Transplant Program

Pediatric Autologous Transplant Manual

Knowledge is Power
SCCA Patient and Family Education
## Important Phone Numbers

<table>
<thead>
<tr>
<th>Service</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Seattle Cancer Care Alliance (SCCA) 6th Floor Reception Desk</td>
<td>206-606-7600 M-F 8am-10pm; Sat-Sun 8am-6pm; Holidays 8 am-5 pm</td>
</tr>
<tr>
<td>Seattle Children’s Hospital</td>
<td>206-987-2032, After Hours</td>
</tr>
<tr>
<td>In the unlikely event of an SCCA phone outage</td>
<td>206-467-8762</td>
</tr>
<tr>
<td>Chaplaincy</td>
<td>206-606-1099</td>
</tr>
<tr>
<td>Children’s General Council</td>
<td>206-987-2044</td>
</tr>
<tr>
<td>Child Life</td>
<td>206-606-7621</td>
</tr>
<tr>
<td>Contacting the Unit at Seattle Children’s</td>
<td>206-987-2032 voice; 206-987-2280 TTY; 866-987-2000 to make an appointment or speak to a clinician from outside the area. Calls are answered 24 hours a day.</td>
</tr>
<tr>
<td>Family Resource Center at Seattle Children’s</td>
<td>206-987-2201</td>
</tr>
<tr>
<td>Getting to Seattle Children’s Hospital</td>
<td>206-987-2226</td>
</tr>
<tr>
<td>Health Information Management/Release of Information</td>
<td>206-606-1114</td>
</tr>
<tr>
<td>Hutch School</td>
<td>206-667-1400</td>
</tr>
<tr>
<td>Institutional Review Board at Seattle Children’s</td>
<td>206-987-7804</td>
</tr>
<tr>
<td>Interpreters at Seattle Children’s</td>
<td>206-987-5010 voice or 206-987-5063 TTY</td>
</tr>
</tbody>
</table>

Interpreter services are offered for deaf, hard of hearing, or non-English speaking families. Request these services from your child’s nurse or doctor, or call the
<table>
<thead>
<tr>
<th>Service</th>
<th>Phone Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Long Term Follow-Up</td>
<td>206-667-4415</td>
</tr>
<tr>
<td>Medical Nutrition Therapy Services</td>
<td>206-606-1148</td>
</tr>
<tr>
<td>Office of Research Compliance</td>
<td>206-884-4054</td>
</tr>
<tr>
<td>Pastoral and Spiritual Care at</td>
<td></td>
</tr>
<tr>
<td>Seattle Children’s</td>
<td></td>
</tr>
<tr>
<td>Patient and Family Education</td>
<td>206-606-1472</td>
</tr>
<tr>
<td>Patient and Family Resource Center</td>
<td>206-606-2081</td>
</tr>
<tr>
<td>Patient Financial Services</td>
<td>206-606-1113</td>
</tr>
<tr>
<td>Patient Relations</td>
<td>(206) 606-1056</td>
</tr>
<tr>
<td>Pharmacy</td>
<td>(206) 606-6500</td>
</tr>
<tr>
<td>Physical Therapy</td>
<td>(206) 606-6373</td>
</tr>
<tr>
<td>Radiation Oncology</td>
<td>(206) 606-7318</td>
</tr>
<tr>
<td>Receptionist 1st Floor</td>
<td>(206) 606-1000</td>
</tr>
<tr>
<td>Social Work Office</td>
<td>(206) 606-1076</td>
</tr>
<tr>
<td>Transition Services</td>
<td>(206) 606-2125</td>
</tr>
<tr>
<td>Security (Lost and Found)</td>
<td>(206) 606-1111</td>
</tr>
<tr>
<td>Volunteer Services</td>
<td>(206) 606-1075</td>
</tr>
</tbody>
</table>
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Chapter 1- Welcome

Welcome to the Marrow Transplant Program
We welcome you to the Seattle Cancer Care Alliance Marrow Transplant Program. This manual has been written to provide answers to your questions. Use it as a resource as you move through each step in the transplant process. Feel free to ask your team questions.

This manual is especially for families who have a child or teen going through a transplant. Feel free to share information in this guide with your child. Older children and teens may want to read it themselves. We welcome your comments about the manual.

Notes from the Editor: “You and your child” refers to the primary caregivers (usually the parents) and the child or teen having a transplant. Instead of using “he or she,” we sometimes use “he” and sometimes use “she.”
The Steps of Autologous Transplant
The cell that is being transplanted is the stem cell, which is made in the bone marrow. Stem cells are immature cells that grow and mature into red blood cells, white blood cells, platelets or plasma cells. Stem cells are an essential part of a person’s immune system. Names you will hear include:
- Bone Marrow Transplant
- Marrow Transplant
- Peripheral Blood Stem Cell Transplant
- Stem Cell Transplant
- Hemopoietic Stem Cell Transplant

Type of Transplant
There are several types of transplant. You may hear others discussing a process different from yours. Below is a chart reviewing each type. This chapter will then go into detail.

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

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

Planning Ahead
This step begins when the family first thinks about transplant as a treatment option for their child. You start to organize yourself and your family to undertake this journey.

Preparation
Once you arrive at the Clinic, you will begin the process of medical evaluation, orientation, informed consent, and get ready to begin conditioning therapy. Family members prepare to assume the caregiver role.
**Conditioning**
High-dose chemotherapy and/or radiotherapy is given to your child.

**Transplant**
Stem cells harvested from the bone marrow or collected from the circulating bloodstream are infused.

**Before Engraftment**
Your child will receive close monitoring, supportive treatment, and management of complications while waiting for signs that the transplanted stem cells are engrafting (growing and developing).

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

**Long-Term Recovery**
Your child will leave the Clinic and further care and treatment will be provided by your hometown doctor. The challenges in this stage include managing possible late complications and resuming life at home.

**Preparation**
When you first arrive, you and your child will go to the Clinic to begin the pre-transplant evaluation. You will learn the proposed treatment plan, meet with your healthcare team, and get answers to your questions about treatment. You and your family members can attend classes on how to manage symptoms at home and prevent infection. All of this is to prepare you for the next step—conditioning therapy. Childcare is not provided during appointments or classes and should be arranged ahead of time if needed.

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

**Arrival Conference (Meeting with the Doctor and Team Members)**
After the health history and physical exam are done, you will be scheduled for a conference. This usually takes place on the 2nd day after you arrive at the Clinic. Your attending doctor will conduct the conference. You may invite members of your family to
attend. We discourage small children from attending. The age and maturity of the child will determine whether they should attend the conference. The doctor will talk to you about the process of having a bone marrow transplant. He or she will discuss the plan of treatment including the risks and benefits. Child Life Specialists can use this time for medical play with small children, if scheduled in advance. Bring the consent packet provided to you to this conference.

**Evaluation and Work-Up**

The evaluation for transplant includes blood draws for tissue typing and clinical tests, a bone marrow aspiration and possible biopsy, chest x-rays, an electrocardiogram (ECG), pulmonary function tests, and other tests the doctor may order. You will meet with a dietitian and possibly have a dental checkup. When the results of these tests are available (5 to 7 days) you will be scheduled for placement of a central venous line catheter. Consults and tests occur both at the Clinic and at Seattle Children’s Hospital. The location and time of appointments will be on your schedule. Schedule changes occur frequently due to testing results.

**Informed Consent Conference**

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

You and your family will:

- Receive copies of all protocol consent forms for the protocols in which your child is participating.
- Be offered copies of all protocols for the protocols in which your child is participating.
- Be offered a copy of the dictated “Data Review Conference” summary.

**Central Venous Line Placement**

Placement of this catheter is done at Seattle Children’s Hospital. Your child will receive sedation (medicine to make them sleep) before the surgery begins. Because of this sedation, your child may not eat or drink anything before the catheter is placed. Not eating or drinking prevents the possibility of vomiting during surgery. **Talk to the Pediatric Team regarding these specific instructions.** We will schedule a time for you to return to the SCCA Clinic the following day so that one of the nurses can teach you how to take care of your child’s catheter.

