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Welcome to Seattle Cancer Care Alliance

A diagnosis of cancer can be overwhelming. We created this manual to help guide you, and your family and friends through your diagnosis and treatment. If you have questions about the information in the manual, please contact your care team.

We invite you to visit the Patient and Family Resource Center on the third floor of the Seattle Cancer Care Alliance (SCCA) clinic for:

- information on different types of cancer, support and survivorship
- a lending library
- a business center with computer workstations, printer/copier, and fax machine
- iPads for check-out within the clinic
- notary services
- wig fittings
- calendar of events
- community resources

The Resource Center is located on the 3rd floor and is staffed Monday through Friday from 8 am to 4:30 pm. It is open 24 hours a day, 7 days a week.

If you would like to read this patient care manual online or download a copy, please visit seattlecca.org/patient-education and click on documents. You can also access videos, a calendar of classes and events, and other helpful information on this page.

Sincerely,

SCCA Patient and Family Education
patienteducation@seattlecca.org
Chapter One: Getting Started

“A diagnosis of cancer caused my world to stop.”
Important phone numbers

How to contact your care team
For scheduling concerns and questions, call your team coordinator (also called your scheduler)

Team coordinator name: ________________________________

Phone number: ________________________________

For questions about your treatment, symptoms and prescription needs, call your clinical nurse coordinator (CNC)

CNC name: ________________________________

Your physician’s name is ________________________________

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<tr>
<th>Clinic phone numbers</th>
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<tr>
<td><strong>Hours</strong></td>
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<tr>
<td>8 am-10 pm, Mon.-Fri.</td>
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<td>8 am- 6 pm, Sat, Sun</td>
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<td>8 am-5 pm, Holidays</td>
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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 (seattlecca.org) for any announcements about operational hours. If you are unable to travel, please call your scheduler to reschedule your appointment.

Other important numbers
- Apheresis (206) 606-2120
- Guest Services (206) 606-6701
- Infusion (206) 606-7500
- Institutional Review Office (206) 667-6567
- Interpreter Access Line (855) 670-9798
- Living Tobacco-Free (206) 606-7766
- Medical Nutrition Therapy (206) 606-1148
- Medical Records (206) 606-1114
Resources

Cancer Library, University of Washington Medical Center (UWMC)
Volunteers also assist patients’ family members and friends in the Cancer Library, located on floor 8 SE of UWMC. The library has oncology-related books, videotapes, support resources and computers to access the Internet.

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.

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.

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 can help with taxis and shuttles. They are available to from 8 am to 4 pm Monday through Friday.

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

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 physician. 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 transplant manuals, chemotherapy cards, and symptom sheets. Visit seattlecca.org/patient-education to access videos and documents about cancer care and treatment and other helpful information.

Patient & Family Resource Center
The Patient and Family Resource Center is located on the 3rd floor of the clinic. It provides educational materials, computer workstations, a business center, notary, and a cancer lending library. We can provide wig fittings, listings for local and clinic events, and help locating support groups and other resources. 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.

The Gift Shop
Products at the Gift Shop, 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 through Friday from 8:30 am to 4 pm.

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

Social Work
Social Work services are available 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.

Spiritual Health
Chaplains provide respectful spiritual and emotional care for people of all faiths and spiritualties, including those that identify as non-religious or non-spiritual. Spiritual Health 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.

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 Services’ provider. Appointments can usually be scheduled within 1 to 2 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.
Suggested questions for your care team

We know you have a lot on your mind. We put together this list of questions you can ask your care team to help you learn more about your diagnosis and treatment.

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?
Family Medical Leave Act (FMLA)

In the event you need to take time off work, below is a list of steps to start the process.

1. Obtain any forms needed for medical leave from your employer or the employer of your caregiver (your company’s human resource’s department should have these forms).
2. Fill out the forms
3. Complete the bottom section of this page and attach it to your FMLA/disability paperwork.
4. Bring the forms and/or any disability, FMLA or other paperwork needed for medical leave to your next appointment.
   - If you are unable to bring these forms to an appointment, please fax your nurse at ______________________ at least 1 week before the paperwork is due. You will be contacted if a phone consult or visit is needed.
5. SCCA will return the forms to your employer and mail you a copy within 1 week.

Your information
Patient’s name: ____________________________
Please confirm your mailing address:

__________________________________________
__________________________________________
__________________________________________

Caregiver’s name ___________________________

Physician’s name: ___________________________

Date forms needed by: _______________________

Employer information
Employer: ____________________________
Main contact: ___________________________
Contact’s phone: ___________________________
Contact’s fax: ___________________________

Employer’s mailing address:

__________________________________________
__________________________________________
__________________________________________

Employee reference or case # (if known):

__________________________________________

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

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

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

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

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

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

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

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

Get Palliative Care
www.getpalliativecare.org

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

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

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.nfcacares.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/supportprogramservices/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

Travelers with disabilities and medical conditions
Transportation Security Administrations
www.tsa.gov/travelers/airtravel/specialneeds/editorial_1059.shtm

Prevention and Cessation of Cigarette Smoking: Control of Tobacco Use

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

Disease-specific websites
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
<table>
<thead>
<tr>
<th>Organization</th>
<th>Phone Number</th>
<th>Website Link</th>
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<tbody>
<tr>
<td>Lung Cancer Alliance</td>
<td>1 (800) 298-2436</td>
<td><a href="http://www.lungcanceralliance.org">www.lungcanceralliance.org</a></td>
</tr>
<tr>
<td>The Skin Cancer Foundation (melanoma)</td>
<td>1 (800) 754-6490</td>
<td><a href="http://www.skincancer.org">www.skincancer.org</a></td>
</tr>
<tr>
<td>International Myeloma Foundation</td>
<td>1 (800) 452-2873</td>
<td><a href="http://www.myeloma.org">www.myeloma.org</a></td>
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<tr>
<td>Multiple Myeloma Research Foundation</td>
<td>1(203) 229-0464</td>
<td><a href="http://www.multiplemyeloma.org">www.multiplemyeloma.org</a></td>
</tr>
<tr>
<td>Support for People with Oral and Head and Neck Cancer</td>
<td>1(800) 377-0928</td>
<td><a href="http://www.spohnc.org">www.spohnc.org</a></td>
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<tr>
<td>National Ovarian Cancer Coalition</td>
<td>1 (888) OVARIAN</td>
<td>(or 1 (888) 682-7426)</td>
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<tr>
<td>Ovarian Cancer National Alliance</td>
<td>1 (866) 399-6262</td>
<td><a href="http://www.ovariancancer.org">www.ovariancancer.org</a></td>
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<tr>
<td>Pancreatic Cancer Action Network (PANCAN)</td>
<td>1 (877) 272-6226</td>
<td><a href="http://www.pancan.org">www.pancan.org</a></td>
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<td>Urology Health (prostate cancer)</td>
<td>1 (800)828-7866</td>
<td><a href="http://www.urologyhealth.org">www.urologyhealth.org</a></td>
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<tr>
<td>Prostate Cancer Foundation</td>
<td>1 (800)757-2873</td>
<td><a href="http://www.pcf.org">www.pcf.org</a></td>
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<tr>
<td>US TOO International (Support groups, info)</td>
<td>1 (800) 808-7866</td>
<td><a href="http://www.ustoo.com">www.ustoo.com</a></td>
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<tr>
<td>Sarcoma Alliance</td>
<td>1 (415) 381-7236</td>
<td><a href="http://www.sarcomaalliance.org">www.sarcomaalliance.org</a></td>
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<tr>
<td><strong>Other diseases</strong></td>
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<tr>
<td>Aplastic Anemia</td>
<td>1 (800) 747-2820</td>
<td><a href="http://www.aplastic.org">www.aplastic.org</a></td>
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<tr>
<td>Myelodysplastic Syndromes Foundation</td>
<td>1 (800) MDS-0839</td>
<td>(or 1 (800) 637-0839)</td>
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<td><strong>Skin cancer organizations</strong></td>
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<td><strong>International Myeloma Foundation</strong></td>
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<td>(or 1 (800) 637-0839)</td>
</tr>
</tbody>
</table>
Sickle Cell Disease Association of America, Inc
www.sicklecelldisease.org
1 (800) 421-8453

