platelet count is less than 50,000 or if you or your partner is neutropenic.
- Condoms should be worn.
- Anal sex should not be performed if there is bleeding, diarrhea, hemorrhoids, anal fissures or tears.

Will I be infertile after treatment?
- The type and dose of chemotherapy and or radiation you receive for treatment, your age, your previous chemotherapy and radiation exposures, and your gender can all influence your fertility.
- Women often stop ovulating for a period of time after treatment or may experience premature menopause.
- Men often stop making sperm completely or have very low sperm counts during cancer treatment and for several months after treatment. Not every male will resume normal sperm production and may be infertile as a result of surgery, chemotherapy or radiation. It is best to see a fertility specialist to monitor fertility after cancer treatment.
- A small percentage of people, usually of younger reproductive age, do regain their fertility after treatment, but this may take months to years to occur and can be hard to predict for each person.
- Routine testing of sex hormones and sperm or ovarian function is often needed to see if fertility will be restored. However, as unexpected pregnancies have occurred, please discuss your plan for birth control with your doctor to prevent unplanned pregnancy.
- It is recommended that all patients who are interested in preserving fertility have their options evaluated prior to treatment. This allows the time, and best chances, for storage of sperm, eggs or embryos. If you are interested in options to preserve your fertility or to have your individual risk for infertility evaluated, talk to your doctor or nurse. A fertility specialist (Reproductive Endocrinologist) can provide more information about your current fertility status and the fertility options available to you.
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 stored for many years for use later.
For women, the standard approach is to harvest eggs which are then fertilized by sperm and stored as embryos. Several weeks may be needed to allow for the harvesting of eggs and a partner or sperm donor is necessary. These embryos can be frozen for many years for use later. Similarly, eggs alone can be harvested and frozen without adding sperm. These eggs can be frozen for many years and used later to create embryos for implantation in the uterus.

There are other techniques used to collect and store sperm, eggs or ovarian tissue, many of which are still considered experimental. Many of the costs associated with fertility preservation are not covered by insurance. However, programs such as Livestrong’s Sharing Hope can increase access to fertility preservation services for cancer patients. Ask your Reproductive Endocrinologist for more details.

Cancer and Sexual Health Resources
Brochures - available in the SCCA Patient and Family Resource Center:
- “Sexuality and Cancer: For the Woman who has Cancer and Her Partner.” American Cancer Society
- “Sexuality and Cancer: For the Man who has Cancer and His Partner.” American Cancer Society
- “Managing Chemotherapy Side Effects: Sexual and Fertility Changes in Men.” NCI
- “Managing Chemotherapy Side Effects: Sexual and Fertility Changes in Women.” NCI

Books - Available at the SCCA Resource Center:

Other Suggested Books:

**Website Resources**
National Cancer Institute  
[www.cancer.gov](http://www.cancer.gov)  
Search for “Sexuality”

The American Cancer Society  
[www.cancer.org](http://www.cancer.org)  
Search for “Sexuality”

University of Washington Reproductive Care  

LIVESTRONG - Lance Armstrong Foundation  
[www.livestrong.org](http://www.livestrong.org)  
Under get help, click on “Cancer Support.” Next click on “Learn About Cancer,” then click on “Cancer Support Topics,” and then on “Physical Effects of Cancer.”

Myoncofertility.com  
[www.myoncofertility.org](http://www.myoncofertility.org)  
Discusses fertility issues before and after treatment

Fertile Hope  
[www.fertilehope.org](http://www.fertilehope.org)

Resolve  
[www.resolve.org](http://www.resolve.org)  
Patient advocacy group addressing reproductive concerns and options for infertile individuals and couples, as well as cancer patients.

WebMD  
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:
  - Have not slept in days.
  - Talk to your Social Work, Psychology, or Psychiatry if you have symptoms of anxiety and depression.
  - Talk to your doctor or nurse about any physical symptoms that keep you from sleeping or cause you to wake up in the middle of the night.