**Conditioning**

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

**Chemotherapy**

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

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

**Safe Management of Chemotherapy at Home**

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

**Disposal of IV Drugs and Equipment**

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

**Federal Prescription Drug Disposal Guidelines for Oral Chemotherapy**

Take unused, unnecessary, or expired oral chemotherapy prescription drugs out of their original containers and remove all personal identifiers. Mix the prescription drugs with an undesirable substance like used coffee grounds or kitty litter and put them in a Ziploc™ bag or empty can to prevent children and pets from accidentally consuming the drugs. Do NOT crush chemo drugs. Throw these containers in the trash. **Do not** flush oral chemotherapy drugs down the toilet.
**Body Wastes**
Your child may use the toilet (septic tank or sewer) as usual. Wash hands with soap and water afterward and wash skin if urine or stool gets on it.

**Laundry**
Wash your child’s clothing and linen normally unless they become soiled with chemotherapy. If this happens, put on gloves and handle the linens or clothing carefully to avoid getting medicine on your hands. Immediately place the contaminated items in the washer and wash separately from other clothing. Do not wash other items with chemotherapy-soiled items. If you do not have a washer, place contaminated items in a plastic bag until they can be washed.

**Skin Care**
Chemotherapy spilled on skin may cause irritation. If this happens, thoroughly wash the area with soap and water, then dry. If redness lasts more than one hour or if irritation persists, call your doctor. To prevent chemotherapy from being absorbed through the skin, wear gloves when working with medicines, equipment, and waste.

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

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

**Questions and Answers**

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

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

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

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

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

**Is it safe for my child to be sexually active during treatment?**
Ask your child’s doctor or nurse this question. It is possible that traces of chemotherapy may be present in vaginal fluid and semen after treatment. Special precautions may be necessary. Women must avoid becoming pregnant or breastfeeding during and after chemotherapy. Men must avoid impregnating their partner while taking chemotherapy. Condoms are advised to prevent exposure to chemotherapy and prevent pregnancy.

**How should I store my child’s chemotherapy?**
Store medicine and equipment in a safe place and keep out of reach of children and pets. Do not store chemotherapy in the bathroom; high humidity may damage the drugs. Check medicine labels to see if your child’s chemotherapy should be kept in the refrigerator or away from light. Be sure all medicines are completely labeled.

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

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

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

For additional information about the drug your child is taking, please refer to the drug information sheet or other instructions provided to you by your child’s doctor or nurse.

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

**What are TBI treatments like?**

There is no pain or discomfort during your child’s treatment due to radiation. Your child will not have any unusual sensations while the radiation machine is on. Your child will not become “radioactive.” A family member may accompany your child to the radiation therapy department. However, it is necessary for your child to be alone in the room during treatment. Your child may feel alone during their treatment. Monitors are outside so that the nurse and radiation technician see and hear your child at all times. You will be given detailed instructions when your child’s nurse teaches you about the radiation course.

**Side Effects**

**Nausea:** Most often occurs 1½ - 2 hours after a dose of TBI. Your child will be started on medication to help any feeling nausea. The day before TBI begins; your team nurse will review the medications your child should take before each TBI treatment.

**Dehydration:** TBI can cause dehydration much like if your child were exposed to the sun for too long. Other side effects such as diarrhea and nausea add to this problem. Some of your child’s hydration may be given through IV during each day of TBI to help prevent dehydration.

**Skin Sensitivity:** TBI acts as a heat source even though your child will not feel this right away. You and your child will notice their skin may appear flushed, or darker following radiation therapy. Following treatment, your child’s skin will be more sensitive, especially to sunlight. Precautions are taken to avoid skin burns during treatment. Loose fitting clothing should be worn to avoid skin burns. All jewelry will be removed during treatments. The clamp used to hold your child’s central catheter will be taken off to avoid metal touching their skin. If your child wears eyeglasses, the radiation technician will have your child remove them during treatment. Contacts should not be worn. The nurse or doctor will assess your child’s skin frequently. Your child should avoid using lotion and deodorant before TBI.

**Alopecia:** Temporary hair loss will occur gradually over about two weeks following treatment.

**Parotitis:** The parotid glands are located near and in front of the ears. Parotitis is swelling of the parotid gland. Parotitis is not a common side effect but has been seen in TBI patients. Symptoms will occur from 4-24 hours after TBI. Ice packs and Tylenol help to relieve the discomfort from the swelling. Parotitis will resolve in 24-72 hours following treatment.
**Diarrhea**: Usually develops within the first week following TBI and can be treated with medications.

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

**Transplant**
The transplant takes place a day or two after the chemotherapy and/or radiation treatment has been completed. The goal is to infuse stem cells from which all types of blood cells grow. These cells can be collected from bone marrow, from circulating blood, or from saved umbilical cord blood after a baby’s birth. Stem cells are infused through your child’s central venous line in the same way that any blood transfusion is given. It takes place either in the Infusion Room at the Clinic or in your child’s room in the hospital.

**Stem Cell Mobilization**
Mobilization of stem cells is achieved by giving special proteins called growth factors. It takes a few days for the body to respond to the mobilization therapy. When blood tests show that the cell count is high enough, collection can begin. Once in a while, a stem cell must undergo more than one cycle of mobilization to collect enough stem cells for transplantation.

**Collecting Stem Cells**
Stem cells are collected in the Apheresis Unit. Before beginning collection, the donor must have a catheter (tube) placed into a large vein. The placement of the catheter may take place several days before or right before the collection procedure. The collection of PBSC’s takes about three hours. During the procedure, the donor relaxes in a chair or bed and can watch television or read.

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

**Before Engraftment**
Signs that the new stem cells are growing (engrafting) and beginning to produce blood cells are expected from 10 to 28 days after transplant. Often the first sign of engraftment is a rising white blood cell count. Your child will be monitored carefully while waiting for engraftment. The goals are to support your child until they are producing blood cells again, to provide prompt treatment if complications occur, and to prevent infections. Most patients experience the uncertainty of waiting for engraftment as stressful; it is common to feel defenseless and vulnerable. Associated with the daily
monitoring, medical procedures, and treatments is a feeling of loss of personal control. Coping at this time can be a challenge. Keep talking to your child’s team about your concerns and concerns your child has.

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

<table>
<thead>
<tr>
<th>Blood Component Name</th>
<th>Function</th>
<th>Normal Ranges</th>
<th>Transplant Transfusion Guidelines</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Hematocrit</strong></td>
<td>Carry oxygen to the body, Give color to the skin, Give energy to the body</td>
<td>Adult: 37 – 52%</td>
<td>Transfuse: If HCT less than 26% OR If patient symptomatic</td>
</tr>
<tr>
<td>% Red Blood Cells per volume of whole blood Erythrocytes HCT</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Platelets</strong></td>
<td>Prevent bleeding, Help blood to clot</td>
<td>150,000 – 500,000 / mm³</td>
<td>Transfuse: If less than 10,000 OR For bleeding OR If otherwise indicated</td>
</tr>
<tr>
<td>Thrombocytes PLTS</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>White Blood Cells</strong></td>
<td>Fight infection</td>
<td>Adult: 5,000 – 10,000 / mm³</td>
<td>Not applicable</td>
</tr>
<tr>
<td>WBC</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Absolute Neutrophil Count</strong></td>
<td>Type of WBC that is first to respond to potentially fatal infections</td>
<td>Over 1,000</td>
<td>Very rare occurrences; Only if life threatening infection is present with no signs of white cell recovery</td>
</tr>
<tr>
<td>ANC</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Neutrophils Polys</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bands Segs Granulocytes</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Effects of Chemotherapy and Radiation on Blood Counts**
The amounts of chemotherapy and radiation used in conditioning cause the bone marrow to stop producing cells for a time. Your child’s blood counts will be low during this period. After your child’s blood counts are drawn, the doctor will determine your child’s transfusion needs. When your child’s stem cells begin to engraft, their blood counts should start to rise. The actual time for recovery of cells will vary from person to person.
Red Blood Cell Transfusions
When your child’s red blood count is low, the doctor will order packed red blood cell (RBC) transfusions. This consists of a bag or bags of concentrated red blood cells, each transfused over 2-4 hours. This blood has been typed and cross-matched with your child’s to minimize the chance of reaction. This means that the RBC donor and your child have a compatible blood type. It’s still possible that your child may have a reaction. Symptoms include fever, chills, hives, itching, and/or breathing problems. If your child has any of these symptoms during transfusion, be sure to report them right away to your nurse.

