General Oncology Program

Patient Care Manual

Knowledge is Power
SCCA Patient and Family Education
Table of Contents

Chapter 1 - Getting Started ................................................................. 3
  Welcome to the SCCA ........................................................................ 4
  Important Phone Numbers .................................................................. 5
  Information to Help You Navigate .................................................. 7
  Treatment Journey Questions .......................................................... 11
  Disability Documents Needed for Family Medical Leave Act (FMLA)  12
  Helping Children Cope When Someone They Love Has Cancer ....... 19
  Diagnostic Tests ............................................................................ 25
  Participating in Research .................................................................. 32

Chapter 2 - Treatment ........................................................................ 35
  Common Treatments ......................................................................... 36
  Safe Management of Chemotherapy at Home .................................... 38
  Treatment in the SCCA Clinic ......................................................... 41
  Treatment in the Inpatient Unit ....................................................... 43
  Cancer History ................................................................................ 47

Chapter 3 - Coping with Symptoms and Common Problems .............. 50
  Important Phone Numbers ............................................................ 51
  Websites and eBooks to Review During Your Journey .................... 52
  Caregiver Organizations .................................................................. 52
  Managing Symptoms at Home ....................................................... 53
  Infection Control ........................................................................... 108
  Food Safety Guidelines .................................................................... 112
  Diet Guidelines for Low White Blood Cell Counts .......................... 117
  Guidelines for the Use of Complementary Therapies ....................... 124

Chapter 4 – What’s Next? ................................................................. 127
  Introduction to Cancer Survivorship ............................................... 128

Chapter 5 - Terms and Helpful Information ....................................... 131
  Glossary of Terms .......................................................................... 132
  Patient Rights and Responsibilities ................................................. 140
  Clinic Directory ............................................................................ 144
  Driving Directions To and From SCCA ......................................... 145
  Conversion Chart for Temperature Taken By Mouth ....................... 147
  Suggested Medication Schedule .................................................... 149

Updated 4/14/15
Chapter 1 - Getting Started

“A diagnosis of cancer caused my world to stop.”
Welcome to the SCCA

A diagnosis of cancer can be overwhelming. This Patient Care Manual is a guide to help you, your family and friends navigate the uncertain waters of diagnosis and treatment. Knowledge is power, it is one way to cope.

Patient Education Videos
Classes are filmed and posted on the SCCA Patient and Family Education Facebook page, so you can share the information with family members. View the monthly calendar for upcoming classes and information at www.seccapatienteducation.org. To find the page, go to Facebook and search “SCCA Patient and Family Education”, or go to facebook.com/SccaPatientFamilyEducation - no Facebook log in is needed. Then, click on the link to the Video Library under the “About” section. Use the search function to find the classes below:

- Relaxation
- Fatigue
- Food Safety
- Memory and Concentration
- Sexuality

Education Materials Online
If you would like to download a digital copy of your manual or other educational materials to your personal computer, tablet, or phone, go to the SCCA website at www.seattlecca.org/patienteducation. You can also find these items by following these steps:

- Go to www.seattlecca.org
- Scroll down to the bottom of the page and click on “SCCA Links”
- Scroll down and click on “SCCA Patient Education Document Downloads”

Never hesitate to contact us if you need information about classes, your manual or other Patient Education questions.

Sincerely,
Patient and Family Education Department

Ann Breen, MN, APRN, OCN  Zara Asch, BA  Patricia Estrada, BS, CHES
abreen@seattlecca.org  zasch@seattlecca.org  pestrada@seattlecca.org
(206) 288-1033  (206) 288-7468  (206) 288-1472
**Important Phone Numbers**

For questions about clinic visits, 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>4&lt;sup&gt;th&lt;/sup&gt; Floor</th>
<th>3&lt;sup&gt;rd&lt;/sup&gt; Floor</th>
</tr>
</thead>
<tbody>
<tr>
<td>8 am-10 pm, Mon.-Fri.</td>
<td>206-288-7400</td>
<td>206-288-7300</td>
</tr>
<tr>
<td>8 am-6 pm, Sat, Sun</td>
<td>206-598-6190</td>
<td>206-598-6190</td>
</tr>
<tr>
<td>8 am-5 pm, Holidays</td>
<td>Ask for the Fellow On-Call</td>
<td>Ask for the Resident On-Call</td>
</tr>
<tr>
<td>10 pm-8 am, Mon.-Fri.</td>
<td>206-598-6190</td>
<td>206-598-6190</td>
</tr>
<tr>
<td>6 pm-8 am, Sat, Sun</td>
<td>Ask for the Fellow On-Call</td>
<td>Ask for the Resident On-Call</td>
</tr>
<tr>
<td>5 pm-8 am, Holidays</td>
<td>Ask for the Fellow On-Call</td>
<td>Ask for the Resident On-Call</td>
</tr>
</tbody>
</table>

Apheresis (206) 288-2120
Chaplaincy (206) 288-1099
Guest Services (206) 288-6701
Infusion (206) 288-7500
Institutional Review Office (206) 667-6567
Interpreter Access Line (855) 670-9798
Living Tobacco-Free (206) 288-7766
Medical Nutrition Therapy (206) 288-1148
Medical Records (206) 288-1114
Patient & Family Education (206) 288-1033 or (206) 288-1472
Patient & Family Resource Center (206) 288-2081
Patient Financial Services (206) 288-1113
Patient Relations Office  (206) 288-1056
Pharmacy Refills
    M-F 8am - 8pm  (206) 288-6500
    Sat & Sun. 8:30am - 5pm  (206) 288-6500
Clinical Pharmacists, M-F 8-5
    Anticoagulation Pharmacist  (206) 288-6756
    GI or GU  (206) 288-2017
    Breast or Gyn Onc  (206) 288-1044
    Heme/Melanoma/Renal Cell  (206) 288-6788
    Head /Lung/Neck/  (206) 288-6279
    Neuro Onc and Sarcoma  (206) 288-7583
Physical Therapy  (206) 288-6373
Procedure Suite  (206) 288-7200
Radiation Oncology  (206) 288-7318
Rain or Shine / Shine Gift Shop  (206) 288-8270 or (206) 288-7560
Receptionist 1st floor  (206) 288-1000
Regulatory Guidance  (206) 616-8222
Security (Lost and Found)  (206) 288-1111
Social Work Office  (206) 288-1076
Survivorship  (206) 288-1024
Volunteer Services  (206) 288-1075
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.
Information to Help You Navigate

Chaplaincy
Chaplains provide respectful spiritual and emotional care for people of all faiths and spiritualities, including those that identify as non-religious or non-spiritual. Chaplaincy provides worship and other services and can assist you in locating religious and spiritual resources. Visit the Sanctuary 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 language appropriate to their age and development. 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 Clinic’s 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 from 8am-4pm Monday-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.

Living Tobacco-Free Services
Living Tobacco-Free Services are available at no charge to SCCA patients, caregivers, and family members who are thinking about stopping tobacco use. You 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.

Cancer Library, UWMC
Volunteers also assist patients’ family members and friends in the Cancer Library, located on floor 8 SE. The library has oncology-related books, videotapes, support resources and computers to access the Internet.
Medical Nutrition Therapy Services
The science of nutrition during cancer treatment is a specialized field. Oncology dietitians provide real-life recommendations based on food preferences and tolerances, interest in food and specific social, economic and medical situations. A visit with a dietitian can provide you with inspiration about how to make healthful eating work even while in treatment. Just being able to actively participate in your own healing process 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 Roosevelt Clinic (206) 548-4055, 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 & Family Education
Knowledge is power! You have the right to information regarding treatment options, disease information, treatment process, managing and monitoring health status in the home setting and maintaining health after treatment. Ask your nurse for Patient and Family Education materials, such as the General Oncology Book, Transplant Manuals, Chemotherapy Cards, Symptom Sheets or Lecture and Lunch Events. Find Patient and Family Education on Facebook. The “About” section has a link to the SCCA video library with several classes to watch.

Patient & Family Resource Center
The Patient and Family Resource Center is located on the 3rd floor of the Clinic. We provide educational materials, computer workstations, a business center, 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 while you move towards improvement of your physical capacity. Our treatment is highly individualized and interventions are informed and guided by the available evidence. To schedule physical therapy, you must be referred by a physician, physician assistant or nurse practitioner.

Psychiatry and Psychology Services
Psychiatry and Psychology Services are available for you if you are experiencing difficulties coping. Specialized medication, coping skills, imagery and behavioral techniques are some of the many options available for managing stress, depression, anxiety, pain, nausea, eating or sleeping difficulty, or other issues that are common during illness and treatment.

Rain or Shine
Products 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, apparel, jewelry, cookbooks, stationery and snacks. Store Hours: Monday-Friday 8:30am-4pm www.seattlecca.org/gift-shop-rain-or-shine.cfm

Shine
Shine is located on the first floor at the SCCA House, and provides an engaging assortment of products intended to serve your needs and the needs of your 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. Hours: M-F 10 am-6 pm, Saturday 10 am-3 pm www.seattlecca.org/shine.cfm

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

Supportive and Palliative Care Services
The goal of palliative care is to prevent and relieve suffering and to support the best possible quality of life for you and your family, regardless of the stage of your disease. Palliative care can be delivered along with life-prolonging treatment. Its goals include enhancing the quality of your 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.
Treatment Journey Questions

Your questions and concerns are important – please express them.

At Diagnosis

• What is the exact name of the diagnosis, disease or condition? If this condition has other names, what are they?
• What can I expect to happen as a result of having this condition? How will it affect my work and everyday activities?
• Will treatment stop me from having children or impact my fertility?
• What test/s do I need to have, and what will the test/s tell me?
• How do I prepare for the test/s?
• When and how will I get the results from the test/s?

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 my 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 medications 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? Whom 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?

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?
Disability Documents Needed for Family Medical Leave Act (FMLA)

You may need to take time off work. Here is a list of what you need to start the process.
1. Obtain any forms needed for medical leave from your employer or the employer of your caregiver. This may require a discussion with Human Resource Department to provide you with the necessary forms.
2. Make sure the patient or caregiver portion of the form(s) are filled out before bringing/sending them in.
3. Bring any disability, FMLA or other paperwork needed for medical leave to your next appointment.
4. If you are unable to bring these forms to an appointment, please fax your nurse office at ______________________ at least one week prior to when the paperwork is due. You will be contacted if a phone consult or visit is needed.
5. Confirm the contact information for you or your caregiver’s employer below.
6. Please allow 1 week for completion of this process. We will fax your completed paperwork to your employer. We will mail you a copy.

Please fill out this bottom section and attach to FMLA/Disability paperwork.

Name of patient: _____________________________  Today’s Date:____________________
Physician Treating Patient: ____________________  U#: _________________________

Name of caregiver: ____________________________
(if forms are for someone other than patient)
Date forms needed by: _________________________

Employer: ___________________________________
Main Employer Contact: _______________________
Employer’s Mailing Address:

____________________________________________

Please Confirm Your Mailing Address:
____________________________________________
____________________________________________

Employer Contact Telephone #: ____________
Employer Contact Fax #: _________________
Employee reference or case # (if known):

____________________________________________

Affix Patient Sticker
Cancer Websites
Organizations that offer Information and Services to people with cancer and their families can be found below. These resources are provided as a service to our patients. Inclusion on this list does not imply endorsement by the Seattle Cancer Care Alliance.

Seattle Cancer Care Alliance  (206) 288-1000
www.seattlecca.org

Fred Hutchinson Cancer Research Center  (206) 667-5000
www.fhrec.org

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

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

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

Fertile Hope  1 (866) 965-7205
www.fertilehope.org

Gilda’s Club Seattle  206-709-1400
www.gildasclubseattle.org

Get Palliative Care  www.getpalliativecare.org

My Oncofertility  1 (866) 708-FERT
( or 1 (866) 708-3378)
www.myoncofertility.org

National Cancer Institute  1 (800) 4-CANCER
( or 1 (800) 422-6237)
www.cancer.gov

Publications available at the 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: Support for People with Cancer
  www.cancer.gov/cancertopics/coping/radiation-therapy-and-you

National Family Caregivers Association
  1 (800) 896-3650
  www.nfcaares.org

Young Cancer Spouses
  www.youngcancerspouses.org

Treatment/Diagnostic Information
National Library of Medicine-Medline
  1(888)-346-3656