**Symptom management**
National Lymphedema Network
www.lymphnet.org
1 (800) 541-3259

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

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

**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
http://www.nccam.nih.gov
1 (888) 644-6226

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

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

American Cancer Society Complementary and Alternative Therapies
1 (800) 227-2345

**Support and networking for youth**
Planet Cancer
http://myplanet.planetcancer.org/

**Survivorship**
Livestrong Foundation
www.livestrong.org
1 (877) 236-8820
The National Coalition for Cancer Survivorship
www.canceradvocacy.org

Beyond the Cure
www.beyondthecure.org
Helping children cope when someone they love has cancer

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

Other recommended reading
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
Diagnostic imaging exams

Type of imaging exam

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

Prior to your exam day

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

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

At the clinic before your exam

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

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

Food and fluid restrictions

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

* Clear liquids are:

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

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

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

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

Scheduling

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

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

Preparing for the appointment

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

Before your mammogram exam,

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

→ Some women avoid having a mammogram because of anxiety or fear. Remember that having a mammogram is a way for you to stay healthy.

The mammogram can catch problems early, which often leads to a complete cure.
MRI screening form

Your physician has ordered an MRI exam for you.

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

→ Review complete “MRI Patient Screening Form” for additional conditions that may affect the exam.

- In most cases, surgical staples, clips, pins, and screws are not a risk during MRI if they have been in place for more than 4 to 6 weeks. If there is any question of metal fragments in the eye, an X-ray may be done to check for them.
- To prevent a delay or cancellation of your exam, if you have ANY of the following implanted devices, allergies or may be pregnant (see complete list below) please tell your team coordinator or call 206-606-1434 to review your eligibility for your exam.

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

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

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

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

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

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

Clinical missions
In choosing to come to 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 physician. You may be asked to return for a periodic check-up.

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

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

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

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

A medical researcher who has such an interest or relationship is required to disclose it. Institutions carefully review 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 Hutch**
Principal investigator for your study: ______________
SCCA Patient Relations Office: (206) 606-1056
Institutional Review Office: (206) 667-6567

**UW Medicine**
Principal investigator for your study: ______________
Human Subjects Division: (206) 543-0098
Office of Regulatory Guidance (Office of Research and Graduate Education): (206) 616-8222,
www.uwmedicine.org/research/regulatory-guidance/pages/default.aspx

**Seattle Children’s**
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 Two: Treatment

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

The goals of treatment are to: cure cancer, control cancer, ease cancer symptoms. Cancer treatment can include chemotherapy, biotherapy, radiation and/or surgery.

Chemotherapy
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 physician 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
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](http://www.cancer.gov/cancertopics/treatment/biologicaltherapy)

Radiation Therapy
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
Surgery is the use of an operation to remove the tumor or some portion of the tumor.

We encourage you to ask your care team about your treatment plan, side effects, and what to expect in the near and distant 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 care team informed regarding your questions and concerns. Ask questions and express your concerns all along the treatment journey. Your care team will help manage your treatment plan.
Websites
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 (NCI) website, cancer.gov, has helpful information about the disease you are dealing with. Below are specific pages from the NCI site:

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
Sarcoma: www.cancer.gov/cancertopics/types/soft-tissue-sarcoma
Eating Hints www.cancer.gov/cancertopics/coping/eatinghints
Taking Time www.cancer.gov/cancertopics/takingtime
Clinical Trials www.cancer.gov/clinicaltrials
Coping with Advance Cancer- eBook www.cancer.gov/cancertopics/cancerlibrary/ebooks/advancedcancer
Safe handling of chemotherapy at home

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

Storing your chemo
Below are some tips for storing chemotherapy safely:

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

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

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

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

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

- Put on 2 pairs of disposable gloves.
- Clamp the IV tubing.
- Turn off the pump if you’re using one.
Managing chemo spills, continued

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

Other instructions

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

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

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

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

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

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

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

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

What if I vomit into a basin?
It’s important for your caregiver to wear gloves when emptying and cleaning your basin. Your caregiver should rinse the basin with water after each use and wash it with soap and water at least once a day.

Is it safe to be sexually active during my treatment?
Please ask your care team this question, as this depends on the type of treatment you are on. Because traces of chemotherapy may be present in your vaginal fluid or semen for up to 48 hours after treatment, you made need to take special precautions.

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

Can I travel with my chemotherapy?
Traveling with chemo is usually fine but check with your care team or home infusion supplier to confirm it is OK. Some chemotherapy requires special storage, so you may need to make plans, such as traveling with a cooler. Regardless of how you travel (by plane, car, or another mode of transportation), always seal your chemotherapy drugs in leak-proof plastic bags.
Sources

Safe handling and Administration Considerations of Oral Anticancer Agents in the Clinical and Home Setting, Clinical Journal of Oncology Nursing, 2012, 16(6), pages 192-197. Joanne Lester, PhD, CRNP, AOCN


Safe Handling of Chemo at Home, 2018, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4324350

Safe Handling: Implementing Hazardous Drug Precautions. Clinical Journal of Oncology Nursing, 2012, 16(3) pages 251-254. Anne Marie Watson, RN, MPH, OCN, CHES, Susan Mason, RN, MSN, OCN, Michele Busshart, RN, OCN, Angela Spruill, RN, BSN, OCN, Summer Cheek, RN, BSN, OCN, Ashley Lane, RN, OCN, Kathy Sabo, RN, BSN, CPHON, ATC, and Amanda Taylor, RN, BSN, CPHON
Treatment in the SCCA clinic

Release of medical information
SCCA clinic medical information can be obtained from SCCA Health Information Management. You will be asked to sign an authorization form to release your personal health information. There is no charge for records released to you or your physician.

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 physician. Please contact your team nurse for more 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 OK. Make sure there is no decorative moss around silk flowers. Only artificial moss is allowed.

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
If you are admitted to the hospital, your care will either be provided at SCCA Hospital or a unit of University of Washington Medical Center (UWMC). Both are located at UWMC and provide the same high-level quality of care. The facilities are located 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 phone 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:

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

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 from the nurses station, to reduce your cost. All SCCA and 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 physician use this information to assess if you need additional IV fluid or nutrition support.