All blood products are tested for infectious diseases such as hepatitis, HIV, (human immunodeficiency virus or AIDS), and West Nile. If your child is cytomegalovirus (CMV) negative, your child will receive CMV safe blood, also known as leuko-reduced blood products.

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

- **Random Pooled Platelets**: from two to six volunteer donors in the community, which are pooled in the same bag
- **Random Apheresis Platelets (RAP)**: From one volunteer donor in the community.
- **Matched Apheresis Platelets (MAP)**: From one HLA matched unrelated donor in the community.

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

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

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

**Cytomegalovirus CMV**

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

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

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

**Sinusoidal Obstructive Syndrome (SOS)**

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

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

**Gastrointestinal (GI) Problems**

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

**Lung Problems**
Your child will be monitored closely for signs of any breathing difficulties due to fluid overload, pneumonia, or side effects of chemotherapy or radiation. Daily physical examinations and routine chest x-rays will be done.

**Skin Problems**
The skin is a sensitive organ often prone to some damage from chemo and radiation. These side effects range from a mild redness like a sunburn to red, dry, and peeling skin.

**Kidney Problems**
Kidneys are organs that produce urine, remove bodily waste, and process some drugs out of the body. Some drugs affect kidney function. Your nurses and doctors keep a close watch on your kidney function through blood tests, the careful monitoring of the quantity and quality of urine, and frequent measurement of body weight. These and other factors help guide them to prevent and treat kidney problems and help return kidney function to normal.

**After Engraftment**
As your child’s new immune system develops, the goal is to support your recovery and manage any complications that may arise. Your child’s immune system is immature and is still vulnerable to infections. Your child may need infusions of red blood cells or platelets. Fluids and nutritional support maybe needed until eating and drinking enough.

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

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

As your child recovers and no longer needs close monitoring and treatment, the team will help you and your child prepare to leave and return to the care of your doctor. Despite the eager anticipation, you and your child may experience separation anxiety as you prepare to leave.
Transitioning Back to the SCCA Clinic
The Transition Nurse will meet with you and your child to help with plans for discharge from the inpatient unit. After discharge, the Clinic nurses will coordinate your care again.

Before leaving the Inpatient Unit, you and your child will receive the information and have an opportunity to learn and practice the skills to manage care at home. Classes are taught covering these skills, and all caregivers are welcome to attend any of the classes a second time to “brush up” on information or skills.

Preventing Infection
Even though your child is well enough to recover at home, his or her immune system is still recovering and you will need to take precautions to guard against infection. We suggest that you do not socialize with other transplant patients, as a protection to your child. Use common sense to guide your decisions. For example, avoid crowds of people. This means that you may go to public places such as restaurants, but avoid peak hours. And, of course, wash your hands.

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

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

Your child should not clean up after animals. Wash your hands if a pet licks you.

Daily Exercise
Regular exercise is important to your child’s recovery. Physical therapy may be ordered. If your child is taking prednisone (steroids), your child may need physical therapy to maintain muscle strength.

Sun Safety
Use sunscreen with sun protection factor (SPF) 30 when outside, and apply it to all exposed skin areas. Even if it is not especially sunny out, it is important to protect your child’s skin from the sun’s rays. Your child’s skin is sensitive to the sun for 2-3 months.
after transplant. There is an increased risk of skin cancer after a transplant, so your child must continue to use sunscreen for the rest of his or her life.

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

**Readmission**
Your child may need to be readmitted to the hospital for management of symptoms that cannot be safely taken care of in the home setting or the Clinic. As soon as your child is medically stable, the medical team will work with the Transition Nurse to have your care returned to the Clinic.

**Departure**

**Long-Term Follow-Up Departure Class**
After you have left the Clinic and you are home, the Long-Term Follow-Up staff will be a resource for you, your child, and your doctor. They are available during business hours to answer questions and concerns. You will be scheduled to attend the Long-Term Follow-Up (LTFU) class to learn how to take care of yourself during the coming year.

**Discharge Papers**
Discharge papers consist of a packet of information that we ask you to take with you to give to your child’s referring doctor. They contain a summary of all your care and recommendations for your further care. These papers will be given to you and your child during your final clinic visit.
Your Transplant Team and Resources
There are many people helping in your child’s care while he or she is having a transplant. Together they are your team. You and your child are the most important members of the team. Talk with all of the other members of your team, and feel free to ask questions and share information. Your core team consists of an attending doctor, primary doctor or physician’s assistant, nurse, transition services (discharge planning), support staff, and consultants. Additional team members are described below.

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

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 for their age and development. Child Life is available to help develop coping skills to care for a sick child.

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

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

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

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

**Medical Nutrition Therapy Services**
The science of nutrition during cancer treatment is a specialized field. A dietitian can provide recommendations based on food preferences and tolerances, interest in food, and specific social, economic, and medical situations. A visit with a dietitian can provide you and your child with inspiration about how to make healthful eating work even while your child is undergoing treatment.

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

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

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

**Patient & Family Education**
Knowledge is power! You and your child have the right to disease-specific information regarding treatment options, side effects, and maintaining your health after treatment. Ask your nurse for materials such as chemotherapy cards or symptom sheets. Go to [facebook.com/sccapatientsfamilyeducation](http://facebook.com/sccapatientsfamilyeducation) (no log-in required) to find Patient and Family Education on Facebook. Click the link in the “About” section to access a video library of Patient and Family Education classes.

**Patient & Family Resource Center**
The Patient and Family Resource Center is located on the 3rd floor of the Clinic. The RC provides educational materials, computer workstations, a business center, notary, and a cancer literature lending library. Listings for local and clinic events, as well as assistance locating support groups and other resources are provided. All services and materials are free.

**Patient Financial Services**
Patient Financial Services staff works with you and your insurance company to obtain approval for procedures. Many insurance companies have managed care or case management as part of their plan design. This means that a nurse reviewer or case manager...
manager must be called to report new admissions and will want updates during your stay. Certification of the inpatient stay is done and payment is authorized based on your plan provisions. To optimize your reimbursement, the Utilization Review staff will maintain contact with your insurance company when required.

**Physical Therapy**

Physical therapy plays a significant role in enhancing the quality life as your child regains his or her health while moving towards improvement in physical capacity. Treatment is highly individualized and interventions are informed and guided by the available evidence. To schedule physical therapy, a referral must be completed by a doctor, physician’s assistant, or nurse practitioner.

**Psychiatry and Psychology Services**

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

**Rain or Shine**

Product offerings at our in-clinic store, Rain or Shine, located on the 1st floor of the Clinic, include quality goods and items, convenience sundries, books and newsstand, gift items, hats, scarves, apparel, jewelry, cookbooks, stationery, snacks, and toys and games for all ages. Store Hours: M-F 8:30 am to 4 pm seattlecca.org/gift-shop-rain-or-shine.cfm.