What You Can Do At Home
Promote sleep:
- Back rubs or massages may be relaxing.
- Keep a regular schedule.
- Limit alcohol and nicotine.
- Limit foods containing caffeine.
- 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 only.
- Create a peaceful environment in which to sleep by decreasing noise, dimming lights, adjusting room temperate, and keeping bedding and pillows clean, dry, and wrinkle-free.
- Try not to drink fluid before bed and empty bowel and bladder before bedtime.
- Avoid drinks with caffeine before bed.
- Minimize daytime naps.
- Listen to relaxation tapes and or peaceful music before bed.
- Avoid alcohol.
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 the information about your white blood cells. White blood cells help protect the body by fighting bacteria and viruses that cause infection. If your white blood count is low, it is important to protect yourself against infection. When your white blood count is low, your own 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 doctor or nurse during clinic hours today.
- Shaking or chills.
- Cough.
- Sore throat.
- 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.
- A general feeling of tiredness or “flu-like” symptoms.
- Painful or frequent urination.

What You Can Do at Home
- 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 doctor or nurse for advice before you self-treat.
- Check with your doctor or nurse regarding dental work.

Information adapted from: Pharmacia and Upjohn Company
Toll-Free Calling for UWMC Patients

Aberdeen/Grayland/Westport (360) 612-5500
Bellingham/Everson (360) 543-5500
Black Diamond/Enumclaw (360) 615-5500
Bremerton/Kitsap (360) 525-5500
Chehalis/Centralia (360) 557-5500
Coupeville/Oak Harbor (360) 544-5500
East King County (425) 519-5500
Everett (Bothell, Mill Creek, Snohomish) (425) 262-5500
Hoodsport/Union (360) 614-5500
Mt. Vernon (360) 542-5800
Olympia (360) 554-5500
Port Angeles/Sequim/Gardner (360) 504-5500
Port Townsend (360) 554-5500
Seattle (206) 685-5500
Tacoma (253) 552-5500
Questions to Assist You During Your Treatment Journey

Your questions and concerns are important. Please express them.

At Diagnosis
- Will I need someone to drive me to and from the hospital when I have this treatment or procedure?
- Will I need a family member or friend to be a caregiver (someone who can help with your care at the hospital or at home)?
- Are there any activities that I need to avoid when undergoing this treatment?
- Are there food or over the counter interactions with the medication I am taking that I need to be aware of?
- What happens if I do not take all of my medications?
- What are the expected side effects? Who do I call to discuss coping with side effects?
- When should I call for help?
- How do I get help on the weekends and after-hours?

Treatment
- What treatments do you recommend I have for this diagnosis and/or problem?
- What are the risks or complications of these treatments or procedures?
- How long does this treatment or procedure take? How many treatments will there be?
- When am I scheduled for treatment?
- Can I have a break in my treatment?
- Will I need someone to drive me to and from the hospital when I have this treatment or procedure?
- Will I need a family member or friend to be a caregiver (someone who can help with your care at the hospital or at home)?

After Treatment
- When should I have follow-up clinic visits and tests?
- How long will it be before I feel like myself?
- Are there any long-term effects from this treatment? When do I make a survivorship appointment?

Additional Questions:
Information to Help You Navigate

Airport Transportation Service
Volunteer drivers provide transportation to and from Seattle-Tacoma Airport or Boeing Field. To request transportation, please call Volunteer Services at least three business days before your arrival or departure. Leave a message with the following information:

- The names of everyone needing transportation, and the amount of luggage that you have.
- Your arrival date, time, airline, flight number and city of the flight's origin.
- For departures from Seattle, please state the airline and flight departure time. You are advised to arrive at the airport at least two hours before the departure time.
- The name and address of your hotel or residence in Seattle.
- Your hometown and daytime telephone number, and the best time to reach you.

Volunteer Services will contact you to confirm transportation arrangements. It may not be possible to arrange for volunteer transportation between 10 p.m. and 6 a.m. and on major holidays.

Chaplaincy
Chaplains provide respectful spiritual and emotional care for people of all faiths and spiritualities, including those that identify themselves as non-religious or non-spiritual. Chaplaincy provides worship and other services and can assist you in locating religious and spiritual resources. You can visit the Sanctuary, located on the 1st floor, for quiet prayer, reflection or meditation.

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 age and development appropriate language. Child Life is available to help you or other family members with coping skills needed to care for a sick child.