SCCA Hospital and UWMC smoking policy
SCCA Hospital and UWMC are committed to providing a non-smoking environment for all patients, visitors, and staff. Smoking is not allowed in any area of the hospital. Smokers must leave the premises to smoke.

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

- **Physical examinations:** The nurses and physicians will, 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 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 physician 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 and provide specific recommendations based on oral and/or gastrointestinal symptoms.

• **Rounds:** Every morning your physician 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 physician________________________________________________________

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 Three: Coping with Symptoms and Common Problems

“Knowing when and who to call for problems really helps.”
## Important phone numbers

<table>
<thead>
<tr>
<th>Hours</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><strong>8am-10pm, Monday-Friday</strong></td>
<td>(206) 606-7400</td>
<td>(206) 606-7300</td>
</tr>
<tr>
<td><strong>8am-6pm, Sat, Sun</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>8am-5pm, Holidays</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>10pm-8am, Monday-Friday</strong></td>
<td>(206) 598-6190</td>
<td>(206) 598-6190</td>
</tr>
<tr>
<td><strong>6pm-8am, Sat, Sun</strong></td>
<td>Ask for the fellow on-call</td>
<td>Ask for the resident on-call</td>
</tr>
<tr>
<td><strong>5pm-8am, Holidays</strong></td>
<td></td>
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</tbody>
</table>
Online resources to help with coping

National Cancer Institute
www.cancer.gov

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

For caregivers
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 physician 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
- Mouth pain/mucositis
- Nausea and vomiting
- Pain
- Peripheral neuropathy
- Sexuality
- Sleep disturbances
- White blood cells
Anemia

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

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

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

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

Information adapted from: Pharmacia and Upjohn Company
Anxiety

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

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

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

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

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

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

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

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

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

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

Important signs and symptoms
Report symptoms to a physician or nurse during clinic hours today.
- Little red or purple spots on the skin or in the mouth.
- New bruising.

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

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

Call for professional help when needed
• If a nosebleed doesn’t stop after 30 minutes of applying pressure, contact the 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, and puffy face—all of these can be distressing if you think of your body as being who you are. Fortunately, most of the side effects of therapy, which affect appearance and stamina, are temporary.

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

Just the facts
Dehydration means there is not enough fluid in your body. It occurs when there is not enough fluid intake or there is excessive fluid losses from diarrhea, vomiting, fevers and/or sweating. Dehydration can cause complications such as increased weakness, dizziness, rapid heartbeat, and confusion.

Your goals
- Fluid intake as recommended by your care team.
- 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 physician or nurse during clinic hours today.
- Decreased urination, dark urine, strong smelling urine.
- Increased weakness.
- Decrease in eating and drinking.
- New or increased vomiting.

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

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

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

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

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

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

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

Ask your physician, nurse, or social worker for a referral.
Diarrhea

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

Your goals
- Prevent dehydration.
- Prevent infection.
- Call for professional help when needed.

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

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

What you can do at home
Prevent dehydration:
- Drink fluids (in suggested amounts).
- Follow dietary recommendations. Note any food allergies or intolerances and discuss with the physician, nurse or dietitian.
- Prevent infection and irritation.
- Wash hands often with soap and warm water.
- Keep anal area clean with mild soap and water.
- Do not use ointment or creams on the anal area unless directed by the nurse/physician.
- Use white, non-perfumed toilet paper.

Call for professional help when needed
- Describe the type of diarrhea to health care staff by including frequency, consistency, color, and presence of cramping.
Exercise and blood value precautions

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

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

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

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

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

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

- If your hematocrit is less than 25% or your hemoglobin is less than 8.0, consultation with your medical provider or a physical therapist is necessary to determine safe exercise options.
Fall prevention

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

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

Your goals
- Prevent injury.
- Prevent permanent disability.
- Prevent death.

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

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

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

What you can do at the clinic
- **Wear safe shoes!** This is one of the most important things you can do to prevent falls while you are here. Our floors can be very slippery. Closed-toe, closed-heel shoes with non-skid soles are the best choice (like tennis shoes). Flip-flops or open sandals are very dangerous. It is OK with us if you put your shoes on our exam tables and beds so that your shoes are always on to keep you safe. We don’t want you to EVER walk around in your socks or with bare feet. Non-skid slippers are available if you forgot your good shoes. Please ask for a pair.
- **Ask for help.** It does not bother the staff for you to ask for help. Even if you get around at home by yourself, you might need extra help while you are in our clinic. We can help you get from one place to another in our clinic, or get on an exam table, or walk you to the bathroom.
- **Move around with care.** A lot of equipment here is on wheels. Be careful that you don’t lean on wheeled equipment for support. Wheelchairs are available to use in the clinic.
- **Get up slowly after treatments and procedures.** Wait to see if you feel dizzy or weak. You might need help from a staff person.
• **Use your assistive devices.** If you use a hearing aid, glasses, prosthesis or walker/cane, be sure to bring it to the clinic and use it while you are here.

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

**Call for professional help when needed**

- If you are groggy, dizzy, or feeling faint.
- If you fall, let staff know RIGHT AWAY by yelling or asking anyone around you to help.
- **Do not** attempt to get up alone. You might hurt yourself trying to get up.
- Think about the shoes you are wearing. Make sure you do not wear footwear that adds to your risk for falls such as slippery slippers, slippery socks, high heels, shoes without backs, or flip-flops. Wear sturdy, non-slip shoes such as tennis shoes. Wear them inside and outside the house. Avoid going barefoot, even inside the house.
- Move furniture so you have clear paths.
- Keep the floor, pathways, and stairs clear of objects. Remove things you can trip over (like paper, books, clothes, and shoes) from stairs and places where you walk.
- Never put small objects inside/outside your house, especially on the stairs.
- Fix loose or uneven steps inside and outside your house.
- Have sturdy handrails and lights in all stairwells/staircase areas. Make sure carpet on the stairs is attached firmly to every step.
- Consider using reflective tape at the top and bottom of stairs.
- Tape cords and wires to the floor/wall away from your path.
- Remove small throw rugs or use double-sided tape to keep the rugs from slipping.
- Enhance/add to the existing lighting in your home. As you get older, brighter lights will be needed to see well. Hang lightweight curtains or shades to reduce glare.
- Place a lamp next to your bed within easy reach and turn on the light when getting out of bed.
- Install nightlights all the way to the bathroom (bedroom, hallways, and bathroom).
- Put a non-slip mat in the bathtub and on shower floors.
- Consider installing a grab bar in the bathtub, shower, and near the toilet.
- If you have balance problems, consider using a shower seat or urinal for showering and dressing.
- Keep items that you use often in cabinets and on shelves that are within easy reach, without use of a step stool.
- Never stand on a chair.
- Get up slowly after sitting up or lying down.
- Consider painting doorsills and other flooring level changes a different color so you don’t trip.
- Review medications regularly with your physicians to identify medicines that cause sleepiness, dizziness, or confusion so you can be extra-safe after taking these medicines.
- Don’t drink alcohol if taking sedating medications.
- Talk to your physician about seeing a physical therapist for mobility aid and balance and strengthening. Practice approved exercises regularly to improve your strength, balance, and coordination.
- If you live alone, consider getting an emergency system that you can wear around your wrist or neck to alert help immediately if you fall.