Radiology
  www.radiologyinfo.org

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

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

Look Good…Feel Better
  1 (800) 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           1 (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
<table>
<thead>
<tr>
<th>Resource</th>
<th>Phone Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Link to Smoking Cessation Fact Sheets</td>
<td>1 (800) 4-CANCER (or 1 (800) 422-6237)</td>
</tr>
<tr>
<td><a href="http://www.cancer.gov/cancertopics/factsheet/Tobacco">www.cancer.gov/cancertopics/factsheet/Tobacco</a></td>
<td></td>
</tr>
<tr>
<td>The Skin Cancer Foundation (Melanoma)</td>
<td>1 (800) 754-6490</td>
</tr>
<tr>
<td><a href="http://www.skincancer.org">www.skincancer.org</a></td>
<td></td>
</tr>
<tr>
<td>International Myeloma Foundation</td>
<td>1 (800) 452-2873</td>
</tr>
<tr>
<td><a href="http://www.myeloma.org">www.myeloma.org</a></td>
<td></td>
</tr>
<tr>
<td>Multiple Myeloma Research Foundation</td>
<td>1(203) 229-0464</td>
</tr>
<tr>
<td><a href="http://www.multiplemyeloma.org">www.multiplemyeloma.org</a></td>
<td></td>
</tr>
<tr>
<td>Support for People with Oral and Head and Neck Cancer</td>
<td>1(800) 377-0928</td>
</tr>
<tr>
<td><a href="http://www.spohnc.org">www.spohnc.org</a></td>
<td></td>
</tr>
<tr>
<td>National Ovarian Cancer Coalition</td>
<td>1 (888) OVARIAN (or 1 (888) 682-7426)</td>
</tr>
<tr>
<td><a href="http://www.ovarian.org">www.ovarian.org</a></td>
<td></td>
</tr>
<tr>
<td>Ovarian Cancer National Alliance</td>
<td>1 (866) 399-6262</td>
</tr>
<tr>
<td><a href="http://www.ovariancancer.org">www.ovariancancer.org</a></td>
<td></td>
</tr>
<tr>
<td>Pancreatic Cancer Action Network (PANCAN)</td>
<td>1 (877) 272-6226</td>
</tr>
<tr>
<td><a href="http://www.pancan.org">www.pancan.org</a></td>
<td></td>
</tr>
<tr>
<td>Urology Health (prostate cancer)</td>
<td>1 (800)828-7866</td>
</tr>
<tr>
<td><a href="http://www.urologyhealth.org">www.urologyhealth.org</a></td>
<td></td>
</tr>
<tr>
<td>Prostate Cancer Foundation</td>
<td>1 (800)757-2873</td>
</tr>
<tr>
<td><a href="http://www.pcf.org">www.pcf.org</a></td>
<td></td>
</tr>
<tr>
<td>US TOO International (Support groups, info)</td>
<td>1 (800) 808-7866</td>
</tr>
<tr>
<td><a href="http://www.us">www.us</a> too.com</td>
<td></td>
</tr>
<tr>
<td>Sarcoma Alliance</td>
<td>1 (415) 381-7236</td>
</tr>
<tr>
<td><a href="http://www.sarcomaalliance.org">www.sarcomaalliance.org</a></td>
<td></td>
</tr>
<tr>
<td><strong>Other Diseases</strong></td>
<td></td>
</tr>
<tr>
<td>Aplastic Anemia</td>
<td>1 (800) 747-2820</td>
</tr>
<tr>
<td>www aplastic.org</td>
<td></td>
</tr>
</tbody>
</table>
Myelodysplastic Syndromes Foundation 1 (800) MDS-0839 (or 1 (800) 637-0839)
www.mds-foundation.org

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)
www.fda.gov/Food/DietarySupplements

NIH Office of Dietary Supplements
www.ods.od.nih.gov/

National Center of Complementary and Alternative Medicine 1 (888) 644-6226
http://www.nccam.nih.gov

Oncolink at the Abramson Cancer Center at the University of Pennsylvania
www.oncolink.org

U.C. Berkeley Wellness Newsletter 1 (800) 829-9170
www.berkeleywellness.com


**Support and Networking for Youth**
Planet Cancer
http://myplanet.planetcancer.org/
Survivorship
Livestrong Foundation
8820 www.livestrong.org

The National Coalition for Cancer Survivorship
7937 www.canceradvocacy.org

Beyond the Cure
www.beyondthecure.org

1 (877) 236-

1 (877) 622-

1 (800) 532-6459
Helping Children Cope When Someone They Love Has Cancer

Important Common Concerns and Fears

Even if the child does not ask these questions, they may wonder:

- **Will I get cancer?**
  Cancer is not contagious. You cannot “catch” cancer.

- **Did something I do cause the illness?**
  No. Cancer can just happen. Scientists are doing research to understand this better, but we know nothing you (the child) did or thought caused the cancer.

- **Is cancer treatment a punishment?**
  No. Cancer treatment is not a punishment. It is a way to get rid of bad cancer cells in the body. Even though it can make you feel bad for a while, it makes your body healthier in the long run. A conversation about cancer cells is often helpful to help children understand the way treatment works. For example, “Your body is made up of tiny building blocks called cells. Cancer happens when cells grow too fast and do not stop. This makes the body not work right. Chemotherapy kills these fast growing cells. During surgery, the doctor takes out the group of cancer cells (tumor). Chemotherapy can affect other fast growing cells in the body such as hair cells and cells in the stomach. This is why a person may lose their hair and feel sick to their stomach during treatment. They will feel better and their hair will grow back after the chemotherapy treatment ends.”

Depending on the child’s age and his/her experience with cancer, he or she may wonder: Are you (or my loved one) going to die from cancer?

Your answer to this question will change based on the child’s age, your family’s beliefs, and your situation. A social worker or other health professional can help you sort through this. For example, “We are working very hard for (the loved one) to get well. I will let you know if this changes or if I am worried about (the loved one)
dying. I also want you to tell me when you are worried. What would you worry about most if (the loved one) died?” A child may have specific fears that he or she wants to talk about (“Where would my room be? Who would watch me after school?”).

**Suggestions for Communication: When and How Much?**

You know best. How you talk about cancer will vary based on your knowledge of your child and your family’s culture, faith, and beliefs about cancer. People have many myths about cancer and treatment. Stay with the facts.

First, learn what you can about the illness, including side effects and the schedule of treatment, so that you are able to prepare the child and answer questions about what to expect.

Choose a time to talk when you feel you can calmly discuss the illness and support your child with his/her emotional reaction. Your child may be upset by the information or he or she may have very little reaction. Children often need to absorb this information over time.

Children can usually sense when something is wrong and often imagine the worst if they do not know what is happening. Teaching children early about your diagnosis helps them feel included and helps them understand the changes they see.

Invite a professional or a close family member to help prepare you mentally and emotionally. If needed, they may help you discuss the illness with your child. You or another loved one should be with the child for support and security if another person provides the information.

Begin with what the child sees and knows: “You know how your aunt has been grouchy and sleeping a lot?”

Use the actual name of the disease, including the word “cancer,” so the child becomes familiar with it. This will help them feel prepared for the terminology they will hear from others.

Remind the child that there are many different types of cancer and treatments. They may think exactly what happened to another relative or friend with cancer will happen to you. It may be very different.

Use language they can understand (see Age Considerations section) about where in the body the disease is, how the disease will be treated, and how this will affect their life, including changes in family system.
Children will vary in how much information they want to have and can cope with; the goal is to give enough information that will address their fears and give them a sense of security in the midst of the upcoming changes. Allow them to guide you with how they are feeling.

Be truthful about things you cannot answer. Sometimes reassuring children that everything will work out well is not possible. Assure them that they will be taken care of no matter what, and use this opportunity to tell your child about how you cope with the unknown.

Encourage your child to ask questions. You may need to answer the same question many times.

Try to help your child draw out his/her feelings (e.g. adult says, “When I feel sad I….”, then asks child to draw picture of that emotion and talk about a time when they felt that emotion).

If it’s a parent that’s ill, give the children tasks to help that parent (making them a picture, etc.); making “books” for younger siblings about illness; scrap-booking about the experience; asking how/if they would like to help the family.

Journaling; scrap-booking; talk about the best and worst parts of each day.

**Meeting Your Child’s Needs**

It is extremely challenging to parent and to manage cancer treatment and side effects. First and foremost, take care of yourself:

- Recognize your limits and adjust expectations of yourself.
- Set aside time every day for yourself.
- Eat healthy foods.
- Maintain physical activity and get enough sleep.
- Allow people to help, and have a list handy of specific things others can do.
- Utilize friends, family members, support groups, and professionals for emotional support.

Children’s emotional needs:

- Be open to discussion, anyplace, anytime. Children may have a question when you least expect it.
- Allow your child to see the treatment clinic or hospital if they show interest in going. Prepare them for what to expect before the visit.
- Your child will cope with this in his or her own unique way. Ask how they are doing and look at their behavior for clues.
- Your time is one of the greatest ways to show your love. Make one-on-one time a priority for each child.
• Allow your child to “help” in ways that are meaningful to them. For example, drawing a get well picture, talking with the loved one about the best and worst of his or her day, filling the loved one’s water pitcher each morning, etc.
• Maintain fun family times as much as possible. Make special adapted plans for holidays or events.
• Discuss changes in routine and what the child can expect.
• Let others help to fill in gaps, such as a trusted uncle or aunt taking your child to a game.
• Invite fun, imagination, and interactive play into everyday activities. For example, an in home “picnic” at meal time, comedy movies at night, or a new craft for family members to work on together.

Social and Developmental needs:
• Help maintain as much contact as they can with friends, family, and others they care about (in person, writing, phone, email).
• Maintain learning opportunities and structure through formal school or tutoring.
• After discussing it with your child, alert school counselors and teachers about the situation and your child’s current needs.
• Discuss any family privacy issues and expectations with your family members, what is and what is not okay to talk about outside of the family.
• It is normal for the child to act younger and test limits during this period. They may be looking for attention from you or a clear sense of safety and security during this period.
• Discipline is hard to maintain, but is very important to help your child continue to develop and function well with family, peers, and school during and after treatment.
• Set clear expectations for your child during treatment and transition times. Rules may need some flexibility during stressful periods (e.g. bedtime). Discuss any changes with your child.
• Involve all caretakers to maintain as much consistency in the child’s care and discipline plan as possible (e.g. Grandma’s rules similar to Mom’s).

Age Considerations
Preschool Age Children (approx. 3-5 years old):
• Tend to be egocentric; believe that the world revolves around them and care mostly about how the illness affects them.
• Inclined to have magical thoughts; think they have the power and ability to control things (e.g. think they can cause someone’s illness by having bad thoughts about that person or by misbehaving).
• Tend to understand well when dolls, pictures and books are used to explain things.
• Need reassurance that someone will always be there to take care of them.
• May react with sadness or may seem indifferent.
• May react to illness by having behavior problems (e.g. will act out more for attention) or acting younger in terms of development (e.g. bedwetting, clinginess).
• Are good at expressing feelings/emotions through play and sometimes need help identifying feelings.
• Often believe that death is reversible and that a person who has died will/can come back.

School Age Children (approx. 6-11 years old):
• May want to do some research about disease on their own.
• Start to understand that death is permanent.
• May want to know more about treatment (e.g. side-effects, physical changes).
• May react by being sad, mad, and/or irritable; have physical complaints or headache, stomachache, etc.; may be angry towards the sick loved one; have poor concentration; or have difficulty adapting to changes in routine.

Teenagers (12 years old and above):
• Adolescents are capable of abstract thinking; understand ethics and ideas they cannot see.
• Tend to have a need for independence.
• Can sometimes deny feelings to avoid talking to you about them.
• Are capable of thinking like adults.
• May want a lot of details.
• Try to encourage them to talk about their feelings, but realize they may be more comfortable talking to a friend, a professional, or another trusted person.
• Try to assure them that you want them to have normal activities outside of the family.
• Watch for signs of them trying to take on too much responsibility or parenting younger siblings.
• May react with anger, rebellion, depression and anxiety, withdrawal, physical symptoms such as stomachaches and headaches, keeping feelings to themselves.

References for More Information
• Helping Children When a Family Member Has Cancer: Dealing With Diagnosis,” the American Cancer Society, [www.cancer.org](http://www.cancer.org)
• “Helping Children When a Family Member Has Cancer: Dealing With Recurrence or Progressive Illness,” the American Cancer Society, [www.cancer.org](http://www.cancer.org)
• Art with Heart (Seattle-based group that uses art therapy to help kids deal with crisis), www.artwithheart.org

Other Recommended Readings
For the parent:
• How to Help Children Through a Parent's Serious Illness, by Kathleen McCue, with Ron Bonn
• Can I Still Kiss You? Answering Your Children's Questions About Cancer, by Neil Russell
• When a Parent Has Cancer: A Guide to Caring for Your Children, by Wendy S. Harpham

For the child (to read with the adult):
• When Someone You Love Is Being Treated For Cancer, by the National Cancer Institute
• Tickles Tabitha's Cancer-Tankerous Mommy, by Amelia Frahm, Elizabeth Schultz (Illustrator)
• What Is Cancer Anyway? Explaining Cancer to Children of All Ages, by Karen L. Carney
• Sammy's Mommy Has Cancer, by Sherry Kohlenberg, Lauri Crow (Illustrator)
• The Year My Mother Was Bald, by Ann Speltz, Kate Sternberg (Illustrator)
• Because Someone I Love Has Cancer: Kids' Activity Book, by American Cancer Society
• Life Isn't Always a Day at the Beach: A Book for All Children Whose Lives Are Affected by Cancer, by Pam Ganz
• When Someone Has a Very Serious Illness: Children Can Learn to Cope with Loss and Change, by Marge Heegaa
• Vanishing Cookies: Doing Ok When a Parent Has Cancer, by Michelle B. Goodman

Questions?
How to contact us:
• Seattle Cancer Care Alliance: 206-288-1000
• Patient and Family Services: 206-288-1076
Diagnostic Tests

Radiology and Medical Imaging
If you are scheduled for certain procedures such as a Magnetic Resonance, Computed Tomography (CT) or an Ultrasound, you will need to go to the 2nd Floor of the Clinic.