Guest Services
To learn about Seattle and services for patients and families, please speak with our friendly Guest Services Volunteers in the main lobby. Volunteers can suggest recreational activities and acquaint you with the Clinic and surrounding areas, distribute donated tickets for attractions and special events, provide wheelchair escorts, give directions, and provide assistance in calling taxis and shuttles. They are available to assist you from 8 a.m. until 4 pm, Monday through Friday.
Interpreter Services
Interpreters are present for non-English and limited English speaking 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.

Cancer Library, UWMC
Volunteers also assist patients’ family members and friends in the UWMC’s Cancer Library, which is located on floor 8 SE. The library has oncology-related books, videotapes, support resources and computers to access the Internet.

Living Tobacco-Free Services
The Living Tobacco-Free Program is available at no charge to SCCA patients, caregivers, and family members who are thinking about stopping tobacco use. Individuals can call and speak with someone directly to discuss quitting, develop a quit plan and to get support during the quitting process. Free nicotine patches, gum and lozenges are available to those who receive counseling. Quitting smoking is often the single most important thing one can do to improve their health. Those with a cancer diagnosis benefit greatly, as well.

Medical Nutrition Therapy Services
The science of nutrition during cancer treatment is a specialized field. An oncology dietitian can provide real-life recommendations that are based on food preferences and tolerances, interest in food and specific social, economic and medical situations. A visit with a dietitian can provide you with inspiration about how to make healthful eating work even while undergoing treatment. Just being able to actively participate in your own healing makes you feel better.

Medical Care for Family Members
The SCCA Clinic provides medical services only to patients. All other family members who need medical treatment while in Seattle have the following options:

- They may go to their local physician.
- They may call Urgent Care at the University of Washington 206-598-4000. Ask for an appointment with Urgent Care.
- They may go to the University of Washington Medical Center, Family Medical Center 206-548-4055 (Roosevelt), or Belltown Clinic 206-443-0400.
- Any family member with symptoms of cold or flu should not come to the Clinic or the Inpatient Units until checked by a nurse or doctor. Please contact the patient’s nurse if you have questions or need help.

Patient and Family Resource Center
The Resource Center is located on the 3rd Floor of the clinic. We provide educational materials, computer workstations and business center, a notary and a cancer lending library. We can provide listings for local and clinic events, as well as assistance locating support groups and other resources and events locally. All services and materials are free of charge.
**Patient Navigators**
Navigators are available to provide resources and support. The Patient Navigator has information available on different cancer types, treatments, coping with cancer, supportive care and survivorship issues.

**Physical Therapy**
Physical therapy plays a significant role in enhancing the quality of your life as you regain a sense of hope and health as you move towards improvement. 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.

**Rain or Shine**
Product offerings at our in-clinic store, *Rain or Shine*, located on the 1st floor of the clinic, consist of quality goods and items requested by our patients, families, staff and visitors. Our product offerings include convenience sundries, books and newsstand, gift items, hats and scarves, pass-time toys and games for all ages, as well as apparel. We also offer jewelry, cookbooks, stationery and snacks. Store Hours: Monday-Friday 8:30a.m. to 4:00p.m. [www.seattlecca.org/gift-shop-rain-or-shine](http://www.seattlecca.org/gift-shop-rain-or-shine)

**Shine**
Shine is located on the first floor at the SCCA House, and provides an engaging assortment of products intended to serve your needs, as well as the needs of caregivers. Specialty 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 the Clinic every 20 minutes for the SCCA House – this is your most convenient way to visit Shine. Location: 207 Pontius Ave N., Suite 101, Seattle WA 98109. Store Hours: Monday-Friday 10 am-6 pm, Saturday 10 am- 3 pm, [www.sccashine.org](http://www.sccashine.org)
Social Work
Social Work services are available to patients and their families. 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 the clinic social worker can offer are:

- Information and referral to community resources, especially resources for cancer patients and their families
- 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 for patients and families during treatment
- Advocacy and help with problem solving at any time during a patient’s treatment.

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 their disease. Palliative care can be delivered along with life-prolonging treatment. Its goals include enhancing quality of life, helping with decision-making and providing opportunities for personal growth. Talk to your oncology team and let them know you are interested in seeing the Supportive & Palliative Care Service provider. Appointments can usually be scheduled within one to two weeks.