**References:**

Fatigue

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

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

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

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

Important signs and symptoms
Report symptoms to a physician or nurse during clinic hours today.
- Fatigue is getting worse.
- Staying in bed all day.
- Other symptoms occur with increased fatigue.
- Increased weakness or exhaustion.
- Drowsiness or confusion.
- Loss of balance.
- Catching your breath.

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

- Rest between bathing, treatments, and exercise.
- Do things or be active only for a short time.
- Plan activities such as exercise, visits, or trips when feeling the most rested and energetic.
- Decide on the most important activities for the day. Be realistic.
- Regular exercise helps reduce fatigue; it sounds contradictory, but it helps.
- Eat snacks between meals to keep up energy.
- Plan 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 physician or nurse during clinic hours today:
- Any new redness or swelling on the skin or at an intravenous (IV) site.
- Cold symptoms (runny nose, stuffy nose, watery eyes, sneezing, coughing).
- New abdominal or back pain.
- Toothache.

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

What you can do at home
Prevent dryness and irritation:
• Before treatment, a pedicure is suggested if you have preexisting buildup of hard skin and calluses on your feet.
• Frequently apply ample moisturizer to hands and feet, especially in the creases. (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 physician suggests a steroid cream, apply it after the skin has been cooled and apply emollients over the top of the steroid cream for maximum effectiveness.
• If blistering and ulceration start, apply gentle moisturizers on your hands and feet and contact your physician or nurse who may suggest further therapies.
• Talk with your nurse about how to change your activities of daily living (bathing, dressing, etc.) if the HFS is severe.
• Contact your physician regarding other over the counter or prescription options to relieve symptoms of Hand-Foot Syndrome.
**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 physician 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 physician 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 physician.

- 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 physician immediately for prompt antibiotics if signs of infection occur. Consult your physician 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 physician.
- 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 physician 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 physician 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) 606-6373; www.seattlecca.org/physical-therapists.cfm

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

Image from *Anatomy of the lymph system*, Women to Women 2006
Memory and concentration

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

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

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

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

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

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

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

• **Puzzle Books**: Crossword puzzles are known to improve mental skills.
• **Sudoku**: Similar to a cross word puzzle, but with numbers instead.
• **Card Games**:
  o 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!
  o 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 CDs that you can purchase in various languages.
• **Read**: Join a book club or attend a book reading. A couple of suggestions include:
  o *The Better Brain Book* by David Perlmutter and Carol Colman
  o *Whole Brain Thinking* by Jacquelyn Wonder and Priscilla Donovan
  o *Carved in Sand* by Cathryn Jakobson Ramin (the story of her struggle with early onset memory loss).
• **Website**: [www.positscience.com/](http://www.positscience.com/) is a website where you can try out a couple of the exercises from their Brain Fitness Program. This program has been used to help veterans with traumatic brain injuries recover some of their capabilities.

Get professional help when needed
If problems persist or affect day-to-day living to a large degree, discuss the symptoms with your physician or nurse. Ask your physician or nurse about a neuropsychological referral and neuro-rehabilitation treatment.
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 physician or nurse during clinic hours today.
- White patches or sores appear on gums or mouth.
- Start to have difficulty eating or drinking.
- Increased sensitivity to foods or significant dryness.
What you can do at home
Prevent infection and irritation:
- Rinse mouth often with salt-water solution every 1-2 hours. Recipe: 1 quart water, ½ to ¾ level teaspoon salt. If the salt solution causes stinging or burning this may be relieved by diluting it or adding 1-2 teaspoons of baking soda. Rinsing with salt/soda solutions may also help reduce thickened secretions and should be done before eating, drinking or taking medications by mouth.
- Spit secretions out often and especially before eating, drinking or taking medications by mouth.
- Brush teeth twice a day with a very soft bristle toothbrush as long as you are able. If it becomes too painful or significant bleeding occurs, a child’s toothbrush or toothettes (sponge brushes) can be substituted. Resume using your normal toothbrush as soon as possible as it is more effective at keeping the bacteria under control and causes less trauma.
- Continue to floss daily as long as it is comfortable, and no significant bleeding occurs.
- Avoid using commercial mouthwashes. Many contain alcohol or peroxide, which can dry and irritate your gums and the tissue in your mouth.

Control pain
- Topical anesthetics such as lidocaine viscous gel can be used to help control pain. They can be used as a rinse or applied directly to localized areas of soreness. These are prescribed by the physician. They are jelly-like liquids which numb the mouth. These gels can be used full strength or diluted 1:1 or 1:2 if they cause stinging or burning. Fill a small container such as a medicine cup with the solution. Take a small amount (5-10 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 physician or nurse if pain medication does not seem to be controlling your pain.
- For chapped lips apply lanolin creams, Chapstick® or Blistex® and lip balms which contain lanolin.
- Place ice packs on painful areas such as cheeks, lips or throat for 10-15 minutes every 2 hours.
- Avoid pretzels, chips, tomato juice, and orange juice or hot drinks.
- All oral rinses can be kept in the refrigerator or placed in an ice bath. This can be soothing, help to reduce swelling or control bleeding.

Maintain adequate nutrition and fluid intake
- Warm fluids - try: soups, chicken or vegetable broth, tea.
- Cool fluids - try smoothies, shakes, iced tea, diluted juices.
Nausea and vomiting

Just the facts
Many patients experience nausea and vomiting at some time during the treatment process. It is one of the side effects of the chemotherapy and radiation.

Contrary to what most people think, nausea and vomiting have little to do with your stomach. They are actions controlled by certain centers in your brain and are involuntary. Willpower alone cannot stop nausea and vomiting.

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

Thankfully, just as medicine has advanced against cancer 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 physician 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 physician 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 physician, nurse or pharmacist.
- Do not take any over-the-counter medicines without checking first with your physician 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 physician 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 physician 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 physician or nurse know.
- Do not increase the amount of medicine you take without checking with the physician, nurse or pharmacist.
- Do not take any additional over the counter medications without checking first with your physician, 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 physician may ask a physician who specializes in cancer pain management to manage your pain.

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

Myths about narcotics/ opioids:
- Some people will think they will become addicted. Research has shown that this is not true. If your pain medication is used the way your physician 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 physician or nurse.
- Ask for pain relief when you first experience pain.
- Inform us if pain treatment is not working.
- Help us develop a treatment plan for you.

Your goals
- Report your pain.
- Rate your pain- keep track of what triggers it and what makes it better.
- Have pain treated promptly.
- Maintain optimal level of physical activity.

Assessment of your pain
Your physician or nurse will ask you to “rate” your pain using a simple method. Remember, only YOU know what and where your pain is, and YOU need to help us help you.