**Shine**

Shine is located on the 1st floor at the SCCA House, and provides specialty products such as skin care, hair alternatives, post-surgical apparel, 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 and supportive staff to assist customers in finding products. Appointments are recommended for fittings of custom compression garments. A shuttle departs from the Clinic every 20 minutes for SCCA House. This is your most convenient way to visit Shine. Store Hours: M-F 10 am to 6 pm, Saturday 10 am to 3 pm seattlecca.org/shine.cfm Location: 207 Pontius Ave N., Suite 101, Seattle WA 98109

**Social Work**

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

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

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

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

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

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

Fred Hutchinson Cancer Research Center  
**www.fhcrc.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

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 website include:
Facing Forward- Life After Cancer Treatment  

When Someone You Love is Being Treated for Cancer  
www.cancer.gov/cancertopics/coping/when-someone-you-love-is-treated

Taking Time: Support for People with Cancer  
www.cancer.gov/cancertopics/takingtime

Eating Hints: Before, During and After Cancer  
www.cancer.gov/cancertopics/coping/eatinghints

Chemotherapy and You: Support for People with Cancer  
www.cancer.gov/cancertopics/coping/chemotherapy-and-you

Radiation Therapy and You: Support for People with Cancer  
www.cancer.gov/cancertopics/coping/radiation-therapy-and-you

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

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  

**Fitness/Exercise**

Team Survivor Northwest  
(206) 732-8350  
[http://teamsurvivornw.org/](http://teamsurvivornw.org/)

**Insurance**

America’s Health Insurance Plans  
1 (202) 778-3200  
[www.ahip.org](http://www.ahip.org)

**LGBT Resources**

National LGBT Cancer Network  

**Prescription Drug Assistance and Issues**

Needy Meds  
[www.needymeds.com](http://www.needymeds.com)

**Travelers with Disabilities and Medical Conditions**

Transportation Security Administration  

**Disease Specific Sites**

National Bone Marrow Transplant Link  
1 (800) 546-5268  
[www.nbmtlink.org](http://www.nbmtlink.org)

Leukemia & Lymphoma Society  
1 (800) 955-4572  

Multiple Myeloma Research Foundation  
1(203) 229-0464  
[www.multiplemyeloma.org](http://www.multiplemyeloma.org)

US TOO International (Support groups, info)  
1 (800) 808-7866  
[www.ustoo.com](http://www.ustoo.com)

Aplastic Anemia  
1 (800) 747-2820  
[www.aplastic.org](http://www.aplastic.org)
Myelodysplastic Syndromes Foundation  
www.mds-foundation.org  
1 (800) MDS-0839  
(or 1 (800) 637-0839)

Sickle Cell Disease Association of America, Inc  
www.sicklecelldisease.org  
1 (800) 421-8453

**Sites for Support and Networking for Youths**

Captain Chemo- A comic strip created by a teenage cancer patient has been turned into an interactive computer game to explain cancer and its treatment.  
www.royalmarsden.org/captchemo

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  
1 (877) 622-7937

Beyond the Cure  
www.beyondthecure.org  
1 (800) 532-6459
Diagnostic Tests

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

Preparing for Imaging Exams: CT, MRI, Nuclear Medicine, PET/CT, Ultrasound, DEXA, Plain X-rays
- Medical Imaging (Radiology) is on the second floor.
- Please arrive 15 minutes before the scheduled appointment time to allow for check-in and screening.
- Your child should 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.
- Your child may be given a gown to wear during the exam.
- Tell your doctor and the technologist if there is any chance that your child may be pregnant.
- Before the day of your exam, please tell your doctor or nurse if your child has an allergy to CT or MR contrast.
- Please turn your cell phones and/or pagers OFF before the exam begins.
- See additional instructions specific to your appointment.
- Check with your doctor or nurse regarding what medications your child should or should not take on the day of the imaging exam and any instructions to follow after the test regarding resuming medications.
Food and Fluid Restrictions for Computed Tomography (CT) Exams

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

CT exams of the abdomen and/or pelvis may require your child to drink an oral contrast product during the hour before your scan time. If your child is given IV contrast, he/she 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 kidney function, please check with your doctor or nurse for special instructions for your exam. Your child may use the restroom any time before your exam unless instructed otherwise.

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

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

Check with your nurse or doctor for clarification of these instructions if needed.
MRI Screening Form

Your doctor has ordered an MRI exam for your child. **Please call (206) 606-1434 for further instructions if you may be pregnant or weigh more than 300 pounds.**

To prevent a delay or cancellation of your exam, if your child 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.

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

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

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

Your child should increase his or her fluid intake before and after the injection. Your child should try to drink 3-4 glasses of a preferred drink after the injection and empty his or her bladder frequently. There are no eating or drinking restrictions.

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

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

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

Clinical Missions
By choosing to come to the SCCA, you directly benefit the knowledge gained by previous patients who participated in various research studies. You and your child, 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 in to 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 your child participates. Your signature indicates that the study has been explained to you, that you understand the risks, that you have had a chance to ask questions, and that you freely agree to participate. Consent forms also state that you remain free to withdraw your consent.

Benefits and Risks of Research
It is often a possibility that your child will personally benefit by participating in research studies. There is also the possibility that your child 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 your child has problems that need ongoing treatment. We are able to carry on this research by working with your doctor. You and your child 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 child’s 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 child’s continued participation remains essential, and we are grateful for your willingness to work with us. If you would like to know more about clinical research, please ask your nurse or doctor.

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

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

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

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

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

Fred Hutchinson Cancer Research Center:
- SCCA Patient Relations Office: (206) 606-1056
- Institutional Review Office: (206) 667-6567
- The Principal Investigator of your study

UW Medicine:
- The Principal Investigator of your study
- Human Subjects Division: (206) 543-0098

Children’s Hospital and Regional Medical Center:
- The Principal Investigator of your study
- Institutional Review Board: (206) 987-2023
- Children’s General Counsel: (206) 987-2044
Chapter 2 - Finding Your Way
Treatment at the Clinic
Care and treatment is provided in the Clinic when possible. This allows you and your child to stay in the comfort of your home.

Your Local Phone Number
Please give us your local phone number so we can reach you when needed. Please include the patient’s name in your message so our staff can be sure they reached the correct number. The receptionist keeps a current list of local phone numbers to reach patients and family members. Please keep the receptionist informed of your current local phone number and address. For your convenience, a pager will be available for your use.

The Mail System
Your child’s mail is sorted by the receptionist and kept behind the reception desk on the 6th floor. Please ask the receptionist to check your mailbox for appointments and messages every day your child receives care in the Clinic.

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

Chest X-Rays
Your child may be scheduled for a routine chest x-ray at Children’s on the 4th floor, main Radiology department. Chest x-rays will be scheduled for you as needed.

Radiology
If you are scheduled for certain procedures such as a Magnetic Resonance, Computed Tomography, or an Ultrasound, you will need to go to Children’s on the 4th floor, main Radiology department.

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

Pharmacy
The Transition Services staff will confirm sources of oral and IV medications. The Pharmacy is located on the 5th floor of the Clinic and is open from 8 a.m. - 8 p.m., Monday through Friday, and 8:30 a.m. - 5 p.m. on Saturday and Sunday. New medication orders can be picked up anytime the pharmacy is open. All refills must be called in 48 hours before the day that you need your refill medications.
If the Pharmacy is providing hyperalimentation, IV hydration fluids and IV medications for your child, they can be picked up from 1-7 pm, Monday through Friday, and 8:30 am - 5 pm on weekends. Heparin and normal saline flush solution for your child’s central line are also dispensed from the Pharmacy. If the Pharmacy does not provide hyperalimentation, IV hydration fluids, or medications for your child, the transition nurse will work with you and your home infusion company to arrange infusion services.

Resources & Announcements for Families
Notice of Clinic activities will be put in your mailbox, posted on the SCCA Patient and Family Education Facebook page, and posted in key spots throughout the Clinic. Family member activity schedules will be communicated via the mailbox system. Other activity information and tickets for special events can be obtained from the Guest Services Information Desk located on the 1st Floor of the Clinic.