Preparing for Imaging Exams: CT, MRI, Nuclear Medicine, PET/CT, Ultrasound, DEXA, Plain X-rays

- Medical Imaging (Radiology) is on the second floor.
- Please arrive 15 minutes prior to your scheduled appointment time to allow for check-in and screening.
- Wear loose-fitting clothing without metal, such as zippers, belts, snaps or buttons.
- Remove all metal objects, such as hairpins, jewelry, eyeglasses, hearing aids and any removable dental work that may obscure images.
- You may be given a gown to wear during the exam.
- Tell your doctor and the technologist if there is any chance that you may be pregnant.
- Prior to the day of your exam, please tell your doctor or nurse if you have an allergy to CT or MR contrast.
- Please turn your cell phones and/or pagers OFF before your exam begins.
- See additional instructions specific to your appointment.
- Check with your doctor or nurse regarding what medications you should or should not take on the day of your imaging exam and any instructions to follow after the test regarding resuming your medications.
Food and Fluid Restrictions for Computed Tomography (CT) Exams

- Do not eat anything for 4 hours before your exam.
- You may continue to drink clear liquids* until your scan.
- Check with your doctor or nurse regarding what medications you should or should not take on the day of your imaging procedure.

CT exams of the abdomen and/or pelvis may require you to drink an oral contrast product during the hour before your scan time. If you are given IV contrast, you will be required to remain in the imaging department for at least 30 minutes after the injection of IV contrast. If there are concerns about your kidney function, please check with your doctor or nurse for special instructions for your exam. You may use the restroom any time before your exam unless instructed otherwise.

*What Are Clear Liquids?

- Water
- Clear juices
- Tea
- Black coffee (do not add milk, cream or sugar, because these are not clear liquids)
- Clear broth
Preparing for a DEXA Exam (Dual-Energy X-ray Absorptiometry)

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

Check with your nurse or doctor for clarification of these instructions if needed.
Preparing for a Mammogram

- Please arrive 15 minutes prior to your scheduled appointment time to allow for check in and screening.
- Schedule your mammogram for the week after your period, or at least two weeks before your next period. This is when your breast tissue is less sensitive. If you no longer have periods, any time of the month is fine.
- Before your mammogram, wipe off any deodorant, talcum powder, or lotion under your arms or on your breasts. These can appear on the mammogram as spots. You will be given special wipes at your appointment to cleanse your underarms and breast.
- If you have had any prior mammograms please have them sent to Breast Imaging. Breast Imaging needs to receive previous mammograms 48 hours prior to your exam in order to have them prepared for comparison. Send mammograms to:
  Seattle Cancer Care Alliance
  825 Eastlake Ave East
  SCCA Radiology Film Room, G2209
  Seattle, WA  98109
- Please wear a two piece outfit, as you will be asked to remove all your clothing and jewelry above the waist. You will be given a gown that opens in the front to wear during your exam.
- Don’t forget to report any unusual findings, such as a lump, thickening, redness, or swelling, to your doctor and the technologist.
- Tell your doctor and technologist if there is any chance you may be pregnant.
- Some women avoid having a mammogram because of anxiety or fear. Remember that having a mammogram is a way for you to stay healthy. The mammogram can catch problems early, which often leads to a complete cure.
MRI Screening Form

Your doctor has ordered an MRI exam for you. PLEASE CALL 206-288-1434 FOR FURTHER INSTRUCTIONS IF YOU MAY BE PREGNANT OR WEIGH MORE THAN 300 POUNDS.

To prevent a delay or cancellation of your exam, if you have ANY of the following implanted devices, allergies or may be pregnant (see complete list below) please tell your team coordinator or call 206-288-1434 to review your eligibility for your exam.

Please see complete “MRI Patient Screening Form” for additional conditions that may affect the exam:

- Pacemaker / defibrillator
- Cerebral (brain) aneurysm clip*
- Cochlear implant*
- Cardiac stents*
- Implanted or external drug pump (including chemotherapy)
- Breast tissue expander
- If pregnant, # of weeks:_______
- Dialysis or renal failure
- Allergy to CT contrast or gadolinium
- Drug or contrast allergies

PLEASE BRING THE WALLET CARD THAT IDENTIFIES THE IMPLANTED DEVICES. In most cases, surgical staples, clips, pins, and screws are not a risk during MRI if they have been in place for more than 4 to 6 weeks. If there is any question of metal fragments in the eye, an x-ray may be done to check for them.
Preparing for Nuclear Medicine Bone Scan or MUGA Exam

You should increase your fluid intake before and after the injection. Try to drink 3-4 glasses of your preferred drink after the injection. Empty your bladder frequently. There are no eating or drinking restrictions.

- If you are unable to remain still for 45 minutes, please speak with your referring physician for pre-medications.
- **Women who are pregnant or breast feeding should not have this exam.**

You will be given a document that states the period of time during which the small amounts of radiation remaining in your body are capable of detection by radiation monitoring equipment. This amount of radiation poses no danger to the public and is allowed by the State of Washington medical use regulations.
Preparing for an Ultrasound Exam

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

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

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

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

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

Some studies involve assigning patients to a treatment by a process called “randomization.” This means that treatment will be decided by random computer selection. This is often done when it is not known whether one treatment is better than another. Comparisons are often made between a “new” treatment and a “standard” treatment. Randomization is a way to avoid any bias that might influence results of the comparison. It increases the confidence that any differences seen between groups reflect the effect of the treatment rather than other factors. You may feel uncomfortable about having aspects of your treatment decided by random computer selection. You might believe that the “new” treatment is likely to be better than the “standard” treatment, or you might be concerned that the “new” treatment may increase the chance of side effects. For either of these reasons, you may prefer to choose one treatment or the other. These feelings are understandable. However, we hope you will understand that there is no factual basis for any preference between treatments in this situation. If there were, we would not need to do a research study to find out which treatment is actually better.
Long-Term Participation in Research
Being involved in research will likely extend beyond your stay, especially if you have problems that need ongoing treatment. We are able to carry on this research by working with your doctor. You may be asked to return for a periodic check-up.

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

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

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

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

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

Connection with Private Industry
For many years, medical researchers and private industry have worked together to study ideas that might become useful to science and patients. Drug companies and biotechnology firms sometimes pay for medical research studies. This financial support can lead to new ways to prevent, diagnose, and treat illness.

Our Commitment to You
The SCCA and its member institutions are committed to protecting the rights and well-being of participants who volunteer for medical research studies.
SCCA’s member institutions have policies and procedures for the disclosure, review and management of the financial interests and relationships between medical researchers and private industry.

If You Wish to Learn More About Policies and Procedures
Each member institution has its own methods for review of financial relationships and interests. If you wish to learn more about these policies and procedures you may contact the resources listed here below:

Fred Hutchinson Cancer Research Center
The Principal Investigator for your study:__________________
SCCA Patient Relations Office: 206-288-1056
Institutional Review Office: 206-667-6567

UW Medicine
The Principal Investigator for your study:__________________
Human Subjects Division: 206-543-0098

Seattle Children’s
The Principal Investigator for your study:__________________
Institutional Review Board: 206-987-2023
Children’s General Counsel: 206-987-2044

Questions to Ask
• Can I withdraw from the research study at any time?
• What are the risks?
• What are the benefits?
• Why is this trial being done?
• How long will I be involved?
• What will this cost?
• Will my insurance cover this?
• Who should I contact for additional questions?

Names of Protocols: __________________________________________________________
Chapter 2 – Treatment

“Knowing what to expect helped decrease my anxiety.”
Common Treatments

The treatment for cancer can include chemotherapy, biotherapy, radiation and/or surgery.

Ask about your treatment plan, side effects and what to expect in the near future and in the long run. Ask what to expect in the future. It is a good idea to review the symptom sheets listed in the section “Managing Symptoms at Home” once you know the symptoms to expect. Keep your doctor and nurse informed regarding your questions and concerns. Ask questions and express your concerns all along the treatment journey. The staff in the clinic will help manage your treatment plan.

Goals of treatment include:
- Cure cancer
- Control cancer
- Ease cancer symptoms

General information about common cancers is available at the National Cancer Institute website. www.cancer.gov

Many people have found the following information helpful as they have gone through treatment. You too may find these resources helpful. The National Cancer Institute website has helpful information about the disease you are dealing with. See below:

Breast:  www.cancer.gov/cancertopics/types/breast
Colon:   www.cancer.gov/cancertopics/types/colon-and-rectal
Endocrine: www.cancer.gov/cancertopics/types/thyroid
Gastric: www.cancer.gov/cancertopics/types/stomach
Head and Neck: www.cancer.gov/cancertopics/types/head-and-neck
Leukemia: www.cancer.gov/cancertopics/types/leukemia
Lung:    www.cancer.gov/cancertopics/types/lung
Ovarian: www.cancer.gov/cancertopics/types/ovarian
Pancreatic: www.cancer.gov/cancertopics/types/pancreatic
Prostate:  [www.cancer.gov/cancertopics/types/prostate](www.cancer.gov/cancertopics/types/prostate)


Other Helpful Information During your Treatment


Clinical Trials  [www.cancer.gov/clinicaltrials](www.cancer.gov/clinicaltrials)

Coping with Advance Cancer- eBook

When Someone You Love Is Being Treated for Cancer- eBook

**Chemotherapy** is the use of drugs to stop the growth of fast growing cancer cells. The downside is that chemotherapy can also affect fast growing healthy cells. Before you have chemotherapy ask your nurse, pharmacist and doctor about the expected side effects. You will get a chemotherapy card from the American Cancer Society (ACS) or the National Cancer Institute (NCI).

A great book to read is **Chemotherapy and You** which is available on line and in the SCCA clinic.

Some patients have an **access line** placed either in the form of a central line or port-a-cath. This access is used to give you fluid, food, medicine, and/or blood products. It is also used to get blood samples without having to draw blood from your arm.

**Biotherapy** is the use of drugs to help your immune system fight cancer. A great book to read about Biotherapy is the NCI booklet, which is available online at this website: [www.cancer.gov/cancertopics/treatment/biologicaltherapy](www.cancer.gov/cancertopics/treatment/biologicaltherapy)

**Radiation Therapy** is the use of high-energy radiation to kill cancer cells. There are a number of ways radiation can be delivered; outside or inside the body. Like chemotherapy, radiation can kill normal cells as well. A great book to read is **Radiation and You** from the NCI. This booklet is available online and the SCCA clinic.

**Surgery** is the use of an operation to remove the tumor or some portion of the tumor.
Safe Management of Chemotherapy at Home

Chemotherapy Drugs Can Be Hazardous
You must take special precautions to prevent chemotherapy medicines from coming into accidental contact with others. Equipment or items that come into contact with the medicines (such as syringes, needles, intravenous [IV] bags, IV tubing, or pill bottles) are considered contaminated. Regardless of how it is administered, chemotherapy remains in your body for many hours and sometimes days after your treatment. Your body eliminates chemotherapy in urine and stool. Traces of chemotherapy may also be present in vomit.

Disposal of IV Drugs and Equipment
Materials contaminated with chemotherapy must be disposed of in specially marked containers. You will be given a hard plastic container labeled “Chemotherapy Waste” or “Hazardous Waste” (or something similar). Place equipment and gloves into this container after use. If the waste is too large to fit in the container, place it in a separate Ziploc™ bag, or a plastic bag sealed tightly with rubber bands. Sharp objects should not be disposed of in anything but the hard plastic container. This prevents others from being pricked accidentally. The company supplying your medicines and equipment will tell you who will remove the waste containers.

Federal Prescription Drug Disposal Guidelines for Oral Chemotherapy
Take unused, unnecessary or expired oral chemotherapy prescription drugs out of their original containers and remove all personal identifiers. Mix the prescription drugs with an undesirable substance like used coffee grounds or kitty litter and put them in a Ziploc™ bag or empty can to prevent children and pets from accidentally consuming the drugs. Do NOT crush chemo drugs. Throw these containers in the trash. Do not flush oral chemotherapy drugs down the toilet.

Body Wastes
You may use the toilet (septic tank or sewer) as usual. Wash your hands with soap and water afterward, and wash your skin if urine or stool gets on it.

Laundry
Wash your clothing and linen normally unless they become soiled with chemotherapy. If that happens, put on gloves and handle the linens or clothing carefully to avoid getting medicine on your hands. Immediately place the contaminated items in the washer and wash separately from other clothing. Do not wash other items with chemotherapy-soiled items. If you do not have a washer, place contaminated items in a plastic bag until they can be washed.
**Skin Care**
Chemotherapy spilled on skin may cause irritation. If this happens, thoroughly wash the area with soap and water, then dry. If redness lasts more than one hour or if irritation persists, call your doctor. To prevent chemotherapy from being absorbed through the skin, wear gloves when working with medicines, equipment, and waste.

**Eye Care**
If any chemotherapy splashes into your eyes, flush them with water for 10-15 minutes and notify your doctor or nurse.

**Pregnancy**
Pregnant women should avoid direct contact with chemotherapy and contaminated wastes.

**Questions and Answers**

*Is it safe for family members to have contact with me during chemotherapy?*
Yes. Eating together, enjoying favorite activities, hugging, and kissing are all safe.

*Is it safe for my family to use the same toilet as me?*
Yes. As long as any chemotherapy waste is cleaned from the toilet, sharing it is safe.

*What should I do if I do not have control of my bladder or bowels?*
Use a plastic-backed pad, adult or pediatric diaper, or sheet to absorb urine or stool. Change it immediately when soiled, and wash skin with soap and water. If you have an ostomy, you or your caregiver should wear gloves when emptying or changing the bags. Discard disposable ostomy supplies in the chemotherapy waste container.

*What if I use a bedpan, urinal, or commode?*
Your caregiver should wear gloves when emptying body wastes. Rinse the container with water after each use, and wash it with soap and water at least once a day.