Your physician or nurse will ask you to “point” to the area of your pain. They will also ask you the following questions:
- What will cause the pain?
- What do you think will get rid of the pain?
- What is the quality of your pain? (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 physician may choose to prescribe Tylenol®, ibuprofen or narcotics/opioids such as morphine. Sometimes he/she may choose to use a local anesthetic. The method depends on the location and severity of your pain.

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

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

Some pain medications should be taken on a regular basis (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 physician.
- Keep a pain journal.
- Use hot or cold packs.
- Find a relaxation technique that works for you such as meditation, guided imagery, hypnosis, massage or therapeutic touch.
- Listen to relaxing music.
- Taking care of your pain will help you sleep better, feel stronger and be better able to cope with your illness.
- Continue activities that are meaningful to you. Such activities may help you notice less pain or discomfort.
- Before taking pain medication/opioids, ask your nurse or physician about ways to prevent constipation.
Peripheral neuropathy

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

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

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

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

Important signs and symptoms
Report symptoms to a physician or nurse during clinic hours today.
- Change in sensation symptoms: Numbness, tingling, tremor, burning, loss of sensation, gait imbalance (unstable walking), sensitivity to touch, weakness, tiredness and heaviness.
- Movement Symptoms: Lack of muscle control, falling, muscle twitching, cramping, foot drop, and muscle atrophy.
- Autonomic Symptoms: Failure of the nerves to work correctly can result in abnormal blood pressure and digestive problems such as nausea, blurred vision, and dizziness.
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 physician, nurse and physical therapist safety measures you should put in place.
- Avoid extreme temperatures. Peripheral neuropathy may make areas of your body more sensitive to hot or cold.
- Wear shoes, slippers, gloves, and other clothing to protect your skin from changes.
- Use extra care when using hot, sharp or potentially harmful objects. You may be more at risk for clumsiness and prone to injury if you have reduced sensations.
- Avoid falls - 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 physician will try to determine the source of the problem. Ask your physician 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
Sexual health

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

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

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

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

What you can do at home

Optimize positive feelings of intimacy:
- Plan sexual activity for the time of day when you are feeling your best. If you are taking pain medication, take it at an hour when it will be in full effect during sex.
- Talk about expectations and what might feel good, or what to avoid.
- Consider other forms of intimacy—holding hands, snuggling, kissing, self-stimulation and talking can happen at any stage of cancer treatment.
- Find a position or activity that puts as little pressure as possible on the sensitive or painful areas of your body.
- Empty your bladder before sexual activity.
- Let your partner know if any kinds of touching causes irritation or pain.
- Use a sexual lubricant to help dry skin areas be slippery.

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

Common questions about sex during chemotherapy

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

What are restrictions for sexual activity?
- When platelet counts are less than 50,000. This is due to the risk for bleeding.
- When white blood counts are low. Neutrophil (ANC) count should be more than 500 to prevent infection with most sexual activity. An ANC of 1,000 or more is needed for anal sex.
- Vaginal or rectal bleeding, sores in your mouth, vagina or rectum.
- If your partner has infections or open sores. Condoms are not always effective at preventing infections.

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

Will I be infertile after treatment?
- Factors that influence fertility include: type and dose of chemotherapy, radiation, and other medications; if you have had a transplant; and, your age at time of treatment.
- Women often stop having periods but resume their menstrual cycle after treatment; some women resume normal menstrual cycles but are still unable to become pregnant due to damage to eggs in the ovary; still, other women may experience complete menopause.
- Men often stop making sperm completely or have very low sperm counts during and for several months after cancer treatment. Not every male will resume normal sperm production and may be infertile.
- Testing of sex hormones, sperm counts, or ovarian function is needed to see if your fertility is intact.
- If you’re interested in preserving fertility, talk with your care team before treatment. This gives you the opportunity to store sperm, eggs, or embryos when appropriate.
- A fertility specialist (reproductive endocrinologist) can provide more information about your fertility status and the options available to you before and after treatment.
- Fertility services are not always covered by insurance, but financial assistance may be available. Don’t let fear of cost prevent you from asking what services are possible.
What options do I have to store my eggs or sperm?

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

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

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


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

**American Cancer Society**
www.cancer.org

**LIVESTRONG**
www.livestrong.com/sscat/sexual-health/
www.livestrong.com/we-can-help/livestrong-fertility

**Look Good Feel Better**
www.lookgoodfeelbetter.org

**Save My Fertility & The Oncofertility Consortium**
savemyfertility.com
www.oncofertility.northwestern.edu/
Fertility resources before and after treatment

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

**University of Washington Sperm Cryopreservation Program**
(877) 520-5000
www.uwmedicine.org/locations/mens-health-center/male-fertility-lab-(mfl)

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

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

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

Emergency signs and symptoms
Call 911 IMMEDIATELY if:
- Patient is unconscious.
- Urgent Signs and Symptoms:
- Call the clinic or the after-hours number NOW if:
  - Have not slept in days.
  - Talk to your Social Work, Psychology, or Psychiatry if you have symptoms of anxiety and depression.
  - Talk to your physician 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 physician 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 physician or nurse for advice before you self-treat.
- Check with your physician or nurse regarding dental work.

Information adapted from: Pharmacia and Upjohn Company
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! You, and your caregiver, family members, friends, nurses, and physicians.

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

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

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

All hematopoietic cell transplant patients are recommended to follow the “Immunosuppressed Patient Diet”. In addition, it is recommended that all patients follow the food safety guidelines discussed below. If you have any questions regarding food safety and diet guidelines, talk to your dietitian.

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

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

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

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

Overview

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

Cutting boards

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

Grocery store

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

Home

- Wash the tops of canned foods before opening. Clean the can opener after each use.
- Throw away eggs with cracked shells.
- Throw away foods older than their “use by” expiration dates.
- Throw away entire food packages or containers with any mold present, including yogurt, cheese, cottage cheese, fruits (especially berries), vegetables, jelly, bread, cereal and pastry products.
Fruit and vegetable handling

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

Use the following guidelines for handling all raw produce, including organic, organically grown, “natural” and general produce:

- Refrigerate fruits and vegetables promptly.
- Do not purchase produce that has been cut at the grocery store (such as melon or cabbage halves). This is particularly true for produce that will not be cooked prior to eating.
- Rinse produce thoroughly under clean, running water just before use, including produce that is to be peeled (such as bananas, melons and oranges) or cooked. Do not wash fruits and vegetables with soaps, detergents or chlorine bleach solutions. Produce can absorb these cleaning agents.
- Commercial produce rinses (such as Fit® Fruit and Vegetable Spray) are not recommended since they have not been shown to be more effective for removing bacteria off the produce than washing under running water.
- Scrub produce that has a thick, rough skin or rind (such as cantaloupe or potatoes) or has visible dirt on the surface using a clean vegetable scrubber.
- Rinse leaves of leafy vegetables (such as lettuce, spinach, cabbage) individually under running water.
- Packaged salads, slaw mixes and other prepared produce, even when marked pre-washed, should be rinsed again under running water; a salad spinner or colander can be used to make this easier. Check for “use by” dates.
- Do not eat any raw vegetable sprouts (avoid all types, including alfalfa sprouts, clover sprouts, mung bean sprouts, and so on) due to high risk of Salmonella and E. coli contamination. Cooked mung bean sprouts are acceptable.
- Throw away fruits and vegetables that are slimy or show mold.
- Review the processing procedure if preparing home-canned foods. Be sure the procedure is appropriate for the acidity of the food, size of the bottle, and elevation above sea level. Look for mold and leaks. Check seals. If you suspect a home-canned food may not have been properly processed (for example, if the lid bulges or if the food has any bad odor or unusual characteristics after opening), THROW IT AWAY. It is recommended to use home canned foods within one year of canning as chemical changes may occur.