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

Sick Family Members
Family members showing symptoms of cold or flu should not come to the Clinic until they have been checked by a nurse or doctor. 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 their dirt or water, which can cause infections. Latex-free balloons and silk flowers are okay. Make sure there is not decorative moss around silk flowers. Only artificial moss is allowed.

Smoke Free Environment
Smoking is not acceptable at the Clinic. It is necessary to leave the Center premises in order to smoke. Washington law prohibits smoking within 25 feet of all entrances, exits, windows, and ventilation system of public places. Contact the Living Tobacco Free program to sign up for smoking cessation or call the Washington State Quit Line at 1-800-784-8669 (1-800-QUIT NOW) for free treatment or referral to other resources.

Guest Wireless Internet Access Guide
Seattle Cancer Care Alliance is proud to offer free wireless high-speed Internet (Wi-Fi) access to our patients and visitors. Guest Wireless works with most wireless-equipped computing devices. For your convenience, connectivity is available throughout the Clinic, including in patient rooms and visitor waiting areas. To connect to Wi-Fi network, follow these steps:
• Enable the wireless feature on your device.
• Connect to the “SCCA-Guest” network.
• Once you are connected, open your web browser. Upon your first attempt to navigate to a website, you will be redirected to the Acceptable Use Policy Logon Page. You must read and accept the policy, by clicking “I Accept” at the bottom of the page. After accepting the policy, your browser will automatically load the Seattle Cancer Care Alliance homepage.
• You can now browse the web normally.

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

Location
Seattle Children’s provides inpatient and some procedure services for Seattle Cancer Care Alliance pediatric patients. The hospital is located at 4800 Sand Point Way N.E., Seattle, WA 98105. This is in northeast Seattle near the University of Washington. Seattle Children’s provides care for bone marrow transplant and other cancer patients on Forest 7 (200/300 wing) and Forest 8 (300 wing), the SCCA patient care unit.

Admission to the Inpatient Unit
When you arrive at the SCCA, our staff will automatically pre-register your child at Seattle Children’s so admission will be smooth. If your child’s admission to the Children’s inpatient unit is scheduled in advance, you will be given the time and date to go to the hospital by the Clinic staff.

Outpatients may develop symptoms that require hospitalization. The Clinic staff can coordinate these admissions at any time. Remember to bring wall decorations from home and toys/games. Older kids may want to bring their address/phone books or laptop computers so they can keep in touch with friends at home. Children’s offers interpreter services for deaf, hard of hearing, or non-English speaking families. To request these services, ask your child’s nurse or health care provider, or you can find their contact number in the important numbers section of this manual.

If the hospitalized infant is less than 120 days old, bed sharing is not recommended. It is recommended for the infant to be placed on a “bassinet” style sleep surface, if available, next to the parent’s couch. If airway support equipment cannot be safely used in the bassinet sleeper, this option should not be used. A crib should remain in the room for infant assessment.

Contacting the Unit
Please see lists of numbers for contacting the unit in the important numbers section of this manual.

The Family Resource Center
The Family Resource Center on the 5th floor, near the Train elevators, offers information about hospital services, community resources, books and pamphlets on child health issues, magazines, and free coffee, tea and cocoa. It is open 7 a.m. - 10 p.m. daily, and staffed 9 a.m. -9 p.m., Monday through Friday, and 1 - 9 p.m., Saturday and Sunday. The hospital chapel is located inside the Family Resource Center. For more information please call the number listed in the important numbers section of this manual. Caregivers need to take breaks and care for themselves in order to continue to care for their child.
Your Child’s Daily Routine
You may wonder what the normal routine day is like for your child in the inpatient unit at Children’s. Remember, there is still time to play, when your child is feeling up to it. What procedures are often done? What tests are usually run? What routine activities will be a part of everyday life on the unit? Routines will be explained in more detail by the inpatient nurse, but in the meantime, here is an overview of what you can expect:

Rounds
Every morning the doctor and other members of the health care team will round with each child and family. This is to check on your child’s progress and to make changes in therapy if needed. This is a good time to ask any questions you or your child may have and to discuss the plan of care. You can ask the day nurse what time rounds are in the morning.

Physical Examinations
The nurse as well as the doctor will, at different times, need to listen to your child’s heart and lungs with the stethoscope. They press lightly and listen to his abdomen with a stethoscope to check for sounds indicating normal functioning of the stomach and intestines. The nurse will look at your child’s mouth daily and more frequently during the period he is likely to experience mucositis, an inflammation of the mouth.

Routine Blood Tests
Early morning, from 4 - 6 a.m., the nurses will draw daily routine blood tests from your child’s central line. We will disturb you and your child as little as possible, but our medical team needs to review the laboratory findings as early in the day as possible.

Vital Signs
Your child’s temperature, pulse, respiration, and blood pressure, all of which we call vital signs, will be taken every four hours as a standard so as not to allow too much time to lapse before we see any change in your child’s condition. Sometimes they are taken more often if we need to monitor her more closely.

Daily Weight
A daily morning weight check is important to monitor the amount of fluid in your child’s body. Occasionally, she may need to have her weight checked twice per day.

Chest X-rays
Chest x-rays are done weekly to check your child’s lungs or, more frequently, as indicated by your child’s health.

Medications and IV Fluids
Many medications such as antibiotics, and anti-nausea medications will be given through the central line. Other fluids will also be given when your child cannot drink to
help keep up fluid intake. Parents may give oral medicine to their child only after being instructed by a nurse.

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

**Transfusions**
Blood and platelet transfusions will be given to your child as needed until she is able to make her own blood cells. Blood counts will be checked every morning.

**Nutrition**
Dietitians will talk to you and your child about his food likes and dislikes. Patients who are not able to eat are given total parenteral nutrition (TPN), also known as hyperalimentation (HA). This goes through the central line and has no taste.

**Recording Intake and Output**
If you give your child food, water, or ice, notify the nurse of the amount given. It is important to keep accurate records of fluid intake and output. Therefore, never empty a urinal, bedpan, or emesis basin. Your nurse will do that for you.

**Exercise**
Your child may feel like she is always connected to some medication going into the central line. We encourage you to arrange with the nurse a time to take a walk and exercise in the halls. The doctor may order Physical Therapists to visit your child to help keep her activity level up.

**Bathing, Showers, and Oral Care**
Daily baths are taken to help cleanse the body of bacteria. This may help lower the chance of infection. Mouth care is also an important part of the transplant. We will encourage your child to do rinses with mild salt water called “normal saline” to help remove bacteria and promote healing. There’s a shower in each room that patients and families can use. Coordinate with your nurse to sign up for a bathroom time to use a bath tub.

**Central Line Care**
The central line dressing will be changed as necessary to guard against bacterial growth. This gives the nurse a chance to inspect the skin around the central line. Nurses will check under the dressing at other times as well.
Making the Transition to Recovery at Home
The Transition Nurse will meet with you and your child to help with plans for discharge from the inpatient unit. Care will then be coordinated by the team nurse in the SCCA Clinic until your child is discharged from the Center. This is the same nurse that prepared your child for transplant and monitored the progress of his therapy until he was admitted to the inpatient unit.

Open Visiting Hours
Parents may be with their child 24 hours a day. Visiting hours for siblings and others are 10 a.m.-8 p.m. We encourage families to keep their own health in mind and to get a good night’s sleep. One parent/legal guardian may stay at the bedside overnight. Siblings and other visitors may not stay overnight in the hospital. A nurse will contact family members at home if any problem occurs.

Siblings
Children are important members of a family, and we encourage them to visit during their hospital stay. These guidelines are for brothers, sisters, and other child or teen visitors:

- Children/Teens must wash their hands like any other visitor.
- Children/Teens that are ill or might be ill are not allowed to visit.
- Children/Teens (or adults) who have been exposed to chickenpox and who have not had chickenpox before are not allowed to visit.
- If children/teens 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/teens may not go into the room of another patient.
- Children under 10 years old must be with an adult when playing in the family room or teen room. Toys from the family room may not be taken into the patient’s room.
- The hallway is not a play area for children. Children are not allowed to play with hospital equipment such as wheelchairs and stretchers.