*What if I vomit?*
Your caregiver should wear gloves when emptying the basin. Rinse the container with water after each use, and wash it with soap and water at least once a day. Call your doctor or nurse about any doses that you missed because of nausea and vomiting.

*Is it safe to be sexually active during my treatment?*
Ask your doctor or nurse this question. It is possible that traces of chemotherapy drugs may be present in vaginal fluid and semen after treatment. Special precautions may be necessary. Women must avoid becoming pregnant or breastfeeding during and after chemotherapy. Men must avoid impregnating their partner while taking chemotherapy. Condoms are advised to prevent exposure to chemotherapy and prevent pregnancy.
How should I store chemotherapy?
Store medicine and equipment in a safe place, out of reach of children and pets. Do not store chemotherapy in the bathroom, as high humidity may damage the drugs. Check medicine labels to see if your chemotherapy should be kept in the refrigerator or away from light. Be sure all medicines are completely labeled.

Is it safe to dispose of IV chemotherapy in the trash?
No. IV Chemotherapy waste is hazardous and should be handled separately. If you are receiving IV chemotherapy at home, you should have a special waste container for the chemotherapy and equipment. This includes used syringes, needles, tubing, bags, cassettes, and vials. This container should be hard plastic and labeled Hazardous Waste or Chemotherapy Waste. For further instructions, please review the brochure, Proper Disposal of Prescription Drugs available at the SCCA Pharmacy.

Can I travel with my chemotherapy?
Yes. Usually, traveling is no problem. However, because some chemotherapy requires special storage such as refrigeration, you may need to make special arrangements. Check with your doctor, nurse, or home infusion supplier for further instructions. Regardless of your means of travel (airplane, car, or other), always seal your chemotherapy drugs in plastic bags.

What should I do if I spill some chemotherapy?
You will have a spill kit if you are receiving IV chemotherapy at home. In the event of a spill, open the spill kit and put on two pairs of gloves, gown, and goggles. Absorb the spill with the disposable sponge. Clean the area with soap and water. Dispose of all the materials including gloves, gown, and goggles, in the chemotherapy waste container.

For additional information about the drugs you are taking, please refer to the drug information sheet or other instructions provided to you by your doctor or nurse.

Treatment in the SCCA Clinic

See your clinic brochure for additional information.

Release of Medical Information
SCCA Clinic medical information can be obtained from SCCA Health Information Management or UWMC Patient Data Services. You will be asked to sign an authorization form to release health management information. There is a charge for records released to the patient. There is no charge for records mailed to your doctor.

Family Members Who are Sick
Any family member who shows symptoms of cold or flu should not come to the SCCA Clinic until they have been checked by a nurse or doctor. Please contact your team nurse for further information.

Fresh Flowers and Plants
Fresh or dried flowers and plants are not allowed in the clinic because of the organisms that grow on them and in the dirt or water, which can cause infections. Balloons and silk flowers are okay. Make sure there is no decorative moss around silk flowers. Only artificial moss is allowed.

Keeping Your Information Safe
In order to keep your information safe and secure through the internet, you will need to follow additional steps when receiving emails. You will need to register and create a password for emails sent to you from SCCA.

Guest Wireless Internet Access Guide
Free wireless high-speed Internet (WiFi) access is available. SCCA Guest Wireless works with most wireless-equipped computing devices. For your convenience, connectivity is available throughout the clinic, including patient rooms and visitor waiting areas. To connect to SCCA’s Wi-Fi network, follow these steps:

- Enable the wireless feature on your device.
- Connect to the “SCCA Guest Wireless Network”.
- Once you are connected, open your web browser. Upon your first attempt to navigate to a website, you will be redirected to the Acceptable Use Policy Logon Page. You must read and accept the policy by clicking “I Accept” at the bottom of the page. After accepting the policy your browser will automatically load the Seattle Cancer Care Alliance homepage.
- You can now browse the web normally.
SCCA Secure Email
To ensure the confidentiality of personal health information that Seattle Cancer Care Alliance sends you via email and to comply with Health Insurance Portability and Accountability Act of 1996 (HIPAA) regulations, SCCA uses an email encryption service. Encrypted emails, also called secure email or secure messages, help keep your personal health information private.

This secure email site requires some extra steps, but we are confident it will allow us to communicate with you safely and efficiently by email. Each email sent will include brief instructions on how to access the secure email site. For more information, please visit the secure email page on our website at www.seattlecca.org/scca-secure-email.cfm.
Treatment in the Inpatient Unit

Location
The adult patient care units are located on 6 SE, 7 NE, 7 SE, 8SA and 8 NE at the University of Washington Medical Center (UWMC) in the Muilenburg Tower, 1959 Pacific Avenue NE, Seattle, Washington 98195.

Admission to the Inpatient Unit
If your admission to the inpatient unit is scheduled in advance, you will be notified of the time and date to go to the hospital. You may develop symptoms that require hospitalization. Hospitalization is made available day or night if needed.

The Telephone System
To reach 6 SE, call 206-598-4410
To reach 7 NE, call 206-598-7770
To reach 7 SE, call 206-598-4818
To reach 8 NE, call 206-598-8902
To reach 8 SA, call 206-598-0700
Your calls to the nurse’s station are answered 24 hours a day.

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

Instructions for making local calls are below:
TO REACH: DIAL:
Outside line: 9 + phone number
UWMC #: 8 + four-digit number
Or dial “6190” and ask the hospital operator to connect you.

For long distance calls, charge the call to your calling card or call collect. Dial 9 + 0 + # and follow instructions, or dial 6190 and ask the hospital operator to connect you.

Mail
Mail will be delivered daily to patient rooms. The outgoing mailbox is at the nurses’ station.

Parking
Your parking in the Triangle Parking garage (an underground garage can be validated with a sticker you can get form the nurses station, to reduce your cost. The SCCA and the UWMC garages (Surgery Pavilion and Triangle) offer same day reciprocal parking. Bring your participating garage receipt to your next same day appointment and it will be honored.
Food Services
Nutrition Services will provide meals and snacks to meet your dietary needs. You will receive a menu daily from which to order your meals. The menu is designed to comply with your diet order. We may be keeping a record of your food and fluid intake to allow the dietitian to determine the amount of calories, protein and fluids you have consumed. Your dietitian and doctor use this information to assess if you need additional IV fluid or nutrition support.

UWMC Smoking Policy
UWMC is committed to providing an entirely smoke and tobacco free environment for all patients, visitors and staff. Smoking is not allowed in any area of the Medical Center including grounds and parking lots.

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

- **Routine Blood Tests:** Early morning routine blood tests will be done. We will disturb you as little as possible, but our medical team needs to review your laboratory findings as early in the day as possible. Some routine tests will be drawn at other times of the day as well.

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

- **Physical Examinations:** The nurses and doctors will, at different times, need to listen to your heart, lungs and abdomen with the stethoscope.

- **Bathing:** Daily baths or showers are required to help cleanse the body of bacteria, and lower the risk of infection. Your nurses will work with you to fit your bath or shower into your schedule.

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

- **Exercise:** We encourage you to arrange with the nurse a time to walk and exercise in the halls. Your doctor may order physical therapists to work with you to help keep your activity level up.

- **Nutrition:** Dietitians will talk to you about your food likes and dislikes.

- ** Rounds:** Every morning your doctor and other members of the health care team will do rounds, a group discussion with each patient. This is to check on your
progress and to make changes in your therapy if needed. This is a good time to ask questions and discuss your plan of care.

- **Transfusions:** Blood and platelet transfusions may be given to you as needed.
- **Visitor Guidelines:** These guidelines are designed to maintain a supportive environment for patients:
  - **Open Visiting Hours:** Check with your nurse regarding the hours. We encourage families to keep their health in mind and get a good night’s sleep. A nurse will call family at home if any problem occurs.
  - **Local Phone Number:** Family members should make sure that the Nurse’s Station has their current phone number(s) on file for emergency use.

**Preventing Infection**

- You are encouraged to walk around the nursing unit, but should avoid other patients, their families and the areas where people gather. Family members or other visitors should not use the bathrooms in the patient rooms. Public restrooms are located on all nursing units.
- Keep surfaces clear of your belongings. Some organisms can survive a long time on the surfaces and equipment in your room. It is very important that these surfaces be cleaned daily by our Environmental Services (ES) staff. If possible leave the room so the ES staff can clean the room thoroughly.
- Minimize the number of personal belongings in the room. To help keep your room as clean as possible, we encourage you to have cards and pictures posted on the wall of your room. Other items should be placed in your bedside cabinet.
- Clean or wash your personal belongings. Staff does not clean your personal belongings. A family member or friend should wipe off your personal belongings daily with a cloth or paper towel dampened with soap and water. Clothing or quilts should be washed when they become soiled. Here are a few reminders to prevent the spread of infection:
  - Place used tissue in the trash can, not on other surfaces (the bedside table or floor).
  - Men, place urinals on the floor, not on the bed rail, the bedside table or cabinet.
  - Wash hands frequently (before eating and after using the bathroom or urinal).
  - Any family member or visitor who has a fever or cold, or who is not feeling well, should not come to visit. Even minor colds and infections carry a risk. Please evaluate the health of children and their exposure to other children that may have been ill, before letting them come to the inpatient unit.
- **Handwashing is the most effective way to prevent the spread of infection. Before entering and when leaving your room, everyone is expected to wash their hands.**
Money and Valuables
Money and valuables should not be left in your room or the family room because of the risk of theft.

Using the Family Room
All who use the family room must help to keep it clean. Please label your food in the refrigerator with your name and the date. Food left too long will be thrown away.

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

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

Children
Children are important members of a family and we encourage them to visit patients during their hospital stay. These guidelines are for children visitors:

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

My Name______________________________________

My Team: (names and phone number)__________________________________________

Primary Care Doctor_______________________________________________________

Oncologist_______________________________________________________________

Radiation Oncologist_______________________________________________________

Surgeon_________________________________________________________________

Social Worker/ Psychologist/Psychiatrist/Pastoral Care____________________________

Family Contact____________________________________________________________

Insurance_________________________________________________________________

Advance Directive or Living Will?    Yes    No

Power of Attorney for Health Care___________________________________________

Type of Cancer___________________________________________________________

Date of Diagnosis___________ Stage of Cancer________________________________

Other Cancers______________________________________________________________

Cancer Related Surgery

Date of Surgery____________ Surgery Facility__________________________________

Surgeon_________________________________________________________________

Type of Surgery ___________________________________________________________

Secondary Surgeries________________________________________________________

Surgeon_________________________________________________________________
Other Surgery

Any Problems

**Chemotherapy**
Take this with you to your treatments to keep track of the medicines you receive and the amount.

Chemotherapy

Dates Received

Route (Oral or IV)

Dose

Chemotherapy Facility (SCCA, UWMC, Hospital, at home)

Medications to treat the side effects of chemotherapy

Dose

Purpose

Did it work

Other Medical Conditions:

**Radiation Therapy Summary**
Dates of Radiation

Radiation Facility

Total Amount (dose)

Area of Body Treated

Radiation Oncologist

Any Problems

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

__________________
Blood Transfusions
Problems or Concerns_____________________________________________________

Allergies to Medication_____________________________________________________

Bone Marrow Transplant
Date of Transplant________________________________________________________

Type of Transplant________________________________________________________

Transplant Facility________________________________________________________

Any Problems____________________________________________________________
________________________________________________________________________
________________________________________________________________________

Other Health Concerns
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

Information adapted from the Sidney Kimmel Comprehensive Cancer Center at John Hopkins
Chapter 3- Coping with Symptoms and Common Problems

“Knowing when and who to call for problems really helps.”
# Important Phone Numbers

<table>
<thead>
<tr>
<th>CALL FOR PROBLEMS</th>
<th>4(^{th}) Floor</th>
<th>3(^{rd}) Floor</th>
</tr>
</thead>
<tbody>
<tr>
<td>8am-10pm, Monday-Friday 8am-6pm, Sat, Sun 8am-5pm, Holidays</td>
<td>206-288-7400</td>
<td>206-288-7300</td>
</tr>
<tr>
<td>10pm-8am, Monday-Friday 6pm-8am, Sat, Sun 5pm-8am, Holidays</td>
<td>206-598-6190 Ask for the Fellow On-Call</td>
<td>206-598-6190 Ask for the Resident On-Call</td>
</tr>
</tbody>
</table>
Websites and eBooks to Review During Your Journey

National Cancer Institute
www.cancer.gov
1-800-4-CANCER (422-6237)

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

Caregiver Organizations

Caregiver.com
www.caregiver.com

Family Caregiver Alliance
www.caregiver.org

Lotsa Helping Hands
www.lotsahelpinghands.com

Well Spouse Foundation
www.wellspouse.org

Personal Websites to Communicate with Friends and Family
www.caringbridge.org/

www.carepages.com/
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
- Blood Cell Development
- Bleeding
- Body Image Changes
- Breathing Problems
- Change and Uncertainty
- Constipation
- Dehydration
- Depression
- Diarrhea
- Fall Prevention
- Fatigue
- Fever
- Hand-Foot Syndrome
- Lymphedema
- Memory and Concentration
- MouthPain/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, amprostin (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 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 tend to make skin pale, sallow or ruddy. Colors and interesting patterns can decrease the intensity of skin changes.
• If your face becomes very round or puffy, wear a “V” shaped neckline.
• If you have lost a lot of weight, try a round or oval neckline.
• Avoid any garment that might puncture or break the central intravenous line such as front clasping underwire bras or pins. Soft fabrics drape best over catheters.