Avoid cross contamination

- Use a clean knife for cutting different foods (for example, use different knives for cutting meat, produce and bread).
- During food preparation, do not taste the food with the same utensil used for stirring. Use a clean utensil each time you taste food while preparing or cooking.
- In the refrigerator, store raw meat separately from ready-to-eat foods.
- When grilling, always use a clean plate and utensils for the cooked meat.
Keep foods at safe temperatures

Proper thermometer use
• Test a thermometer’s accuracy by putting it into boiling water. It should read 212°F.
• Read the manufacturer’s instructions. Insert the meat thermometer into the middle of the thickest part of the food to test for doneness. The entire part of the stem, from the dimple to the tip, must be inserted into the food. For thin foods, insert the thermometer sideways.
• A refrigerator thermometer should be placed on a shelf toward the back of the refrigerator. It should read 40°F or less.

Refrigeration
• Keep the refrigerator temperature between 34°F to 40°F.
• Keep the freezer temperature below 0 to 2°F.
• Never leave perishable food out of the refrigerator for over two hours. Throw away food left out longer than two hours.
• Marinate foods in the refrigerator.
• Thaw foods in the refrigerator, never on the counter.
• Thaw meat, fish or poultry in the refrigerator away from raw fruits and vegetables and other prepared foods. Place on a dish to catch drips. Cook defrosted meat right away; do not refreeze. If you are in a hurry you can thaw meat in the microwave. The meat must be cooked immediately after thawing.
• Cool hot foods uncovered in shallow containers in the refrigerator. Cover storage containers after cooling. Make sure that covers seal tightly.
• Throw away all prepared food after 72 hours (3 days). Use labels or masking tape to write dates on containers.
• Freeze foods that will not be used within 2 to 3 days.
  • NEVER TASTE FOOD THAT LOOKS OR SMELLS STRANGE!

Cook foods adequately
• Cook meat until it is no longer pink, and the juices run clear. These are signs that the meat may be cooked to a high enough temperature. However, the only way to be sure that the meat has been cooked to the proper temperature is to use a food thermometer (See Table 1 on the next page).
• Thoroughly heat until steaming (165°F) all hot dogs and “ready to eat” luncheon meats, cold cuts and “deli-style” meats before eating.
• Do not eat raw, lightly cooked, or soft-boiled eggs.
• Do not eat uncooked foods containing raw or undercooked eggs, such as raw cookie dough, cake batter or salad dressings containing raw or coddled eggs.
• Pasteurized eggs and liquid pasteurized egg products (such as EggBeaters®) may be used in recipes calling for raw eggs in foods that will not be cooked.
• Hold food at safe temperatures: hot food above 140°F, cold food below 40°F.
Recommended minimum cooking temperatures

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

Microwave cooking

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

*Low white blood cell count refers to a neutrophil count less than 1000/mm³ or when chemotherapy is held due to low neutrophil count.

Dining out safely

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

Other foods

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

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

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

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

Examples of ways well water could become contaminated:
- construction occurs near the well
- well depth is shallow
- well is located near a dairy or large number of livestock
- flooding has recently occurred in the well area

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

Private and small community wells: The quality of well water from these sources cannot be guaranteed unless it is tested daily and found to be negative for coliforms and Cryptosporidium organisms. It is recommended that other approved water sources be used instead, including: boiled water or bottled water (see guidelines below).

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

Safe water sources
The following sources of water are suggested if your water is not from a city water or municipal well supply:

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

Distilled water
Water may be distilled using a steam distillation system. After processing, the water should be stored in a clean, covered container in the refrigerator; discard water not used within 72 hours (3 days).
**Bottled water**
Acceptable forms of bottled water have been processed to remove organisms known to cause stomach or intestinal infection. Bottled water labels reading “well water”, “artesian well water”, “spring water”, or “mineral water” do not guarantee that the water is safe to drink. Water labeled as having been treated with one or more of the following are considered safe:

- Reverse osmosis treated
- Distillation
- Filtered through an absolute 1 micron or smaller filter (NSF Standard #53 for cyst removal)

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

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

**Water filters**

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

a. The filters must be designed to remove coliforms and *Cryptosporidium*. Any of the following are acceptable:
   - Reverse osmosis filter
   - Absolute pore size of filter 1 micron or smaller
   - Tested and certified by NSF Standard #53 for cyst removal
b. The water tap filter must be installed immediately before the water tap
c. Manufacturer directions must be followed for filter maintenance and replacement

Portable water filters (such as a Brita® or Pur® system) as well as refrigerator-dispensed water and ice machine systems do not meet filtration standards. Portable water systems filter out chemical impurities, not bacteria. If a portable water system (such as a Brita® pitcher) is used in combination with a safe water supply (to improve water flavor and remove chlorine and other impurities), it is recommended to change the system’s filters frequently according to manufacturer’s guidelines.

For a list of approved filtration systems, call the *National Sanitation Foundation International*, at 1-800-673-8010 or visit their home page at [www.NSF.org](http://www.NSF.org) (go to the section entitled “Home Water Treatment Devices”).
Diet guidelines for immunosuppressed patients

Overview

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

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

- **For autologous transplant patients undergoing chemotherapy treatment only:** follow this diet during the first three months after chemotherapy or transplant.
- **For allogeneic transplant patients:** follow the diet until you are off all immunosuppressive therapy such as cyclosporine, prednisone, Tacrolimus®, Myfortic®, sirolimus, or MMF.

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

### Food groups

<table>
<thead>
<tr>
<th>Food groups</th>
<th>May eat</th>
<th>Do not eat</th>
</tr>
</thead>
</table>
| **Dairy**   | - All pasteurized, grade “A” milk and milk products including eggnog, yogurt, ice cream, frozen yogurt, sherbet, ice cream bars, milkshakes, processed cheese slices and spreads, cream cheese, cottage cheese and ricotta cheese  
- Dry, refrigerated, or frozen pasteurized whipped topping  
- Commercially packaged hard and semi-soft cheeses such as cheddar, mozzarella, parmesan, Swiss, Monterey Jack, etc.  
- Cooked and pasteurized soft cheeses such as brie, goat, camembert, feta, farmer’s cheese. Though not completely risk free, the risk of contracting food borne illness from COOKED soft cheeses is low.  
- Mexican-style soft cheese such as queso fresco, queso blanco (Unless made with pasteurized milk and cooked)  
- Commercially sterile ready-to-feed and liquid-concentrate infant formulas (avoid powdered infant formulas if a ready-to-feed or liquid concentrate alternative is available) | - Non-pasteurized or raw milk and milk products made from non-pasteurized or raw milk.  
- Cheeses from delicatessens  
- Cheese containing chili peppers or other uncooked vegetables  
- Cheeses with molds (such as blue, Stilton, Roquefort, gorgonzola) |
## Meat and meat Substitutes