Volunteer Services
Compassionate volunteers provide practical and social support for patients and their families (or caregivers) in a variety of ways. For more information on the SCCA Volunteer Program, please call the appropriate contact numbers listed in the important phone numbers section of this document.

Family and Caregiver Support
Patient/Family Volunteers offer companionship and practical assistance for families and caregivers of patients who are from outside of Western Washington with no local support. When possible, we match a volunteer with a family based on similar interests. Bilingual volunteers can assist families who do not speak English, if available. Following are examples of ways that a Patient/Family Volunteer can be supportive:

- 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 and provide transportation for grocery shopping and errands once or twice a week.
- Offer social activities and opportunities to take relaxing breaks (examples: go out to lunch, visit parks, enjoy movies and sightseeing).
- Offer weekly recreational outings for children and teens.
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.
Resources, Support, and Information
These resources are provided as a service to our patients. Inclusion on this list does not imply endorsement by the Seattle Cancer Care Alliance.

Cancer Organization Websites

**Seattle Cancer Care Alliance**
www.seattlecca.org

**Fred Hutchinson Cancer Research Center**
www.fhcrc.org

**American Cancer Society**
www.cancer.org (or 227-2345)

**Cancer Hope Network**
www.cancerhopenetwork.org

**Cancer Lifeline**
www.cancerlifeline.org/ (or 1-800-225-5505)

**Fertile Hope**
www.fertilehope.org

**Gilda’s Club Seattle**
www.gildasclubseattle.org

**Get Palliative Care**
www.getpalliativecare.org

**My Oncofertility**
www.myoncofertility.org (or 708-3378)

**National Cancer Institute**
www.cancer.gov (or 422-6237)

Publications available at NCI 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-and-you
- Radiation Therapy and You
  www.cancer.gov/cancertopics/coping/radiation-therapy-and-you

National Family Caregivers Association
  www.nfcacares.org

Young Cancer Spouses
  www.youngcancerspouses.org

Treatment/Diagnostic Information
National Library of Medicine-Medline

Radiology
  www.radiologyinfo.org

Interventional Radiology
  www.SIRweb.org

Appearance
Beauty and Cancer Program (UW Medicine)
  206-598-3604

Look Good...Feel Better
  1-800-227-2345
  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
  202-778-3200
  www.ahip.org

LGBT Resources
National LGBT Cancer Network
  www.cancer-network.org/

Prescription Drug Assistance and Issues
Needy Meds
  www.needymeds.com
Transportation Security Administration: Travelers with Disabilities and Medical Conditions
www.tsa.gov/travelers/airtravel/specialneeds/editorial_1059.shtm

Disease Specific Sites

American Urological Association (bladder cancer) 1-866-746-4282
www.auanet.org

National Bone Marrow Transplant Link 1-800-546-5268
www.nbmtlink.org

Susan G. Komen Foundation (breast cancer) 1-877-465-6636
www.komen.org

National Cervical Cancer Coalition 1-800-685-5531
www.nccc-online.org

Colon Cancer Alliance 1-877-422-2030
www.ccalliance.org

Kidney Cancer Association 1-800-850-9132
www.kidneycancer.org

Leukemia & Lymphoma Society 1-800-955-4572
www.leukemia-lymphoma.org

Lung Cancer Alliance 1-800-298-2436
www.lungcanceralliance.org

Prevention and Cessation of Cigarette Smoking: Control of Tobacco Use

Link to Smoking Cessation Fact Sheets 1-800-4-CANCER (422-6237)
www.cancer.gov/cancertopics/factsheet/Tobacco

The Skin Cancer Foundation (Melanoma) 1-800-754-6490
www.skincancer.org

International Myeloma Foundation 1-800-452-2873
www.myeloma.org

Multiple Myeloma Research Foundation 1-203-229-0464
www.multiplemyeloma.org

Support for People with Oral and Head and Neck Cancer 1-800-377-0928
www.spohnc.org

National Ovarian Cancer Coalition 1-888-OVARIAN
www.ovarian.org (or 1-888-682-7426)