Receiving Mail at Children’s
Friends and relatives may send mail to your child by addressing it to the following:
Your Child’s Name
Hematology/Oncology Unit
P.O. Box 5371, MS CH-58
Seattle, WA 98105-0371

Local Phone Number
Family members should make sure that the unit coordinator has their correct phone number on file for emergency use.
Preventing Infection
Patients and family members are not allowed to visit other patient rooms. This helps to prevent the spread of infection. Patients are encouraged to walk around the patient care 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’s rooms. There is a danger of infections both to the patient and to the visitor. Public restrooms are located on all nursing units.

- **Keep surfaces clear of patient/family belongings.** Some organisms can survive a long time on the surfaces and equipment in the patient’s room. It is very important that these surfaces be cleaned daily by Environmental Services (ES). The ES staff cleans bed rails and other items close to the patient if the patient is present. To help them do a complete cleaning, please leave the room if possible. Taking a shower, a walk, or sitting in a chair are options.

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

- **Clean or wash the patient’s personal belongings.** Environmental Services staff does not clean patient’s personal belongings. Daily, a family member or friend should wipe off the patient’s personal belongings and toys, or play activities provided by the hospital, with a cloth or paper towel dampened with soap and water. Hospital toys can also be put in the waiting room to be cleaned by volunteers. Items such as clothing or quilts should be washed periodically or when they become soiled.

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

- Place used tissue in the trash can, not on other surfaces such as the bedside table or floor.

- If you have a son who is using a urinal, please place it on the floor, not on the bed rail or on the bedside table or bedside cabinet. Please ask for help if you are not able to put it on the floor safely.

- You and your child need to wash hands frequently, before eating and after using the bathroom or urinal.

**Summary of Infection Control Concerns**
It can take as much as a year for the infection-fighting immune system to get back to normal. It is important to make the steps in preventing infection a part of daily life. Microorganisms, which can cause infection, are present everywhere in the environment as well as on and in a person’s body. Even when careful attention is paid to infection prevention procedures, it may not be possible to prevent infection during the entire recovery period. Be sure to seek medical care at the first sign of infection so treatment can be started early.
Any family member or visitor who has a fever or cold, or who is not feeling well, should not come to visit the patient. Even minor colds and infections carry a risk to the patient. Children, in particular, are known to get many viruses. Please evaluate the health of children, and their exposure to other children that may have been ill, before letting them come to the inpatient unit. If a family member needs to see a doctor, ask your nurse for a referral.

Handwashing is the single most effective way to prevent the spread of infection. Before entering and when leaving a patient's room, everyone is expected to follow a simple but thorough handwashing procedure.

**What to Bring from Home**

Bring wall decorations and your child’s favorite toys and games. Older kids may want to bring their address/phone book or laptop computers so they can keep in touch with friends at home.

**Service Dogs, Therapy Dogs, Pets**

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

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

A therapy dog is trained to provide affection and comfort to people. A therapy dog’s primary job is to allow people (who may or may not have disabilities) to make physical contact with it and enjoy that contact. Although the emotional benefits of therapy dogs are significant, physical contact to the dog is an infection concern in cancer centers that serve patients with weakened immune systems. **This is one of the reasons why the SCCA does not allow therapy dogs, other therapy animals, or pets. Please do not bring therapy dogs, therapy animals or pets to the clinic.**

**Fresh Flowers and Plants**

Fresh flowers and plants are not allowed in your child’s room. There are organisms that grow on them and in their dirt or water, which can cause infections. Mylar balloons and silk flowers are okay. Latex balloons are not allowed at Children’s Hospital.

**Money and Valuables**

Money and valuables should not be left in your child’s room or the family room because of the risk of theft. There is a safebox in each room that you can access with your chosen code.
Family Space/Kitchen
All who use these areas must help to keep them clean. There are two family spaces, one quiet space and one play area for siblings by the Unit Coordination desk. Transplant patients cannot use these areas because of infection concerns. If you bring food into the Family Space, please clean up food items before leaving the area. You are encouraged to use this as a quiet space for reading, conversation, and other relaxing activities. Each room has a small refrigerator. Items that need to be in the freezer can be placed in the family room’s freezer labeled with your child’s name.

Teen Space-3B
Teen Space is a hang-out for siblings 12-21 years of age. Adults must be accompanied by their teenager. If you have any questions or requests, you can call Child Life at x3646. Please help us keep the Teen Space safe and clean by following these infection control guidelines:

- **Wash your hands** as you enter the room! The nearest sink is in the Family/Play Space.
- **If you are ill, please do not enter the Teen Space.**
- **Please place any games, craft materials, etc. that get soiled into the “Clean Me” bin!** If it’s sneezed on, coughed on, or has come into contact with any bodily substances it qualifies for the “Clean Me” bin.
- **Please do not bring food into the Teen Space.** You can eat in the Family/Play space.
Chapter 3 - Managing Care at Home

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

Rosalynn Carter’s book Helping Yourself Help Others begins with the above quote. Education and support have been developed to meet the needs of your child and family caregivers. Weekly group classes, videos, individualized instruction, and written materials are offered. Support is offered by team members including nursing, social work, chaplaincy, Please review the next two sections for details of caregiving.
Suggestions for Coping with Care at Home

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

Outline of Typical Caregiver Responsibilities

Making arrangements:
- Transportation
- Financial
- Tracking appointments

Giving emotional support:
- Being physically present
- Giving encouragement

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

Maintaining the home environment:
- Cleaning
- Food preparation
• Shopping

Patient advocacy:
• Gathering information and assuring that pertinent information is given to medical staff
• Helping with decision-making

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

Taking Care of the Caregiver
Caregivers are encouraged to take care of themselves through exercise, proper diet, and adequate sleep. Caregivers benefit from breaks. Caregivers are at risk for becoming ill if they ignore their own health.

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

Develop a Plan of Care
The nursing staff will work with you to develop a unique Home Care Plan. You and your child have a nurse available 24 hours a day to answer questions. Other family members and friends can help during different stages of transplant with various tasks. Caregivers need to develop a schedule and division of tasks that is satisfactory to all. Your child can participate in self-care, as long as they feel well enough to do so. Other adult family members can learn to operate the ambulatory pump. When a different person takes over line care, they should review the steps with a nurse.
The Home Care Plan should meet safety needs. The following recommendations give an idea of the different levels of caregiving needed throughout the transplant and recovery process. Each patient and family organizes their routines differently. Some patients and families like to keep a logbook of activities, infusions, and medications. Please see the examples of a home care schedule at the end of the manual.

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

Clinic Phases and Support Levels: Young children need consistent support on an ongoing basis. Older children in late teens and young adults may reach a point when intermittent or minimal supports are appropriate.

- Consistent Support Criteria for recommending a consistent caregiver for the patient are:
  - During conditioning (including Dilantin administration), chemotherapy, and radiation therapy
  - First 1-2 weeks in the SCCA Clinic after initial discharge after transplant
  - Three different IV infusions such as hydration, medications, or hyperalimentation over a 24-hour period
  - Neutropenia (ANC < 500)
  - Altered mental status: drowsy, confused, impaired judgment, poor memory
  - Weakness/limited mobility (cannot walk without assistance)
  - Sliding scale insulin (when starting therapy)

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

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

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

- Individual teaching
- Classes
- Videos on Facebook
Individual teaching is offered on topics such as care of the central line, medications, blood glucose monitoring, and specific needs that may arise during the treatment and recovery process. Educational classes focus on gaining an understanding about the treatment process and developing the skills needed for the patient’s treatment, and recovery in the home setting.