- All meats cooked to well done (see temperature guide attached) or canned meats (beef, pork, lamb, poultry, fish, shellfish, game, ham, bacon, sausage, hot dogs)
- Eggs cooked until both white and yolk are firm
- Pasteurized eggs and egg substitutes (such as Egg Beaters®), and powdered egg white (all can be used uncooked)
- Commercially-packaged salami, bologna, hot dogs, ham and other luncheon meats, heated until steaming
- Canned and shelf-stable\(^1\) smoked fish (refrigerate after opening)
- Pasteurized or cooked tofu\(^2\)
- Refrigerated smoked seafood such as salmon or trout if cooked to 160°F or contained in a cooked dish or casserole
- Raw or undercooked meat, poultry, fish, game, tofu\(^2\)
- Raw or undercooked eggs and non-pasteurized egg substitutes; no eggs over easy, soft-boiled eggs, or poached eggs.
- Meats and cold cuts from delicatessens
- Hard cured salami in natural wrap
- Uncooked refrigerated smoked, seafood such as salmon or trout labeled as “nova-style,” “lox,” “kippered,” “smoked” or “jerky”
- Pickled fish
- Tempe (tempeh) products

## Fruits and nuts

- Well washed\(^3\) raw and frozen fruit; foods containing well washed raw fruits
- Cooked, canned and frozen fruit
- Pasteurized juices and frozen juice concentrates
- Dried fruits
- Canned or bottled roasted nuts
- Shelled, roasted nuts and nuts in baked products
- Commercially-packaged nut butters (such as peanut butter, almond butter, soybean butter)
- Unwashed raw fruits
- Unroasted raw nuts
- Roasted nuts in the shell
- Non-pasteurized fruit and vegetable juices
- Fresh fruit salsa found in the grocery refrigerator case
- Non-pasteurized items containing raw fruits found in the grocery refrigerator case

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

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

\(^3\) Rinse under clean, running water before use, including produce that is to be cooked or peeled (such as bananas, oranges and melon).
<table>
<thead>
<tr>
<th>Entrees, soups</th>
<th>• All cooked entrees and soups</th>
<th>• All miso products (such as miso soup and miso paste)</th>
</tr>
</thead>
</table>
| Vegetables     | • Well washed³ raw and frozen vegetables  
• All cooked fresh, frozen or canned vegetables, including potatoes  
• Shelf-stable¹ bottled salsa (refrigerate after opening)  
• Cooked vegetable sprouts (such as mung bean sprouts)  
• Fresh, well washed³ herbs and dried herbs and spices (added to raw or cooked foods) | • Unwashed raw vegetables or herbs  
• Fermented vegetables such as kimchi or sauerkraut  
• Fresh, non-pasteurized vegetable salsa found in the grocery refrigerator case  
• Non-pasteurized items containing raw vegetables found in the grocery refrigerator case  
• All raw vegetable sprouts (alfalfa sprouts, clover sprouts, mung bean sprouts, all others)  
• Salads from delicatessens and restaurants |
| Bread, grain, and cereal products | • All breads, bagels, rolls, English muffins, muffins, pancakes, sweet rolls, waffles, French toast  
• Potato chips, corn chips, tortilla chips, pretzels, popcorn  
• Cooked grains and grain products, including pasta and rice  
• All cereals, cooked and ready-to-eat | • Raw (not baked or cooked) grain products (such as raw oats) |
| Beverages      | • Boiled well water⁴  
• Tap water and ice made from tap water⁵  
• Commercially-bottled distilled, spring and natural waters⁶  
• All canned, bottled and powdered beverages  
• Instant and brewed coffee and tea; cold brewed tea made with boiling water  
• Herbal teas brewed from commercially-bottled water | • Unboiled well water  
• Cold-brewed tea made with warm or cold water  
• Non-pasteurized fruit and vegetable juices  
• Mate´ tea  
• Kombucha  
• Wine, unpasteurized beer |

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

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

⁶ See Water Safety Guidelines in “Food Safety Guidelines” for approved bottled water treatments.
### Packaged Tea Bags
- Commercial nutritional supplements, both liquid and powdered
- Commercially sterile ready-to-feed and liquid-concentration infant formulas (avoid powdered infant formulas if a ready-to-feed or liquid concentrate alternative is available)

### Note
(Note: All alcoholic beverages should only be consumed following health care provider approval)

### Desserts
- Refrigerated commercial and homemade cakes, pies, pastries and pudding
- Refrigerated cream-filled pastries
- Cookies, both homemade and commercially prepared
- Shelf-stable<sup>3</sup> cream-filled cupcakes (such as Twinkies®, Ding Dongs®) and fruit pies (such as Poptarts® and Hostess® fruit pies)
- Canned and refrigerated puddings
- Ices, popsicles and similar products
- Candy, gum

### Fats
- Vegetable oils and shortening
- Refrigerated lard, margarine, butter
- Commercial, shelf-stable<sup>3</sup> mayonnaise and salad dressings including Blue Cheese and other cheese-based salad dressings (refrigerate after opening)
- Cooked gravy and sauces

### Other
- Commercial pasteurized Grade A honey<sup>7</sup>
- Salt, granulated sugar, brown sugar
- Jam, jelly, syrups (refrigerate after opening)
- Catsup, mustard, BBQ sauce, soy sauce, other condiments (refrigerate after opening)
- Pickles, pickle relish, olives (refrigerate after opening)
- Vinegar

- Raw honey; honey in the comb
- Herbal and nutrient supplement preparations (refer to Guidelines for Use of Herbal and Nutrient Supplements in Patient & Caregiver Resource Manual)
- Brewer’s yeast, if uncooked

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

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This education resource was intended to be given as a part of a nutrition consult by an SCCA dietitian. Questions? Ask an SCCA dietitian at nutrition@seattlecca.org
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 physician 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 physician 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 physician 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 physician 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 physician. Such patients should be under the care of a naturopathic physician (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 physician, 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 physician 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 Four: Life after Cancer

“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) 606-1024.

The Washington Department of Health has a Survivorship Care Plan, Life’s Transition handout at the link listed below:
Chapter Five: Terms and Practical 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 physicians, 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 care 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).

**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

SCCA respects the rights of all our patients equally and individually.
Seattle Cancer Care Alliance (Fred Hutch, Seattle Children’s and UW Medicine) 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. SCCA does not discriminate against any patient or patient’s family member on the basis of race, color, religion, creed, national origin, sex, age, disability, marital or veteran status, sexual orientation, gender identity. If you feel you experienced discrimination as a patient at SCCA, please contact SCCA Patient Relations at (206) 606-1056.

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) 606-1056.