Ovarian Cancer National Alliance 1-866-399-6262
www.ovariancancer.org

Pancreatic Cancer Action Network (PANCAN) 1-877-272-6226
www.pancan.org

Urology Health (prostate cancer) 1-800-828-7866
www.urologyhealth.org

Prostate Cancer Foundation 1-800-757-2873
www.pcf.org

US TOO International (Support groups, info) 1-800-808-7866
www.ustoo.com

Sarcoma Alliance 415-381-7236
www.sarcomaalliance.org

Aplastic Anemia 1-800-747-2820
www.aplastic.org

Myelodysplastic Syndromes Foundation 1-800-MDS-0839
www.mds-foundation.org (or 1-800-637-0839)
Sickle Cell Disease Association of America, Inc 1-800-421-8453
www.sicklecelldisease.org

Symptom Management
National Lymphedema Network 1-800-541-3259
www.lymphnet.org

United Ostomy Associations of America 1-800-826-0826
www.uoaa.org

The Cancer Journey 1-866-257-4667
www.thecancerjourney.org

Complementary Treatments
Food and Drug Administration (FDA) 1-888-675-3388
www.fda.gov/Food/DietarySupplements
A comic strip created by a teenage cancer patient has been turned into an interactive computer game to explain cancer and its treatment.

Planet Cancer

Survivorship
Livestrong Foundation

The National Coalition for Cancer Survivorship

Beyond the Cure
SCCA Patient Rights Statement

The Seattle Cancer Care Alliance (Fred Hutchinson Cancer Research Center, UW Medicine, and Children’s Hospital and Regional Medical Center.) was formed to provide state-of-the-art, patient-focused cancer care, support the conduct of cancer clinical research and education, enhance access to improved cancer interventions, and advance the standard of cancer care, regionally and beyond. The Seattle Cancer Care Alliance (SCCA) staff are committed to work as a team that includes you, as a patient and your family members. The 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; authorization to disclose information, you can revoke that authorization at a later time to stop any future use and disclosure. We may change our policies at any time but with any significant policy change the new notice will be changed and posted. You may request a copy of this notice from the SCCA Health Information Management Department.
• 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 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 healthcare 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 healthcare, 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 on-line at www.jointcommission.org or e-mailing your concerns to complaint@jointcommission.org.

Medicare and Medicaid patients may also make complaints to Qualis Health, PO Box 33400, Seattle, WA 98133-0400, www.qualishhealthmedicare.org 800-949-7536, Fax: 206-440-2644.

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

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

Notice of Information Release Practice
Uses and Disclosure of Health Information: We use health information about you for treatment, to obtain payment for treatment, for administrative purposes, and to evaluate the quality of care that you receive.

We may use or disclose identifiable health information about you without your authorization for several other reasons. Subject to certain requirements, we may give out health information without your authorization to facilitate continuity of care, or for public health purposes, chaplaincy, auditing purposes, research studies (aggregate data), and emergencies. We may provide information limited to your name and general health condition [i.e., “critical”, “poor”, “fair”, “good”, “excellent” or similar statements]. We must provide information when required by law, such as for law enforcement activities in specific circumstances. In any other situation, we will ask for your written authorization before using or disclosing any identifiable health information about you. If you choose to sign an authorization to disclose information, you can revoke that authorization at a later time to stop any future use and disclosure. We may change our policies at any time but with any significant policy change the new notice will be changed and posted. You may request a copy of this notice from the SCCA Health Information Management Department.
Individual Rights: In most cases, you have the right to look at or order a copy of your health information. You also have the right to receive a list of instances where we have disclosed information for reasons other than treatment, payment or related administrative purposes.

If you believe that information in your record is incorrect or if important information is missing, you have the right to request that we correct the existing information or add the missing information. Contact the Director of Health Information Management.

You may request in writing that we not use or disclose your information for treatment, payment and administrative purposes except when specifically authorized by you, when required by law, or in emergency circumstances. We will consider your request but are not legally required to accept it.

Questions or Complaints: If you have any questions or complaints, or if you are concerned that we have violated your privacy, or you disagree with a decision we made about access to your records, you may contact Quality/Risk Management Administrator 206-606-1056, or send a written complaint to the Washington State Department of Health -- 510 4th Avenue West, Suite 404; Seattle, Washington 98119 -- TOLL-FREE 1-800-633-6828.