Class Descriptions

**Managing Care at Home and Review of Transplant Process**
This class includes an overview of the Bone Marrow/Stem Cell Transplant Process, review of the patient/caregiver role and resources and how to prevent infection. Content of this class includes Managing Symptoms, emergency plan development (mucositis, dehydration, diarrhea, bleeding, and breathing problems) and adjusting to recovery at home.

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

**Long-Term Recovery Class**
Information on how to manage care after leaving the Center is presented. Content includes immune system recovery, assessing symptoms, guidelines for daily living, and coping with the common psychological reactions after transplant.

**Computerized Scheduling System**
Classes are scheduled by the clinical support staff. A personalized list of appointments and scheduled classes is placed in your patient mailbox.

**Guidelines for Preventing Infection**

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

During transplant, your child’s immune system will be weak, so he or she will be at a higher risk for getting infections. Infections after transplant are more serious than in those people who are otherwise healthy. It is critical to limit exposures to sources that might increase your child’s risk for acquiring an infection, and to seek help when your child develops infectious symptoms. While it is not possible to prevent all infections, there are a number of simple steps that you and your child can take to help prevent many common infections. While this section cannot cover all scenarios or possible situations, it includes basic information on how to prevent infections during your child’s transplant.
**Clean Your Hands Often**
Cleaning your hands is one of the best ways to prevent infections. Hand hygiene is key, especially during the first year after your child’s transplant and/or while he or she is taking immunosuppressive medicines (medicine that weakens the immune system).

You, your child, and anyone you come into contact with, including all members of your household, your doctors, and nurses, should clean their hands frequently. Do not be afraid to ask if visitors or healthcare staff if they cleaned their hands before they meet with you.

There are two options for cleaning your hands. Standard washing with soap and water is a great way to clean your hands. Alcohol hand sanitizer (hand gel such as Purell®) is another good way to reduce the number of germs on your hands. For home use, be sure to select a hand sanitizer that contains at least 60% alcohol. Hand sanitizers are not as effective when hands are visibly dirty or greasy. Also, keep in mind that these hand sanitizers do not prevent some gastrointestinal infections, such as *C. diff* and norovirus. Persons with these infections and their caregivers should wash their hands with soap and water instead.

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

At the Clinic and the hospital, hand sanitizer is located in elevator lobbies, waiting rooms, and exam rooms. Please use hand gel frequently while at the Clinic or hospital.

**When Should You Clean Hands?**
It is important for all family members to clean hands frequently throughout the day, particularly when you are in public places (the Clinic, restaurants, shopping, common areas/waiting rooms, etc.). Some specific times that are important to make sure you clean your hands:

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

**How to Wash Hands with Soap and Water**
It may sound a bit funny, but washing your hands properly is important. Read through the steps and practice them. Make this process a habit.

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

How to Apply Hand Sanitizer (Hand Gel)
• Apply one to two pumps of hand sanitizer to the palm of one hand.
• Rub your hands together.
• Rub the product over all surfaces of your hands and fingers until your hands are dry. Make sure you get the product between your fingers and on the back of your hands.

Cleaning
At least once a week and as needed, clean the kitchen and bathroom with a bleach solution. Make the solution daily with one part bleach to ten parts water. The solution needs to be made daily to make sure that the bleach solution is effective. You can also buy a pre-made bleach solution, such as “Clean-Up Cleaner with Bleach” spray made by Clorox®. Key kitchen areas to clean are:
• Sinks, which can be very dirty because grime and mold often stick to their surfaces
• Faucets and faucet handles
• Countertops
• Cutting boards
• Refrigerator and microwave handles
• Stovetops
• All areas that hands have touched or where food has been prepped

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

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

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

**Safe Eating**
Both how you prepare your food and what you eat play a role in keeping you healthy. Your doctor and nutritionist may provide a special diet to follow depending on your child’s situation. Your child might need more protein or calories, or might need to avoid certain foods such as fresh produce. Follow that diet and these other tips to prevent infections:

- Do not allow your child to share cups, glasses, or eating utensils with other people.
- Cook food thoroughly. Leftovers should be stored in small containers and refrigerated within 2 hours of cooking. Reheat leftovers thoroughly.
- Keep food at its proper temperature. Keep hot foods hot and cold foods cold.
- Avoid salad bars, buffets, deli counters, and food in bulk bins.
- Avoid using ice machines in locations outside of the healthcare center and Clinic.
- Follow recommendations and check the guidelines for dietary restrictions.
- Ask your nutritionist questions if you don’t know if something your child is eating is safe.
- Keep foods fresh and buy in small amounts to avoid spoilage and mold contamination if possible.
- Do not allow your child to eat or drink foods that are beyond their expiration date.

**Prevent Infection by having your child avoid the following:**

- Avoid activities such as gardening, raking, mowing, farming, or direct contact with soil and plants. These activities create plant or soil aerosols which increases exposure to fungi and bacteria. Potted plants should be avoided. You child should avoid working in green houses or managing plants at home. Ask friends and visitors to avoid bringing fresh flowers and potted plants as gifts following your transplant.
- **Plants or flowers in your home.**
- People who have respiratory illnesses (cough, cold, etc.). Be especially careful around school-aged children and those that attend daycare, since they are often exposed to other children who are ill.
- Should not be in the same home as someone with a respiratory virus.
- Avoid crowded areas where you are unable to control the distance between you and others, such as at movie theaters or sporting events.
- Construction sites, including homes or buildings that are being repaired or remodeled. These dusty environments increase your exposure to molds.
- Tobacco and marijuana use. The use of these substances, along with exposure to environmental tobacco smoke (second-hand smoke), increases your risk for bacterial and fungal infections.
• Wood-burning fireplaces, because wood contains fungus. If a wood stove is your only source of heat, have someone else touch the wood and manage the fire.
• House cleaning that will disturb dust and mold, causing it to be stirred up in the air (such as vacuum cleaning, dusting, and scrubbing down showers). If cleaning needs to be done, it is best to clean when you are not in the home, and use a wet washcloths or wipes as they capture dust. Do not use feather dusters. Once you have the energy, it is not harmful to iron, wash clothes, dry clothes, and wash dishes.
• Use of room humidifier because of bacteria that live in water.
• If you like to use air conditioners (AC) and fans during warm weather, they should be cared for properly as they can bring dust and mold into your home. Regular inspection and cleaning of the AC unit is critical. AC Filters should be changed regularly per manufacturer recommendations.
• Swimming in recreational water such as ponds, swimming pools, lakes, whirlpools, and hot tubs.
• Changing a baby’s diaper.
• Touching bird droppings.
• Cleaning a fish tank.
• Emptying and cleaning litter boxes.
• Cleaning up after pets.
• Your child may feel “safer” wearing a mask when you are outside, but you are not required to wear a mask when you go out. This is a personal choice. If your child chooses to wear a mask, you should still avoid situations as described above.

Prevent Infections Spread from Animals
Wash your hands immediately after petting your animals. It is not necessary to part with pets. Your child should delegate the majority of pet care to other family members or friends. It is important to minimize direct contact with animals, especially animals that are ill, and avoid getting any new pets during your transplant. Do not allow your child to sleep with pets.

If you have a cat, do not place the litter box in kitchens, dining rooms, or other areas where food preparation and eating occur. Have someone else handle the daily litter box cleaning during the first year after transplant and when your child is are immunosuppressive medicines to reduce your risk of acquiring toxoplasmosis, a parasitic disease. Keep your cats inside and do not adopt or handle stray cats.

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

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

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

It is very important that family members and household contacts receive the flu (influenza) shot every year. The flu vaccine is the best way to prevent the flu. The Clinic offers the flu vaccine to family and household contacts. If your family or household contacts opt to receive the nasal spray flu vaccine (Flumist®), avoid contact with that person for five days, as the nasal spray vaccine contains a weakened live flu virus that could spread to your child.