**Patient responsibilities**
As a patient at SCCA, you share in the responsibility for your care. You have the responsibility to:
• Participate in decisions involving your care;
• Provide complete information about your health, symptoms, and medications;
• Ask your provider questions when you do not understand the planned treatment, care or what is expected of you;
• Follow the treatment plan, which you and your provider have agreed upon;
• Keep appointments or let us know if you cannot make them;
• Take responsibility for the outcomes if you do not follow the treatment plan;
• Be considerate of the rights of other patients, personnel, and property;
• Follow SCCA rules and regulations;
• Provide accurate and timely information about sources of payment and your ability to meet financial obligations;
• Promptly meet any financial obligation agreed to with SCCA;
Let your providers know if you have concerns or complaints about any aspect of your care. SCCA encourages you, the patient, to talk with your healthcare team initially. Your nurse or social worker can be an advocate for you. If this course of action does not meet your needs, we encourage you to speak with Patient Relations at (206) 606-1056. You may also make complaints to the Washington State Department of Health at 1-800-633-6828 or to the Joint Commission by calling 1-800-994-6610, or on-line at www.jointcommission.org or e-mailing your concerns to complaint@jointcommission.org. Medicare and Medicaid patients may also make complaints to Livanta LLC BFCC-QIO Program, 9090 Junction Drive, Suite 10, Annapolis Junction, MD 20701. Phone: 1-877-588-1123, Fax (appeals): 1-855-694-2929, Fax (all other types): 1-844-420-6672

**Personal valuables**
SCCA (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, Spiritual Health, auditing purposes, research studies (aggregate data), and emergencies. We may provide information limited to your name and general health condition [i.e., “critical”, “poor”, “fair”, “good”, “excellent” or similar statements]. We must provide information when required by law, such as for law enforcement activities in specific circumstances. In any other situation, we will ask for your written authorization before using or disclosing any identifiable health information about you. If you choose to sign an authorization to disclose information, you can revoke that authorization at a later time to stop any future use and disclosure. We may change our policies at any time but with any significant policy change the new notice will be changed and posted. You may request a copy of this notice from the SCCA Health Information Management Department.

**Individual rights:** In most cases, you have the right to look at or order a copy of your health information. You also have the right to receive a list of instances where we have disclosed information for reasons other than treatment, payment or related administrative purposes.
If you believe that information in your record is incorrect or if important information is missing, you have the right to request that we correct the existing information or add the missing information. Contact the Director of Health Information Management.

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

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

Our legal duty: We are required by law to protect the privacy of your information, provide this notice about our information practices, and follow the information practices that are described in this notice.
Clinic directory

1st floor
Blood Draw
Guest Services
The 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
Immunotherapy
Parking
You may park in the SCCA parking garage. The parking fee is no more than $4 per day with ticket validation. Parking fees will be prorated for shorter visit times at the clinic. The parking garage is open Monday through Friday from 6:30am to 8pm and weekends/holidays from 6:30am-5pm. You must notify the attendant if your car is being left overnight. The height limit in the garage is 6'7”.

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

There is limited metered street parking near all buildings.

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

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

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

To UWMC Roosevelt, 4245 Roosevelt Way N.E.:
• From Interstate 5: Take the N.E. 45th St. exit and go east on N.E. 45th St. Turn right heading south on Roosevelt Way N.E. Go 2½ blocks. UWMC Roosevelt is on the right.
Questions?
Your questions are important. Ask your caregiver any questions you may have about the care you receive. If you have concerns, tell a staff member or call UWMC’s Patient Relations at (206) 598-8382. UWMC clinic staff is also available to help
Maps and directions

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

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

The SCCA and the University of Washington Medical Center garages (Surgery Pavilion and Triangle) offer same day reciprocal parking. Simply bring your receipt from a participating garage to your next appointment and it will be honored.

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

To UW Medical Center from SCCA:
1. Travel north on Fairview Ave N or Eastlake Ave E (street becomes Eastlake Ave E)
2. Cross the University Bridge
3. Turn Right at NE Campus Pkwy
4. Turn Right at Brooklyn Ave NE
5. Turn Left at NE Pacific St

To UWMC Surgical Pavilion: On Pacific Street, turn left at turning lane toward the Surgical Pavilion. Veer left into the Pavilion Parking Garage. Take garage elevator up to third floor (garage height restriction is 6’ 8”).

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

To UWMC Triangle Garage: Access from NE Pacific Place off of Pacific Street, across the street from the Medical Center via a pedestrian tunnel under NE Pacific (garage height restriction is 6’ 8”).
Fever and Temperature Conversion Chart – Oral (Taken by Mouth)

<table>
<thead>
<tr>
<th>°F</th>
<th>°C</th>
<th>Directions for oral temperature (taken by mouth)</th>
</tr>
</thead>
<tbody>
<tr>
<td>96.8</td>
<td>36.0</td>
<td></td>
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<td>97.8</td>
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<td>36.8</td>
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<tr>
<td>98.2</td>
<td>36.8</td>
<td>96.8 to 99.2°F (36.0 to 37.3°C)</td>
</tr>
<tr>
<td>98.4</td>
<td>36.9</td>
<td>This is the normal temperature range.</td>
</tr>
<tr>
<td>98.6</td>
<td>37.0</td>
<td>Call for chills or shaking chills.</td>
</tr>
<tr>
<td>98.8</td>
<td>37.1</td>
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<td>99.0</td>
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<td>37.3</td>
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<tr>
<td>99.4</td>
<td>37.4</td>
<td>99.4 to 100.3°F (37.4 to 37.9°C)</td>
</tr>
<tr>
<td>99.6</td>
<td>37.6</td>
<td>Re-check in 30 to 60 minutes for a temperature in this range.</td>
</tr>
<tr>
<td>99.8</td>
<td>37.7</td>
<td>Call for chills or shaking chills.</td>
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<tr>
<td>100.0</td>
<td>37.8</td>
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<tr>
<td>100.2</td>
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<tr>
<td>100.3</td>
<td>37.9</td>
<td></td>
</tr>
<tr>
<td>100.4</td>
<td>38.0</td>
<td>100.4 to 100.8°F (38.0 to 38.2°C)</td>
</tr>
<tr>
<td>100.6</td>
<td>38.1</td>
<td>Call when temperature in this range continues for 1 hour or longer.</td>
</tr>
<tr>
<td>100.8</td>
<td>38.2</td>
<td>Call for chills or shaking chills.</td>
</tr>
<tr>
<td>100.9</td>
<td>38.3</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>Greater than or equal to 100.9°F (38.3°C)</td>
</tr>
<tr>
<td>101.8</td>
<td>38.8</td>
<td>Call when temperature is this high or higher.</td>
</tr>
<tr>
<td>102.0</td>
<td>38.9</td>
<td></td>
</tr>
<tr>
<td>103.0</td>
<td>39.4</td>
<td></td>
</tr>
<tr>
<td>104.0</td>
<td>40.0</td>
<td>And above</td>
</tr>
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</table>

Note: Do not take Tylenol® unless instructed by your care team. Call for chills or shaking chills, with or without a fever.
# Suggested medication schedule

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

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<thead>
<tr>
<th>Medication</th>
<th>Dosage Directions</th>
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<th>7a</th>
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<th>9a</th>
<th>10a</th>
<th>11a</th>
<th>12a</th>
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<th>5p</th>
<th>6p</th>
<th>7p</th>
<th>8p</th>
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