Take Care of Skin
• Select skin care products that you like and are inexpensive, fragrance-free, hypoallergenic and alcohol-free.
• Cleanse skin twice a day. Mild soap and water is the most basic cleanser, especially good for oily skin. Cleansing creams are good for dry and normal skin because of their moisturizing effect. All cleansing products should be applied gently to avoid pulling the delicate surface of your skin. Use caution to avoid bruising the skin.
• Use a moisturizer to help skin retain its moisture.
• Avoid 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:
- Fever greater than 1 degree above usual when the patient is on Prednisone or steroids.
- 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.
- 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.
Hand-Foot Syndrome

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

Your Goals
- Avoid tight fitting shoes or gloves
- Control skin irritations with moisturizers and avoid activities that can make HFS worse.
- Call for professional help when needed, especially if pain becomes a problem.
- Important Signs and Symptoms:
  - Palms or soles of the feet are red or tender.
  - Skin of palms and soles peeling.
  - Numbness, burning or tingling sensation.

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

- Place palms or bottoms of feet on an ice pack or a bag of frozen peas to provide temporary relief of pain and tenderness. Alternate on and off for 15-20 minutes at a time. (May use gel insoles that can be cooled prior to insertion in shoes.)
- Apply emollient cream of choice AFTER the area has been cooled for maximum comfort.
- If your doctor suggests a steroid cream, apply it after the skin has been cooled and apply emollients over the top of the steroid cream for maximum effectiveness.
- If blistering and ulceration start, apply gentle moisturizers on your hands and feet and contact your doctor or nurse who may suggest further therapies.
- Talk with your nurse about how to change your activities of daily living (bathing, dressing, etc.) if the HFS is severe.
- Contact your doctor regarding other over the counter or prescription options to relieve symptoms of Hand-Foot Syndrome.
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](http://www.cancer.org)

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

National Lymphedema Network  
1-800-541-3259; [www.lymphnet.org](http://www.lymphnet.org)

Seattle Cancer Care Alliance, Physical Therapy Department  
206-288-6373; [www.seattlecca.org/physical-therapists.cfm](http://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 a 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, 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/](http://www.positscience.com/) is a website where you can try out a couple of the exercises from their Brain Fitness Program. This program has been used to help veterans with traumatic brain injuries recover some of their capabilities.

**Get Professional Help When Needed**

If problems persist or affect day-to-day living to a large degree, discuss the symptoms with your 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 checks, lips or throat for 10-15 minutes every 2 hours.
- Avoid pretzels, chips, tomato juice, and orange juice or hot drinks.
• All oral rinses can be kept in the refrigerator or placed in an ice bath. This can be soothing, help to reduce swelling or control bleeding.

Maintain 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
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
Search for “Sexuality”

The American Cancer Society
www.cancer.org
Search for “Sexuality”

University of Washington Reproductive Care

LIVESTRONG - Lance Armstrong Foundation
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
Discusses fertility issues before and after treatment

Fertile Hope
www.fertilehope.org

Resolve
www.resolve.org
Patient advocacy group addressing reproductive concerns and options for infertile individuals and couples, as well as cancer patients.

WebMD
http://women.webmd.com/tc/kegel-exercises-topic-overview
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.
- 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.
- Sore throat.
- A general feeling of tiredness or “flu-like” symptoms.
- Painful or frequent urination.

What You Can Do at Home
Preventive measures:
- Look at your mouth and skin for signs of infection. Exercise excellent mouth care. See Mucositis information sheet.
- Brush your teeth after each meal and at bedtime. Use a soft-bristle toothbrush and be careful to avoid injury to the gums. Avoid use of mouthwashes that contain alcohol.
- Keep your skin clean and avoid cuts and scratches. Report any changes in skin including rashes, sores and cuts.
- Wash hands frequently.
- Wear gloves when washing dishes.
- Shave with an electric razor.
- Use lotion for dry skin.
- If you have hemorrhoids, ask your 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
Infection Control

Handwashing
People have many kinds of microorganisms on the skin as well as inside the body. They are like hitchhikers and they usually don’t cause infections. However, immune-suppressed patients are vulnerable to infection. They may acquire infections from the microorganisms on or in their own body or from microorganisms transferred from another person. Infectious organisms are easily transported by touching. A person who touches their nose or mouth and then touches the patient may transfer organisms to the patient. A person with organisms on their hands may touch a surface. If the patient touches the surface and then touches his or her nose, mouth, or eyes the infectious organisms may gain entrance into the patient’s body.

The best way to avoid infectious organisms is HANDWASHING!

Handwashing Procedure
Use plenty of soap and warm water, and scrub for at least 15 seconds. Then rinse well and dry hands thoroughly. Then turn off water using a towel. Please use soap pumps instead of bar soap. Alcohol hand sanitizer is also an acceptable method of handwashing as long as hands are not soiled. Hands should be washed with soap every 3-5 hand cleansings.

Who should wash hands? Everyone: the patient, caregiver, family members, friends, nurses, doctors .everyone!

Protect Yourself During Building Construction
Why is building construction a concern?
Building construction can disturb soil and create bursts of airborne dust containing fungal spores. Building construction can pose a health risk to immunocompromised patients who may inhale airborne dust particles that carry fungal spores, such as aspergillus.

What is Aspergillus?
Aspergillus is a mold that is widespread in nature especially in decaying matter, water and soil. The disease caused by Aspergillus is called Aspergillosis. In patients with an impaired immune system, Aspergillus can cause infections of the lungs, skin, sinuses, or brain. Previous studies have shown that Aspergillus is frequently detected in urban air samples, even in the absence of construction. The increased risk of developing disease from Aspergillus near construction sites has not been determined, but several simple steps can help reduce the risk of infection:

• If you live near construction, keep your windows closed.
• Keep your car windows closed when driving past construction.
• Perform frequent hand washing. Washing your hands with soap and water is an effective way to remove any dust that may be on your hands.
• Sticky mats are used to help trap any dust that may be on your shoes. You may notice that these mats are used within the Seattle Cancer Care Alliance and Fred Hutchinson Cancer Research Center buildings when there is construction in the area.
• Construction is often very interesting to watch, but we would ask you not to go and observe the construction if you are outside. Observation from a closed window is fine.

**Wearing a Mask at the Clinic: Information for Patients**

Are masks recommended at the Seattle Cancer Care Alliance (SCCA) Clinic? Yes, if you are coughing, sneezing, have a cold, the flu, or if you are a transplant patient on respiratory isolation. If worn correctly, masks help decrease the spread of respiratory viruses and bacteria to others.

Where are Masks Located in the Clinic?
Masks are located throughout the Clinic. You may obtain masks at the front desk on each clinic floor or at the hand hygiene station on the 1st floor.

I do not have a cold or the flu, should I be wearing a mask while in the Clinic?
No, if you do not have a respiratory infection, it is not recommended that you wear a mask. Masks are not an effective way to prevent persons from catching a respiratory infection.

What type of mask should I wear in the Clinic?
Masks that help decrease the spread of respiratory viruses and bacteria are known as surgical or procedure masks. These masks are designed to cover the mouth and nose loosely, strap behind the ears or head, are made of soft materials, and are comfortable to wear.

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

How should I dispose of a mask?
• Dispose in an area where hand washing or hand gel can be utilized before touching surrounding areas.
• To remove the mask, grasp the ear bands on both ears and pull the mask off of your face.
• Dispose of the mask in nearest waste container.
• Use hand gel or wash your hands after removing the mask.
What else should I be doing to prevent the spread of infection?
Precautions are necessary when patients have the cold or flu. It is recommended that patients with a cold or the flu:

- Perform frequent hand washing. Washing your hands with soap and water is an effective way to remove any dust that may be on your hands.
- Avoid high-traffic areas in the clinic, such as the food service area and crowded elevators.
- Use hand gel or wash hands frequently.

Additional Tips on Wearing Masks:
- Masks are effective in preventing the spread of infection if worn for short periods of time, usually 60 minutes. Masks lose their protective properties when they become wet from saliva, by talking, coughing, or sneezing. If you anticipate being in the SCCA Clinic for over an hour, obtain more than one mask from SCCA staff.
- Do not handle the front part of the mask. If a person touches the front of the mask, the bacteria or virus may now be spread with the person’s contaminated fingers.

Air Conditioners & Fans
Air conditioners and fans are a great way to cool off during the summer, but if not cared for properly they can bring dust and mold into your home. Below are some helpful tips on how to safely use air conditioners and fans. Be sure to turn off and unplug them before you inspect or clean them.*

Air conditioners (AC):
- Most have an energy saver switch. When turned on, it brings outside air inside. To prevent dust accumulation and mold growth, the energy saver switch must be turned off.
- Regular inspection and cleaning of the AC unit is critical*. Before cleaning the unit, vacuum it and the area around it. Then with a wet cloth, wipe down the unit with soap and water or bleach and water (1:10 dilution) solution. There are two parts of air conditioners that are most likely to accumulate molds, the cooling coils and the drip pan. Special attention should be paid to these two areas during cleaning.
- Filters should be changed per the manufacturer recommendations.

Fans:
- Fans should be inspected and wiped down on a regular basis*. Use a soap and water or bleach and water (1:10 dilution) solution to clean fans.
- Window fans are not recommended because they pull in outside air.
• Purchase fans that can be easily cleaned, such as the standalone oscillating fans. The
tower fans are complicated to clean, as they are big and have crevices where dust
settles.

*Immunocompromised persons should not clean AC units or fans. Please have your
caregiver or family member inspect and clean the AC unit and/or fan.
Food Safety Guidelines

Foodborne illness, or “food poisoning,” is any illness caused by eating food that is contaminated with a bacteria, virus, mold or parasite. Organisms that can cause a foodborne illness include E. coli, salmonella, and listeria. Foodborne illness may come from several sources, including improper food handling, a contaminated work surface, or the food itself.

Bacteria and other organisms exist commonly in foods. Most of these organisms are of little risk to the average healthy person. However, if you are undergoing treatment such as chemotherapy or radiation, you are at a higher risk for infections, including foodborne illness. Following food safety guidelines reduces risk for foodborne illness.

For more detailed information, see the “Guidelines for Immunosuppressed Patients” at [www.seattlecca.org/client/documents//practical-emotional-support/HSC-Diet-for-Immunosuppressed-Patients-032508_5888_0.pdf](http://www.seattlecca.org/client/documents//practical-emotional-support/HSC-Diet-for-Immunosuppressed-Patients-032508_5888_0.pdf)

If you have any questions regarding food safety and diet guidelines, please ask your scheduler or team coordinator to set up an appointment with a registered dietitian.

Steps to Food Safety

- Wash hands and surfaces often.
- Avoid cross contamination of raw and ready-to-eat foods.
- Keep foods at safe temperatures. Keep hot foods hot and cold foods cold.

Tools for Food Safety

- Food and refrigerator thermometer.
- Hand soap.
- Clean cloth or paper towels.
- Bleach solution to sanitize surfaces and cookware.

Bleach Solution

- Mix 1/3 cup unscented household bleach with 3 1/3 cups water. Keep in a spray bottle.
- Use solution to clean and sanitize kitchen, cutting boards, and other household surfaces.
- Remake solution daily.
Personal Hygiene
Wash hands frequently with soap and warm, running water. Use a rubbing motion for 15 seconds prior to food preparation, before eating, after using the restroom, handling garbage, and touching pets.

Kitchen Cleanliness
- Sanitize sponges daily. You may soak them in the bleach solution for five minutes, heat them in a microwave on high for one minute, or run them through the dishwasher.
- Air dry dishes instead of towel drying them.

Prevent Contamination
At the grocery store:
- Avoid unpasteurized products, including juice, milk, yogurt, and cheese such as queso fresco or camembert, and unpasteurized pickles.
- Do not taste unpackaged food samples.
- Check eggs before purchasing. Do not purchase or use cracked eggs. Pasteurized eggs, liquid pasteurized egg products, such as Eggbeaters®, and powdered egg whites may be used in recipes calling for raw eggs in foods that will not be cooked.
- Place meat, poultry, and fish in separate plastic bags. Keep these bags separate from each other and other food items.

At home:
- Use a clean knife for cutting different foods. For example, use different knives for cutting meat, produce and bread.
- During food preparation, do not taste food with the same utensil used for stirring.
- Use a clean utensil each time you taste food while preparing or cooking.
- In the refrigerator, store raw meat separately from ready-to-eat foods, preferably on the bottom shelf.
- When grilling, always use separate plates for raw and cooked meat.

Fruit and Vegetable Handling
Fresh produce may carry bacteria or other organisms that can cause foodborne illness. The term “natural” or “organic” refers to growing without the use of chemical fertilizers or pesticides. It has no relationship to the cleanliness or safety of the product. Use the following guidelines for handling all raw produce:
- Rinse produce thoroughly under clean, running water just before use, including produce that is to be peeled, such as bananas, melons and oranges, or food that is to

113
be cooked.

- Do not wash fruits and vegetables with soaps, detergents or chlorine bleach solutions. Produce can absorb these cleaning agents, and they are not any more effective at removing bacteria than running water.
- Do not purchase produce that has been cut at the grocery store, such as melon or cabbage halves. This is particularly true for produce that will not be cooked before eating.
- Scrub produce that has a thick, rough skin or rind, such as cantaloupe or potatoes, or has visible dirt on the surface by using a clean vegetable scrubber.
- Rinse leaves of leafy vegetables, such as lettuce, spinach, or cabbage, individually under running water. Wash packaged salad, slaw mixes or other prepared produce, even those marked pre-washed. You may use a salad spinner or colander.
- Do not eat any raw vegetable sprouts. Avoid all types, including alfalfa sprouts, clover sprouts, mung bean sprouts, and so on, due to high risk of salmonella and E. coli contamination. Cooked mung bean sprouts are acceptable.
- Throw away fruit and vegetables that are slimy or show mold.