Our Legal Duty: We are required by law to protect the privacy of your information, provide this notice about our information practices, and follow the information practices that are described in this notice.
Drain Care

Caring for a Jackson-Pratt (JP) or Blake Drain

When you go home, you may have drains still in place. You will have a Jackson-Pratt (JP) or Blake self-contained drainage system. This handout explains how to care for your drains at home until your doctor or nurse takes them out.

Your closed bulb drain helps your wound heal because it drains fluid away from your surgical site. This helps keep blood and body fluids from building up under your skin and causing swelling. The drainage tube goes through your skin near your surgical incision. It is held in place by a stitch (suture).

While you have the drain:

- You will need to change your dressing (bandages) at these times:
  - If you have an antimicrobial disk (BioPatch® or Tegaderm®), change the dressing on day 7. See “How to Change Your Dressing” on page 3.
  - If you are using gauze and tape, change the dressing around the tube once a day. See “How to Change Your Dressing” on page 3.

- Empty the bulb/collection container at least 2 times a day (morning and before bedtime). Empty it more often if needed, whenever it is 1/3 full.

- When you empty less than 30 cc of drainage from the bulb/collection container in two 24-hour periods, for 2 days in a row, call your health care provider. It may be time to remove the drain.

- Keep the area where your drain leaves your body clean and dry.

How to Empty Your Drain

Empty your drain at least 2 times every day, or whenever it is 1/3 full.

Follow these steps:

- Wash your hands with soap and warm water.
- You will receive a measuring cup when you leave the hospital. Use this to measure your drainage. Record the drainage amount on the record sheets. See “Record for Drain 1” and “Record for Drain 2” at the end of this handout.
- Wash your hands well with soap and warm water before and after you empty your drain.
- Loosen the safety pin(s) or clip that holds the drain tubing to your clothing.
- Strip the tubing if your doctor or nurse has told you to do so. See “How to Strip Your Drain” below.
- Clean the plug and spout with an alcohol wipe.
The parts of the closed bulb drain.

**Open the plug on the drain:**
- Turn the drain collection container upside down over the measuring cup. Gently squeeze the bulb to empty it into the cup.
- Clean the plug and spout again with an alcohol wipe.
- Squeeze the bulb flat with your hand. Put the plug back into the spout.
- Never squeeze the bulb after you have put the cap back in place. This can push the drainage back into your wound.
- Look on the side of the measuring cup to see how much fluid you drained. Write this amount, in milliliters (mL), on your drainage record sheet. If you have more than one drain, label them 1 and 2.
- Check the drainage for color and smell. If it smells badly, call your clinic or the doctor on call if your clinic is closed.
- Empty the drainage into your toilet and flush.
- Pin or clip the drain bulb back onto your clothing.
- Wash your hands with soap and warm water.
How to Change Your Dressing
Remove your dressing and the antimicrobial disk 7 days after you leave the hospital. Remove the dressing and disk before then if your dressing gets wet or dirty. The disk will swell if your dressing gets wet.

- Use your best judgment to decide whether the disk is wet or not. Also look for moisture that may collect under the dressing from sweat. Call your nurse if you are not sure if you need to change the dressing.
- Leaving the disk on your skin too long when it is wet may cause skin problems.

When you change your dressing:
- Carefully remove the clear plastic tape and disk at 7 days. Do not pull on the tube. You will see a stitch holding the tube in place.
- Do not use scissors around the tube.
- After you remove the disk, change your dressing every day until your follow-up visit. Use dry gauze as the dressing when you change it.

If you have a gauze and tape dressing:
Change your dressing once every day, or more often if your dressing gets wet, dirty, or if the JP insertion site is oozing. To change the dressing:

- Gather and prepare supplies:
  - Tape
  - Slit gauze (such as drain gauze) or 2 pieces of gauze folded in half to put around the drain where it goes into your skin
- Wash your hands with soap and warm water.
- Loosen the tape and remove the old dressing from the drain site. Check for any redness or bad smell. It is best to change your dressing after you shower.
- Use warm soapy water and a washcloth or cotton ball to clean around the tube. Use unscented soap that does not contain oils. Let your skin dry completely.
- Remove the slit gauze from the package or use 2 pieces of folded gauze. Touch only the edges of the gauze and place it on your skin around the tube.
- Tape the gauze in place. Try not to put the tape on the tube itself