Cutting Boards

- Use different cutting boards for raw meat and animal products, produce, and bread. We suggest using different colored cutting boards for different foods, such as red for meat, green for produce, yellow for bread.
- Wooden cutting boards are considered safe if they are used exclusively for raw meat and poultry.
- Wash cutting boards with hot, soapy water after each use; then air dry. Non-porous acrylic, plastic or glass boards and solid wood boards can be washed in a dishwasher. Laminated boards may crack or split.

Food Storage

- Check expiration dates. Do not use foods past the expiration dates. These include fresh meats, poultry, seafood, dairy products, eggs, cereals, and canned goods.
- Keep food storage areas clean.

Keep Foods at Safe Temperatures

Refrigeration:

- Keep the refrigerator temperature between 34° and 40°F
- Keep the freezer temperature between 0° and 2°F.
- Thaw and marinate foods in the refrigerator, never on the counter or at room temperature.
- Store and thaw meat, fish and poultry on the bottom shelf of the refrigerator, with no other raw fruits and vegetables near. Cook defrosted meat immediately, do no
refreeze it.

- Cool hot foods in shallow dishes in the refrigerator, cover storage container tightly after cooling.
- Throw away or freeze all prepared foods/leftovers within 72 hours or 3 days. Use labels or masking tape to write dates.
- Never taste food that looks or smells strange.

Cook foods thoroughly:

- Use a thermometer to test if food has heated to the proper temperature.
- Cook meat until it is no longer pink and the juices run clear. These are signs that the meat may be cooked to a proper temperature. However, the only way to be sure that the meat has been cooked to the proper temperature is to use a food thermometer.
- Heat all hot dogs, ready-to-eat luncheon meats, cold cuts and deli-style meats to 165°F (or until just steaming in the microwave) before eating.
- Do not eat uncooked foods containing raw or undercooked eggs, including soft boiled eggs, raw cookie dough, cake batter, or salad dressings.
- Hold foods at safe temperatures: hot food above 140°F, cold food below 40°F.
- If using a microwave, rotate the dish a quarter or half turn once or twice during cooking and stir food several times during heating.

Dining Out Safely

- Ask that fast-food establishments prepare food fresh. For example, a hamburger should be fresh off the grill, not under a heat lamp.
- Avoid raw fruits and vegetables when dining out. Eat these foods at home where you can control the safety and preparation.
- Ask for single-serve condiment packages. Do not use self-serve condiment containers, including salsa.
- Avoid salad bars, delicatessens, buffets, smorgasbords, potlucks, food trucks, and sidewalk vendors. Pack your own leftovers; have the server bring you a box. Refrigerate promptly.

Water Safety Guidelines

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

Well water:

- Well water from private or small community wells is not considered safe if you are immunosuppressed and at risk for infection unless it is tested daily and found to be negative for coliforms and Cryptosporidium organisms. Use other approved water sources instead, including boiled water or bottled water.
• Municipal wells serving highly populated areas are considered safe because the water is tested for bacterial contamination more than twice daily.
• Common home filtration systems (Brita® or Pur®) and refrigerator-dispensed water and ice machines do not remove bacteria or viruses, and therefore are not considered safe. If the well water supply is chlorinated per guidelines provided by your local health department, the chlorinated water that is treated with one or more of the following is considered safe to consume:
  o Reverse osmosis
  o Distillation
  o Filtered through an absolute 1 micron or smaller filter (NSF Standard #53 for cyst removal)

Safe water sources if your water is not from a city water or municipal well supply:
• Boiled water: Bring water to a rolling boil for at least fifteen to twenty minutes. The boiled, cooled water should be stored in a clean, covered container for up to 48 hours or two days.
• Bottled water: Bottled water labeled as having been treated with one or more of the following are considered safe: reverse osmosis treated, distilled, or filtered through an absolute 1 micron or smaller filter (NSF Standard #53 for cyst removal).

Contact the International Bottled Water Association (www.bottledwater.org, or 1-800-928-3711) to be sure a specific brand of water has undergone one of the above processes.
Diet Guidelines for Low White Blood Cell Counts
(Absolute Neutrophil Count less than 1000)

Persons with decreased immune function due to chemotherapy or persons receiving radiation therapy which affects the stomach, intestines, colon or rectum are at increased risk of developing a food-related infection. You can protect yourself from many infections by preparing food and drinks properly and by avoiding specific foods that are more likely to contain infection-causing organisms while allowing you to have healthy food choices. You may want to discuss the safety of these or other foods with an SCCA dietitian. Your doctor can provide guidelines as to when the diet guidelines are no longer required.

Milk and Dairy Products
- Eat or drink only pasteurized milk, yogurt, cheese or other dairy products (pasteurized, grade “A” milk and milk products).
- Avoid soft mold-ripened and blue-veined cheese including: Brie, Camembert, Roquefort, Stilton, Gorgonzola, Blue. (Note: COOKED soft cheeses such as brie, camembert, feta, farmer’s cheese may be acceptable as the risk of contracting food borne illness from COOKED soft cheeses is low)
- Avoid Mexican-style cheeses (such as queso blanco fresco) since they are frequently made from unpasteurized milk and are associated with a higher rate of food-borne illness.

Eggs
- Cook eggs until the yolk and white are solid, not runny.
- Do not eat foods that may contain raw eggs, such as hollandaise sauce, cookie dough, homemade mayonnaise, and Caesar salad dressing. If you prepare these foods at home, use a pasteurized egg product instead of eggs in the shell. (You can find pasteurized eggs in the dairy case at your supermarket; such as Egg Beaters®)

Meat, Poultry, Fish and Tofu
- Use a meat thermometer. The temperature inside the meat or poultry should be cooked to the temperatures listed in Table 1 (see page 3).
- Do not eat meat, game, poultry and fish that are spoiled, raw or undercooked.
- Do not eat raw or lightly cooked fish, shellfish, lox, sushi or sashimi.
- It is recommended to thoroughly heat until steaming all hot dogs and “ready to eat” luncheon meats, cold cuts and other “deli-style” meats before eating.
- Cut tofu into 1-inch cubes or smaller and boil 5 minutes in water or broth before eating or using in recipes. (Note: aseptically packaged, shelf-stable tofu does not need to be boiled.)
Fruits and Vegetables

- Raw fruits and vegetables and fresh herbs are safe to eat if you wash them carefully under cold running water. You don’t need to use special sprays. Do NOT use soap since soap can cause diarrhea if not thoroughly rinsed off the food.
- Avoid fresh salsas and salad dressings found in the refrigerated section of the grocery store. Choose shelf-stable salsas and salad dressings instead (shelf-stable refers to unopened canned, bottled, or packaged food products that can be stored at room temperature before opening; the container may require refrigeration after opening.)
- Do not eat any raw vegetable sprouts (alfalfa, radish, broccoli, mung bean, all others).

Bread, Grain, and Cereal Products

- Avoid foods from “reach in” or “scoop” bulk food containers.
- Avoid food from any type of bulk food container if it will not be cooked prior to consumption.

Desserts and Sweets

- Avoid unrefrigerated, cream- and custard-filled pastry products, such as fresh bakery cream pies, Éclairs, cream-filled doughnuts and pastries. Commercial, shelf-stable items such as Danish pastries, Hostess® fruit pies, Twinkies® and Ding Dongs® are allowed; follow the “use by” date and store them according to the manufacturer’s guidelines after opening.
- Do not consume raw honey or honeycomb. Select commercial, grade A, heat-treated honey.

Water

- Do not drink water straight from lakes, rivers, streams, or springs.
- Do not consume well water unless it is tested at least yearly and contains no coliforms. (It is recommended to use distilled or bottled water if using a water service other than city water service; please see “Water Safety Guidelines” at the end of this chapter.)

Beverages

- Do not drink unpasteurized fruit and vegetable juices.
- Do not drink “sun” tea. Make tea with boiling water, using commercially packaged tea bags.
Guidelines for the Use of Complementary Therapies

If you think about the use of vitamins, minerals or herbs during your cancer treatment, please read below. Your doctor and nurse want to help you choose what is appropriate for you while undergoing chemotherapy, radiation, surgery or other treatments. Undesirable interactions may occur between herbal, vitamin, mineral, botanical or other supplements and your medications. Just because a product claims to be natural does not mean it is safe for you.

You are encouraged to discuss both the advantages and risks of complementary treatments with your doctor or nurse before making a decision.

Definitions

• **Complementary Methods** are defined as supportive methods used in addition to standard treatment such as radiation, chemotherapy and surgery. Complementary therapies do not replace cancer treatments. Complementary methods are not promoted to cure disease.

• **Alternative Methods** are defined as unproved methods, rather than conventional methods to prevent, diagnose and treat cancer. Some people choose alternative methods to replace mainstream cancer treatments.

Herbals and Other Complementary Products Safety

The production, distribution and labeling of herbal, nutrient, botanical and other supplement preparations are not regulated by the U.S. Food and Drug Administration (FDA). Here are several concerns about their use:

• Undesirable interactions may occur between herbal, vitamin, mineral, botanical or other supplements and your medications. These interactions may change the effectiveness of cancer therapy or result in toxicities of drugs routinely used during the course of chemotherapy. This is why it is important that your doctor and pharmacist know everything you are taking.

• Both the dosage and purity of the product may vary from one brand (or even bottle) to another.

• Preparations that come from plants may be contaminated with bacteria, fungus, molds or parasites; these can result in life-threatening infections if persons are immunosuppressed or have low white blood counts.

• Some preparations have been found to be contaminated with chemicals that can be extremely dangerous to humans.

• Several specific substances have been repeatedly associated with serious organ toxicity.
A Few Helpful Guidelines

- If you take herbals, nutrients, botanicals or other products, choose those labeled with a USP (United States Pharmacopoeia) seal, NSF seal or ISO-9000. These seals mean the product has been made using good manufacturing practices.
- Investigate the proper supplement dose and appropriate length of therapy.

Avoid Herbals During the Following Periods

- When you are significantly immunosuppressed (low white blood count, absolute neutrophil count below 1000)
- If you have a disease that causes immunosuppression (examples are HIV, aplastic anemia, Hodgkin's disease, ALL, non-Hodgkin's lymphoma, CLL, myeloma)
- If you are receiving treatment that significantly decreases white blood cell counts including: chemotherapy, monoclonal antibodies, interferon, interleukin-2, corticosteroids, cyclosporine, tacrolimus, sirolimus, azathioprine and other immunosuppressive therapies
- Talk with your doctor about the use of herbal or other complementary therapies if you are receiving an investigational drug.
- Be VERY cautious about taking herbs, herbal teas and tinctures, vitamins or other supplements if you are taking medications for high blood pressure, phenylzine, tranylcypromine, or medications that affect blood clotting (such as Warfarin or Coumadin®, enoxaparin or Lovenox®).

The decision to initiate or resume therapy with herbals or other products should be made only after discussion with your doctor. Such patients should be under the care of a naturopathic doctor (N.D.) familiar with the potential effects of herbals or botanicals on immune, kidney and liver function, as well as the potential for drug interactions.

If you have questions about herbals, nutrient supplements or other products, talk to your doctor, pharmacist or dietitian.

Questions to ask About Complementary and Alternative Methods

How can you know if complementary products or approaches are safe and if they can help you? Here are some questions to ask:

- What claims are made for the treatment? Can the provider give you references published in respected medical journals?
- Does it claim to cure cancer?
- Does it claim to enable the conventional treatment to work better? To relieve symptoms or side effects?
- What does the treatment involve? Are there side effects of the treatment?
• What are the credentials of the people or organizations supporting the treatment? Are they recognized experts in cancer treatment? Have their findings been published in trustworthy medical journals? Be skeptical of treatments promoted by people or organizations giving vague credentials such as “expert” or treatments for which only anecdotal evidence is available.

• How is the method promoted? Is it promoted only in the mass media (books, magazines, TV, radio, etc.)? Is it mentioned in scientific journals?

• What are the costs of the therapy?

• Is the method widely available for use within the health care community, or is it controlled with limited access to its use?

• Does the method require that you forego conventional therapy? If so, will doing this affect chances for cure? Is the cancer stage likely to advance during the delay?

Spotting Fraudulent or Questionable Therapies

• Consider the following points to avoid falling prey to fraudulent or questionable treatment methods. If you are still unsure if the treatment is safe and valid, discuss it with your doctor or nurse before trying it.

• Is the treatment based on an unproven theory?

• Does the treatment promise a cure for all cancers?

• Do the promoters tell you not to use conventional medical treatment?

• Is the treatment or drug a secret that only certain people can give?

• Is the treatment or drug offered by only one individual?

• Does the treatment require that you travel to another country?

• Do the promoters attack the medical or scientific establishment?

For additional information, please review the Thinking About Complementary & Alternative Medicine booklet from the National Cancer Institute at: www.cancer.gov/cancertopics/cam/thinking-about-CAM
Chapter 4 – What’s Next?