Supplies You Will Need
- Measuring cup (you will get this in clinic or when you leave the hospital)
- Alcohol wipes (for cleaning Jackson-Pratt stopper and for stripping your drain)
- 2-inch x 2-inch gauze pads
- AquaGuard® or other plastic wrap
- Paper tape
Showering
Do not take a bath, sit in a hot tub, or go swimming while you have the drain.
- You may shower after you have had the drain in place for 48 hours, after you have removed your outer surgical dressing (if you have one), or if you do not have an outer dressing.
  - To keep your drain in place in the shower, attach it to a lanyard or shoelace looped loosely around your neck.
  - Protect your dressing as much as possible from getting wet. Cover it with plastic wrap and tape the edges to your skin to make it waterproof. If your dressing gets wet, remove it after the shower. Let your skin dry completely and then change your dressing.
- To keep the drainage tube from falling out, do not let the drain hang loosely. Hold the drain in one hand or place it somewhere near you where it will not fall. You may need help in the shower.
- You may take a bath after the drain is removed, your skin has healed, and there is no more drainage from the site.

How to Strip Your Drain
Stripping your drain will keep it from clogging. If your doctor or nurse has told you to strip your drain:
- With one hand, wrap an alcohol wipe around the tubing near your dressing.
- With your other hand, keep the tubing in place by holding it firmly between your dressing and the alcohol wipe.
- With your first hand, squeeze the section of the tubing covered by the alcohol wipe. Keep this pressure while sliding the wipe down the tubing to the bulb, and then let go.

If You Have a Drainage Bag
Flushing the Drain:
- Turn the switch so it points to the drainage bag (see top picture below). The word “OFF” (or the longest part of the stopcock) will be closest to the drainage bag. This position allows you to inject fluid into the tube from the flush port.
- Inject the amount of fluid (most times about 10 cc) your doctor told you to use.
- Turn the switch so it points to the flush port again (see bottom picture below). The word “OFF” (the longest part of the stopcock) will be closest to the flush port. Your drain will now drain into the bag.
- If your instructions include “clamping” the tube or allowing it to drain internally, turn the switch so it is pointed at your body. This means the word “OFF” (the longest part of the stopcock) is closest to your body. This position closes the channel that drains from your body. Use this position ONLY to change or empty the bag. This position prevents your tube from draining.
In this drawing, the stopcock switch points to the drainage bag. (The word “OFF” is closest to the drainage bag.) This position allows you to inject fluid into the tube from the flush port.

In this drawing, the stopcock switch points to the flush port. (The word “OFF” is not pointing to your body or the drainage bag.) This position allows your drain to drain into the bag.

**When to Call the Clinic**

Call the clinic if:
- You have redness, swelling, or drainage at your incision or drain site.
- Your bulb/collection container refills with blood or drainage right after you empty it.
- You have more pain than usual, or your pain is not eased by your pain medicines.
- Your drain bulb will not stay compressed.
- Your drainage is cloudy or has a bad smell.
- The tube falls out.
- The suture comes out.
• 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 (99.5-99.9°F) for one hour or more, or a temperature that is 37.8°C (100°F) or above.

Adapted with permission from “Caring for Your Closed Bulb Drain” © 2013 University of Washington Medical Center, Seattle, Washington.
## Drain Care Tracking Log

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<tr>
<th>Day/Date</th>
<th>Pre-Breakfast</th>
<th>Pre-Lunch</th>
<th>Pre-Dinner</th>
<th>Bedtime</th>
<th>Comments</th>
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**Pain Intensity Instrument**

![Pain Intensity Instrument Diagram]

Instructions for Use

- What number would you give your pain right now?
- What number on a 0 to 10 scale would you give your pain when it is the worst that it gets and when it is the best that it gets?
- At what number is the pain at an acceptable level for you?

0 = No Pain

1-3 = Mild Pain (nagging, annoying, interfering little with activities of daily living)

4-6 = Moderate Pain (interferes significantly with activities of daily living)

7-10 = Severe Pain (disabling; unable to perform activities of daily living)
<table>
<thead>
<tr>
<th>Date</th>
<th>Time</th>
<th>How severe is the pain?</th>
<th>Medicine or non-drug related pain control</th>
<th>How severe is the pain after one hour?</th>
<th>Activity at the time of pain</th>
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