“It is wonderful knowing that there are experts on long term and survivorship issues right here at the SCCA.”
Introduction to Cancer Survivorship

“There is life after cancer, and all cancer survivors deserve access to long-term survivorship programs like this one.”
-Breast Cancer Survivor, female, 45 years old

Cancer is now a disease that most diagnosed people can expect to survive. Each year, more patients benefit from early detection of cancer and effective medical treatments, leading to a remarkable increase in long-term cancer survivors to a current rate of 66% for adults and 80% for childhood cancer survivors. Roughly 12 million Americans are now living more than 5 years after a diagnosis of invasive cancer. Although cured from their cancer, many survivors who have completed their medical treatment are facing distressing late and long-term effects from their illness and their treatment.

What are long-term and late effects?
Long-term effects of cancer therapy are medical problems that develop during treatment and persist for months or years after treatment ends. Late effects are medical problems that do not develop or become apparent until years after treatment ends. Some examples of long-term and late effects include:

- Pain
- Fatigue
- Fear of recurrence
- Living with uncertainty
- Neuropathy
- Lymphedema
- Bone loss
- Sexual dysfunction
- Cardiovascular disease
- Memory issues
- Future cancer risk

Treatment Summary and Survivorship Care Plan
The Institute of Medicine recommends that cancer survivors receive a Treatment Summary and Survivorship Care Plan after completing their medical treatment. Contact your oncologist or cancer treatment facility to request a Treatment Summary and Survivorship Care Plan. If you are no longer following up with your treating oncologist or cannot obtain these documents through your treatment facility, consider an appointment in the Survivorship Clinic.

Treatment summaries should include:
- Details of diagnosis, such as the type of cancer and its stage, date diagnosed, age at diagnosis
- Treatments received, including the specifics of any surgeries, radiation (dose and site) and/or chemotherapy (drug names and doses) and any complications
• The names and contact information for all health care providers and institutions

Care plans are tailored to each patient, based on diagnosis and treatment. Care plans should include:
• Specific screening recommendations due to treatment received
• Suggestions or referrals for treating ongoing symptoms related to treatment
• Wellness advice, including exercise, diet and health maintenance recommendations to increase overall health and decrease risks of recurrence or new cancers

Survivorship at SCCA: Empowered Living After Cancer

“I love the Survivorship Clinic. They take over where the oncologists leave off. They really helped me fill in the blanks so I’d know if I’m on the right track.”
-Breast Cancer Survivor, female, 54 years old

Cancer and its treatment can result in some potentially long-lasting or late-onset effects. The Survivorship Clinic addresses various problems cancer survivors may face after therapy ends. During your visit, our medical staff will talk with you about how to assess and manage late complications or issues you may be experiencing, and develop a plan to support your future health.

Frequently Asked Questions

How will you benefit from this clinic?
The knowledge gained from reviewing your cancer treatment can help you understand your future health risks. We have experts available to assist and educate you regarding your risks and how to prevent and manage them. We can also address current physical or social survivorship concerns you may be facing as a result of your treatment.

Will my insurance cover this visit?
Most insurance plans consider this a necessary visit for individuals who have received treatment for cancer. Prior to coming in for an appointment, we recommend that you check with your insurance company to review your coverage and any out of pocket expenses. A Patient Financial Services representative is available to provide counseling for those with concerns.

What can I expect from my Survivorship Clinic appointment?
We provide an individualized Treatment Summary and Survivorship Care Plan. This includes an evaluation and information on the prevention of the late effects of your cancer and cancer treatment, recommendations and resources for dealing with long-term effects, and suggestions for healthy lifestyle behaviors. Copies of the treatment summary, survivorship
care plan, and any recommendations made during the appointment are shared with your health care team, including your oncologist and primary care provider. We will work in partnership with these providers to make sure your survivorship needs are being met. We do not provide testing for recurrence of your cancer; this care will continue to be provided by your oncologist.

**How many appointments will I have in the Survivorship Clinic?**
The number of appointments you will have depends on your preference. Your personal situation will be discussed with you during your initial appointment. You may have one appointment, an annual appointment, or an appointment every few years.

You should identify a local primary healthcare provider that you can visit or call to monitor your overall health with you. We are happy to work with your primary care provider in identifying what problems to monitor. If a problem comes up that may be related to cancer treatment, the primary healthcare provider can discuss this with your oncology survivorship team.

To learn more about the SCCA Survivorship Clinic, or to schedule an appointment for yourself or a family member, please contact us at survivor@seattlecca.org or 206-288-1024.

The Washington Department of Health has a Survivorship Care Plan, *Life’s Transition* handout at the link listed below:  
Chapter 5 - Terms and Helpful Information

“Knowing the definition of terms really helps.”
Glossary of Terms

Absolute Neutrophil Count (ANC): A laboratory procedure which determines the number of neutrophils, a type of white cell, in a blood sample.

Adverse Reaction: An unwanted effect caused by the administration of the drug.

Adjuvant Therapy: A treatment added to the main therapy.

Alopecia: Hair loss.

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

Antibiotic: Medication that fights germs or bacteria that cause infection.

Anemia: Low counts of red blood cells.

Anti-emetic: Medicine to prevent or treat nausea and/or vomiting.

Apheresis: A procedure used to collect certain types of blood cells. Blood from a donor/patient is passed through a continuous-flow blood processor; the platelets or white blood cells are extracted from normal whole blood and the remaining blood components are returned to the donor.

Attending Physician: Leads the Healthcare Team. Conducts patient/family conferences, obtains informed consent. Selects appropriate treatment plans and protocols.

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

Benign Tumor: A tumor that is not cancerous.

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

Biologic Therapy: Treatment that uses the immune system to fight infection and/or disease; also called immunotherapy or immune therapy.

Biopsy: The removal of a sample of tissue that is examined to see if cancer is present.
**Bone Marrow Aspiration:** The removal of bone marrow using a needle and syringe. This is done to obtain a sample for laboratory study.

**Bone Scan/DEXA (Dual-Energy X-Ray Absorptiometry or DXA):** A Bone Scan/ DEXA or DXA is a non-invasive medical test used to measure bone loss. This x-ray test involves exposing a part of the body to a small dose of ionizing radiation to take a picture of the inside of the body.

**BRCA1 and BRCA2:** Changes, called alterations or mutations, in certain genes make some women more susceptible to developing breast and other types of cancer. Inherited alterations in the genes called BRCA1 and BRCA2 (short for breast cancer 1 and breast cancer 2) are involved in many cases of hereditary breast and ovarian cancer.

**Bone Marrow Transplant:** The process of treating disease with high doses of chemotherapy, radiation therapy or both. This treatment destroys the bone marrow's ability to produce blood cells. Bone marrow or peripheral blood stem cells are given following treatment to restore the production of blood cells.

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

**Caregiver:** A responsible family member or friend who is able to provide physical care, observation, and emotional support for a patient in the home setting. They help make arrangements, maintain the home environment, provide assistance and support to other family members, and act as a patient advocate.

**Carcinoma:** Cancer that begins in the internal tissue.

**Carcinoma in situ:** A cancer that has not spread to other parts of the body or invaded nearby tissue.

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

**Chemotherapy:** Medication(s) used to destroy or slow the growth of abnormal cells, usually cancer cells.

**Central Intravenous Catheter:** A small, flexible tube inserted into a large vein near the heart. This serves as a route for medications, nutritional supplements, and to obtain blood samples. Also known as Hickman line, Central line, Tunneled Catheter or Port-a-Cath.

**Clinical Pharmacist:** A person who know about medications and side effects.
**Clinical Trials:** New and promising ways to treat cancer. A research study can be offered at various phases such as phase I, II, III or IV.

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

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

**Conditioning:** The treatment given to the patient prior to transplant which is intended to kill cancer cells and prepare the bone marrow to receive the transplant. This consists of chemotherapy and/or radiation therapy.

**Consultants:** Provide specialized advice to the attending physician.

**Contrast Agent:** A substance injected into your vein that helps make Magnetic Resonance (MR), X-Rays, and CT images clearer and easier to evaluate.

**Counts:** Usually refers to monitoring the absolute neutrophil count (ANC), when watching for signs of engraftment.

**Computed Tomography (CT):** A CT is a non-invasive and painless medical test that helps physicians diagnose and treat medical conditions. CT imaging uses special x-ray equipment to produce multiple images of the inside of the body. This test produces cross-sectional views of organs, blood vessels, bones and soft tissues. Often IV or Oral contrast is used for better imaging purposes.

**Drug Resistance:** The result of cancer cells’ ability to resist the effects of a specific drug.

**Dysuria:** Difficult or painful urination.

**Edema:** Swelling, the accumulation of fluid within tissue.

**Erythrocytes:** Red blood cells that use their main component, hemoglobin, to carry oxygen as it is breathed in through the lungs to all parts of the body.

**External Radiation:** Radiation therapy that uses a machine located outside of the body to aim high-energy rays at cancer cells.

**Fractioned Radiation:** Smaller, divided doses of radiation that are given over several days.
**Growth Factors:** Substances naturally occurring in the body which control the production and function of blood cells. These substances may be given after chemotherapy and/or transplant to speed up engraftment.

**Hematopoietic Stem Cell Transplant (HSCT):** Using your own cells or cells of donor to rescue your immune system after chemotherapy and radiation.

**Hormone:** A substance produced by certain organs of the body which stimulates and regulates the body's function.

**HPV (Human Papilloma Virus):** A general term for more than 80 similar viruses that cause warts to grow, such as the fairly common warts that grow on hands and feet or papillomas (non cancerous tumors). Some HPVs are transmitted sexually. HPV is a major cause of cervical cancer.

**Immunosuppression:** A decrease in the ability of the immune system to fight infection, which can be caused by chemotherapy and/or radiation therapy.

**Informed Consent:** The process in which a patient learns about and understands the purpose, potential risks and benefits of a protocol and/or procedure and then agrees to participate. A patient may decline to participate.

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

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

**Intramuscular (IM):** A route of administration of medications given into the muscle.

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

**Leukocytes:** White blood cells, which play a major role in the body's immune system.

**Lymph Nodes:** Tissue in the lymphatic system that filters lymph fluid and helps the immune system fight disease.

**Malignant:** Cancerous.

**Melanoma:** A cancer that starts in the skin cells.

**Metastasis:** The spread of cancer cells to distant areas of the body by way of the lymph system or bloodstream.
**Magnetic Resonance Imaging (MRI):** A MRI is a non-invasive process that uses a powerful magnetic field, radio wave and computer to produce detailed pictures of organs, soft tissue, bones and all internal body structures.

**Mucositis:** Reddening and soreness of the tongue, lips, mouth, throat, and gastrointestinal tract from chemotherapy and/or radiation therapy.

**Mucosa:** The lining of the mouth and gastrointestinal tract.

**Myeloma:** A malignant tumor of the bone marrow associated with the production of abnormal proteins.

**Needle Biopsy:** Incorporating a large needle to remove a small cylinder of tissues from a lump for analysis.

**Neutropenia:** Low neutrophil count. A person with neutropenia is at high risk for developing an infection.

**Neoplasm:** An abnormal growth of tissue from a single cell. A neoplasm can be cancerous or noncancerous sometimes called a malignant neoplasm.

**Neutrophil:** A type of white blood cell which provides defense against infection.

**Neuropathy:** Nerve damage causing abnormal sensations, and/or impaired muscle movements.

**Non-steroidal Anti-inflammatory Drugs (NSAID):** A class of pain medications, often sold over the counter that includes ibuprofen, and similar pain killers.

**Nuclear Ventriculography (MUGA):** A MUGA is a non-invasive test using radioactive traces to view the heart chambers and major blood vessels entering and exiting the heart. A radioactive isotope is injected into your vein, and while it circulates through your body, special cameras and scanners take pictures of your heart. This test is often administered at rest and then repeated with exercise, or after certain medications.

**Nutrition/Dietitian:** Evaluates nutritional status. Makes recommendations on food management.

Nurse practitioner: A registered nurse (RN) who has completed an advanced training program in a medical specialty. May function as a primary direct provider of health care and prescribe medications.

Oncology: An area of medical science that studies tumors and cancer.

Oral Medicine: Assists with the management of mucositis (sore mouth).

Pain Clinic: Specialists from several areas such as doctors, nurses, pharmacologists. Assist with keeping you comfortable during your treatment. Work with the staff to provide relief from pain, nausea, and stress reactions.

Palliative Care: Treatment intended to relieve symptoms caused by cancer.

Pastoral Care/Chaplain: Addresses spiritual concerns of patients and family. Provides worship and meditation classes and support groups. Provides spiritual/emotional support to patient and family. Assists in locating local religious/spiritual resources.

Pathology: The study of the causes and characteristics of disease.

Positron Emission Tomography (PET): A PET Scan is a non-invasive and painless test that helps physicians diagnose and treat medical conditions. A PET scan measures important body functions such as blood flow, oxygen use and sugar (glucose) metabolism to help evaluate how organs and tissues are functioning.

Peripheral Blood Stem Cell (PBSC): Blood cells which are circulating in the blood stream and which have the ability to develop into white blood cells, red blood cells, and platelets.

Petechiae: Small, red or brown spots on the skin, which are tiny hemorrhages. These spots are caused by a low blood count and decreased clotting. May be the result of chemotherapy, leukemia and other disorders.

Physical Therapy: Provides exercise programs to maintain strength and energy.

Platelets: Tiny disc-shaped blood cells which help prevent bleeding and help the blood clot.

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

Polyp: A growth of tissue protruding into a body cavity, such as a nasal or rectal polyp. They may be benign or malignant.
**Primary Physician or Physician Assistant:** Manages physical care. Performs history and physical examinations of patients and donors. Reviews status daily. Makes decisions about medical care consulting with the attending physician.

**Primary Tumor:** The original cancer site, i.e. breast cancer that has spread to the bone is still called breast cancer.

**Protocol:** The outline or specific plan for a treatment, usually an experimental procedure or experimental treatment.

**Prognosis:** A statement about the likely outcome of a disease in a particular patient.

**Radiology:** A branch of medicine that focuses on the use and study of radioactive substances to treat and diagnose conditions.

**Radiation Therapy:** A type of treatment for cancer that uses radiant energy waves to damage or kill cancer cells.

**Red Blood Cell (RBC):** A type of blood cell, an erythrocyte that carries oxygen in the body.

**Relapse:** The recurrence of disease after an apparent recovery.

**Respiratory Syncytial Virus (RSV):** RSV causes mild, cold-like symptoms in adults and children. It can also cause serious problems including pneumonia and severe breathing problems. In rare cases it can lead to death. Individuals with other health problems and weakened immune systems have the highest risk. RSV may have a fever, stuffy nose, cough and trouble breathing. Tests can tell if you have the virus. RSV easily spreads from person to person. You can get it from direct contact with someone who has it or by touching infected objects such as toys or surfaces such as countertops. Washing your hands often and not sharing eating and drinking utensils are simple ways to help prevent the spread of RSV infection. There is currently no vaccine for RSV.

**Sarcomas:** Cancers that form in connective tissues.

**Stage:** Staging is a method of deciding the extent of the cancer, or how far the disease has spread. The extent of spread is determined by diagnostic tests.

**SCCA:** Seattle Cancer Care Alliance

**Side Effect:** An additional and usually undesirable effect or symptom from a drug or other treatment.
Skeletal Survey: A series of X-rays of all the bones in the body or the axial skeleton and large bones. This test is very common in the diagnosis of multiple myeloma, where tumors deposits appear as “punched out” lesions. The standard set of x-rays includes: skull, spine, pelvis, ribs, and legs bones.

Standard Treatment: A treatment or other intervention currently being used and considered to be of proven effectiveness on the basis of past studies.

Social Worker: Provides assistance with resources such as housing, school and financial issues. Provides family or individual support and counseling.

SQ (Subcutaneous Injection): A route of administration of medications given into the fatty tissue under the skin.

Support Staff: Schedules appointments. Answers the telephone and accesses members of the Health Team. Organizes your medical records.

Tissue Typing: A series of tests done to determine how closely the tissues of a donor and the recipient (patient) match.

Tumor: An abnormal lump or mass of tissue. Tumors are either benign or malignant.

Total Parenteral Nutrition (TPN): A form of nutritional support given intravenously (IV). Hyperalimentation.

Upper Respiratory Infection (UTI): An infection in the respiratory system caused by a virus. It can affect nose, throat, sinuses and ears. Symptoms include: sore throat, sneezing, runny nose, nasal congestion cough, watery eyes and headache.

UTI (Urinary Tract Infection): An infection in the urinary tract. You may have a UTI if you notice pain or burning when you use the bathroom, fever, tiredness or shakiness, an urge to use the bathroom often, pressure in your lower belly, urine that smells bad or looks cloudy or reddish, and less frequently, nausea or back pain.

Volunteer: Provides a variety of practical and social services.

White Blood Cells (WBC): A type of blood cell, the leukocyte, that helps fight infection.
Patient Rights and Responsibilities

The SCCA respects the rights of all our patients equally and individually. Seattle Cancer Care Alliance (Fred Hutchinson Cancer Research Center, UW Medicine, and Seattle Children’s) was formed to provide state-of-the-art, patient-focused cancer care, support the conduct of cancer clinical research and education, enhance access to improved cancer interventions, and advance the standard of cancer care, regionally and beyond. Seattle Cancer Care Alliance (SCCA) staff is committed to work as a team that includes you, as a patient and your family members. SCCA respects the rights of all our patients equally and individually. The SCCA does not discriminate against any patient or patient’s family member on the basis of race, color, religion, creed, national origin, sex, age, disability, marital or veteran status, sexual orientation, gender identity. If you feel you experienced discrimination as a patient at SCCA, please contact SCCA Patient Relations at (206) 288-1056.

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

- Reasonable access to medical care within the capability of our mission, purpose, and principles, and in compliance with the appropriate laws and regulations;
- Medical care guided by the best medical practice;
- Confidentiality regarding your care and medical records;
- Understand how SCCA uses and discloses your health information (“Notice of Privacy Practices”);
- Access your medical records (upon request) and an explanation of this information as necessary, except when doing so is restricted by law;
- Receive information in a manner that you can understand;
- Access interpreter services if you are non-English speaking or with vision, speech, hearing, or cognitive impairment;
- Voluntary participation in all medical research studies;
- Care that is respectful of your cultural, psychosocial, and spiritual preferences;
- Care that supports privacy, personal dignity, and individual needs;
- Delivery of care that is free from mental, physical, sexual, or verbal abuse, neglect, or exploitation;
- Security and protection of your physical person and rights;
- Priority of medical needs over the objectives of any research study;
- Participate and make informed decisions in all aspects of your care;
- Open discussions about your care;
- Refuse treatment or services to the extent permitted by law, and be informed of the potential consequences of such an action;
- Treatment that does not prolong suffering, if your medical condition reaches a point where recovery is not realistically possible;
- End-of-life care that maximizes comfort, dignity, and quality of life as defined by you and your family;
- Appropriate assessment and management of pain;
- Be informed of options for ongoing medical care if 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:
- for care, treatment or services (including discharge or transfer);
- Inspect and clarify your billing statements.
- 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) 288-1056.

**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) 288-1056. 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.qualishealthmedicare.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) 288-1056, 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.
Clinic Directory

1st Floor
Blood Draw
Guest Services
Rain or Shine Gift Shop
Main Reception
Patient & Family Office
Patient Finance & Registration
Radiation Oncology
Sanctuary
Security

2nd Floor
Medical Imaging
Pulmonary Function Lab
Red Brick Bistro – Cafeteria
Procedure Suite

3rd Floor
Survivorship Clinic
Resource Center & Navigator
Women’s Center

4th Floor
General Oncology Clinics
Physical Therapy

5th Floor
Apheresis
Infusion
Pharmacy
Playroom
Supply Center

6th Floor
Oral Medicine Service
Transplant Clinic
Driving Directions To and From SCCA

**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”)

To Seattle Children’s from SCCA:
1. Travel north on Fairview Ave N or Eastlake Ave E (street becomes Eastlake Ave E)
2. Cross the University Bridge
3. Continue North on 11th Ave NE
4. Turn Right at 45th Ave NE
5. Turn Left at Sand Point Way NE
6. Follow signs for Seattle Children’s Hospital

SCCA Clinic
825 Eastlake Avenue East
Seattle, WA 98109-1023
(206) 288-7222
Parking at SCCA is $4.00 with validation

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

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

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.
## Conversion Chart for Temperature Taken By Mouth

<table>
<thead>
<tr>
<th>°F</th>
<th>°C</th>
<th>What to do:</th>
</tr>
</thead>
<tbody>
<tr>
<td>96.8</td>
<td>36.0</td>
<td>This is “normal” temperature range. CALL DOCTOR for shaking chills.</td>
</tr>
<tr>
<td>97.8</td>
<td>36.6</td>
<td></td>
</tr>
<tr>
<td>98.0</td>
<td>36.7</td>
<td></td>
</tr>
<tr>
<td>98.2</td>
<td>36.8</td>
<td></td>
</tr>
<tr>
<td>98.4</td>
<td>36.9</td>
<td></td>
</tr>
<tr>
<td>98.6</td>
<td>37.0</td>
<td></td>
</tr>
<tr>
<td>98.8</td>
<td>37.1</td>
<td></td>
</tr>
<tr>
<td>99.0</td>
<td>37.2</td>
<td></td>
</tr>
<tr>
<td>99.2</td>
<td>37.3</td>
<td></td>
</tr>
<tr>
<td>99.4</td>
<td>37.4</td>
<td></td>
</tr>
<tr>
<td>99.6</td>
<td>37.6</td>
<td></td>
</tr>
<tr>
<td>99.8</td>
<td>37.7</td>
<td></td>
</tr>
<tr>
<td>100.0</td>
<td>37.8</td>
<td></td>
</tr>
<tr>
<td>100.2</td>
<td>37.9</td>
<td></td>
</tr>
<tr>
<td>100.3</td>
<td>37.9</td>
<td></td>
</tr>
<tr>
<td>100.4</td>
<td>38.0</td>
<td></td>
</tr>
<tr>
<td>100.6</td>
<td>38.1</td>
<td>Do not take Tylenol®. Re-check in 30-60 minutes for a temperature in this range taken by mouth. CALL DOCTOR for shaking chills.</td>
</tr>
<tr>
<td>100.8</td>
<td>38.2</td>
<td></td>
</tr>
<tr>
<td>101.0</td>
<td>38.3</td>
<td></td>
</tr>
<tr>
<td>101.2</td>
<td>38.4</td>
<td></td>
</tr>
<tr>
<td>101.4</td>
<td>38.6</td>
<td></td>
</tr>
<tr>
<td>101.6</td>
<td>38.7</td>
<td></td>
</tr>
<tr>
<td>101.8</td>
<td>38.8</td>
<td></td>
</tr>
<tr>
<td>102.0</td>
<td>38.9</td>
<td></td>
</tr>
<tr>
<td>102.2</td>
<td>39.0</td>
<td></td>
</tr>
<tr>
<td>102.4</td>
<td>39.1</td>
<td></td>
</tr>
<tr>
<td>102.6</td>
<td>39.2</td>
<td></td>
</tr>
<tr>
<td>102.8</td>
<td>39.3</td>
<td></td>
</tr>
<tr>
<td>103.0</td>
<td>39.4</td>
<td></td>
</tr>
<tr>
<td>103.2</td>
<td>39.6</td>
<td></td>
</tr>
<tr>
<td>103.4</td>
<td>39.7</td>
<td></td>
</tr>
<tr>
<td>103.6</td>
<td>39.8</td>
<td></td>
</tr>
<tr>
<td>103.8</td>
<td>39.9</td>
<td></td>
</tr>
<tr>
<td>104.0</td>
<td>40.0</td>
<td></td>
</tr>
<tr>
<td>104.2</td>
<td>40.1</td>
<td></td>
</tr>
<tr>
<td>104.4</td>
<td>40.2</td>
<td></td>
</tr>
<tr>
<td>104.6</td>
<td>40.3</td>
<td></td>
</tr>
<tr>
<td>104.8</td>
<td>40.4</td>
<td></td>
</tr>
<tr>
<td>105.0</td>
<td>40.5</td>
<td></td>
</tr>
<tr>
<td>105.2</td>
<td>40.6</td>
<td></td>
</tr>
<tr>
<td>105.4</td>
<td>40.7</td>
<td></td>
</tr>
<tr>
<td>105.6</td>
<td>40.8</td>
<td></td>
</tr>
<tr>
<td>105.8</td>
<td>40.9</td>
<td></td>
</tr>
<tr>
<td>106.0</td>
<td>41.0</td>
<td></td>
</tr>
<tr>
<td>106.2</td>
<td>41.1</td>
<td></td>
</tr>
<tr>
<td>106.4</td>
<td>41.2</td>
<td></td>
</tr>
<tr>
<td>106.6</td>
<td>41.3</td>
<td></td>
</tr>
<tr>
<td>106.8</td>
<td>41.4</td>
<td></td>
</tr>
<tr>
<td>107.0</td>
<td>41.5</td>
<td></td>
</tr>
<tr>
<td>107.2</td>
<td>41.6</td>
<td></td>
</tr>
<tr>
<td>107.4</td>
<td>41.7</td>
<td></td>
</tr>
<tr>
<td>107.6</td>
<td>41.8</td>
<td></td>
</tr>
<tr>
<td>107.8</td>
<td>41.9</td>
<td></td>
</tr>
<tr>
<td>108.0</td>
<td>42.0</td>
<td></td>
</tr>
<tr>
<td>108.2</td>
<td>42.1</td>
<td></td>
</tr>
<tr>
<td>108.4</td>
<td>42.2</td>
<td></td>
</tr>
<tr>
<td>108.6</td>
<td>42.3</td>
<td></td>
</tr>
<tr>
<td>108.8</td>
<td>42.4</td>
<td></td>
</tr>
<tr>
<td>109.0</td>
<td>42.5</td>
<td></td>
</tr>
<tr>
<td>109.2</td>
<td>42.6</td>
<td></td>
</tr>
<tr>
<td>109.4</td>
<td>42.7</td>
<td></td>
</tr>
<tr>
<td>109.6</td>
<td>42.8</td>
<td></td>
</tr>
<tr>
<td>109.8</td>
<td>42.9</td>
<td></td>
</tr>
<tr>
<td>110.0</td>
<td>43.0</td>
<td></td>
</tr>
</tbody>
</table>

CALL DOCTOR for a temperature greater than or equal to 38.3°C or 100.9°F.
Suggested Medication Schedule

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

<table>
<thead>
<tr>
<th>Medication</th>
<th>Dosage Directions</th>
<th>6a</th>
<th>7a</th>
<th>8a</th>
<th>9a</th>
<th>10a</th>
<th>11a</th>
<th>12p</th>
<th>1p</th>
<th>2p</th>
<th>3p</th>
<th>4p</th>
<th>5p</th>
<th>6p</th>
<th>7p</th>
<th>8p</th>
<th>9p</th>
<th>10p-12a</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>