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

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

**How Does the Clinic Work to Prevent Infections?**
Infection prevention is a very high priority at the Clinic and a cornerstone of preventing major post-transplant complications. All infections cannot be avoided, but here are some of the steps taken in order to ensure that your child receives care in a safe environment:

- All staff cleans their hands while performing patient care. If you would like to confirm that the staff caring for your child has cleaned their hands, we encourage you to ask them. Staff know that we all need to work together to prevent infections. By asking, you are helping us maintain a high standard of care.
- In the Clinic, isolation precautions are used as a way of stopping the spread of germs from one person to another. Your child may be placed on isolation if he or she has an infection that can be transmitted or harmful to other people. If your child is in isolation, staff will take extra precautions to ensure that those germs do not spread. Staff may place your child in an exam room right away, clean their
hands more often, and wear protective equipment, like gowns, gloves, and masks. If your child is in isolation, make sure to remind staff when you arrive at clinic or are admitted to the hospital.

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

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

- If you have a cold or the flu, it is especially important that your child avoid riding any of the shuttles. Let your team know and your nurse will give you taxicab vouchers to use until your cold and flu symptoms go away.

- The flu vaccine is provided to caregivers and household members of transplant patients. Information about flu vaccine clinics are posted starting in October yearly.

References


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 your child’s symptoms early.
- Get professional help when needed.

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

What Your Child Can Do At Home
- Get plenty of sleep.
- Save your child’s energy by resting between short periods of activity.
- To avoid getting dizzy, your child should move slowly when getting up from a lying position and sit up for several minutes before standing.
- Add green leafy vegetables and liver to your child’s diet when possible.
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. Your child 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, and 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.

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

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

What You and Your Child 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 your child is anxious about a medical procedure, ask him what it is about the procedure that is upsetting. Staff may be able to assist and help you find ways to cope with your child’s anxiety.
- Getting the facts can help. For example, if you are worried about your child’s 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 efforts to reduce it, discuss it with your doctor, nurse, or social worker.
Bleeding

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

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

Emergency Signs and Symptoms
Call 911 IMMEDIATELY if:
- Uncontrolled, constant bleeding.
- Patient is unconscious.

Urgent Signs and Symptoms
Call the Clinic or the After Hours Clinic NOW if:
- New or increased bleeding or bruising.
- Bloody urine.
- Little red or purple spots on the skin
- Unable to stop nosebleed
- Bloody diarrhea.
- Vomiting of blood.
- Patient falls or is injured.
- One or more feminine pads per hour are used.

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

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

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

Call for Professional Help When Needed
• If a nosebleed doesn’t stop after 30 minutes of applying pressure, contact the 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 child’s body and life in ways that may be hard on your child’s 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 child’s energy and thoughts toward what they can control. Paying attention to skin care, diet, exercise, and positive attitudes are healthy ways to cope with body image changes. Finding ways for your child to express his or her feelings about the changes is very important.

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

Important Signs and Symptoms:
Report symptoms to a doctor or nurse during clinic hours today.
- Feeling or acting 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 Your Child Can Do at Home
- Maintain a confident and positive self-image.
- Encourage your child to express feelings to trusted family members, friends, doctor, nurse, or social worker.
- Talk with other people who have had similar treatment about what they did and how they coped with changes in body image.
- List your best points, 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 your child 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 for wig resources.

**Your Child can 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 child’s face becomes very round or puffy, wear a “V” shaped neckline.
• If your child has 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 Your Child’s Skin**
• Select skin care products that your child likes 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 doctor or nurse.

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

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

Just the Facts
Difficulty breathing may occur during your child’s 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.

Goals
- Keep your child’s lungs healthy.
- Call for professional help when needed.

Emergency Signs and Symptoms
Call 911 IMMEDIATELY if your child is:
- Unable to breathe.
- Choking/not able to move air.

Urgent Signs and Symptoms
Call the Clinic or the After Hours Clinic NOW if your child:
- Trouble breathing/shortness of breath.
- Gets “winded” more easily with normal activity.
- Feeling as if your child can’t get enough air.
- Troubled breathing when lying flat.
- Wheezing with breaths.
- New or recurrent cough.
- Uncontrollable or continuous cough.
- Tightness or wheezing with each breath.
- Coughing blood or green/yellow sputum.

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

What Your Child Can Do at Home
Keep lungs healthy:
- Avoid smoke or being 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 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 your child has 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 a family plan ahead? Answers to these questions are difficult because each patient responds differently to treatment. Complications are hard to predict. Take it day by day.

Goals
- Adapt to change.
- Cope with uncertainty.

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

What You and Your Child 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 child’s 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 doctor or nurse.

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

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

What You and Your Child Can Do At Home
Preventing constipation:
- Drink plenty of fluids. 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 your child is taking pain medication, ask your doctor or nurse about the use of laxatives and stool softeners.
- Keep your child as physically active as possible.

Ask your doctor or nurse if your child needs a laxative.
Dehydration

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

Goals
- Fluid intake.
- Call for professional help when needed.

Urgent Signs and Symptoms
Call the Clinic or the After Hours Clinic immediately if your child:
- Dizzy or lightheaded.
- Fainting.
- Confused.

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

What You and Your Child Can Do at Home
- Promote fluid intake.
- Drink as many liquids as possible. If you detect early signs of dehydration in your child, have them drink more.
- Avoid caffeinated beverages such as: coffee, cola, diet cola, hot or iced tea, and hot chocolate.
- Check with the dietitian or nurse for goals or restrictions.

Get Professional Help When Needed
- Monitor for signs of dehydration such as decreased amounts of urine and dark urine.
- Report symptoms to the doctor or nurse promptly.
Depression

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

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

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

What You and Your Child Can Do at Home
- Allow you and your child to feel sad at times.
- Talk about these feelings with someone who listens (family member, social worker).
- Talk with other patients in your situation (support groups, phone contact, Internet).
- Use spiritual resources.

Get Professional Help When Needed
Psychiatrist and Psychologists can provide:
- Evaluation of cause of depression (sometimes medications can cause depression).
- Medication to manage depression.
- Counseling.

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

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

Goals
- Prevent dehydration.
- Prevent infection.
- Call for professional help when needed.

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

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

What You and Your Child Can Do at Home
Prevent dehydration:
- Drink fluids (in suggested amounts).
- Follow dietary recommendations. Note any food allergies or intolerances and discuss with the doctor, nurse, or dietitian.
- Prevent infection and irritation.
- Wash hands often with 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/doctor.
- Use white, non-perfumed toilet paper.

Call For Professional Help When Needed
• Describe the type of diarrhea to health care staff by including frequency, consistency, color, and presence of cramping.
Exercise and Blood Value Precautions

**Platelets** are parts of your blood that are important for blood clotting. Your child’s platelet count must be greater than 20,000 before he or she can do any type of cardiovascular exercise or strength training with weights (cuff weights, dumbbells, machines, and elastic tubing). If your child’s platelet count is consistently below 100,000, you need to check his blood counts before exercising to know whether or not you he can do strength training and/or cardiovascular exercise. If your child’s 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 – 100,000:** cardiovascular exercise and strength training with weights are allowed. If your child has any signs of bleeding (i.e., from the nose), your child should **NOT** exercise and you must notify your physician or care team, even if your child’s platelets are in this range.
- **Platelet count 20,000 – 49,999:** strength training with weights and cardiovascular exercise are ok if you have no signs of bleeding, but exercise must be performed without strain, such as holding your breath. Strain during exercise can spike your blood pressure and increase your risk for a stroke or major bleed. Massage at this platelet count 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 – 19,999:** strength training **WITHOUT** weights (machines, dumbbells, or elastic tubing), 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 and to the bathroom is ok as long as your child is steady on his or her feet and has 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 child’s red cell number and oxygen-carrying capacity (Hct and Hgb) are too low and your child exercises anyway, he is diverting needed oxygen from his vital organs to his muscles, which may cause micro-damage to his organs. When your child’s Hct or Hgb are too low, your child is not allowed to perform strength training or cardiovascular exercise until he has had a red blood cell transfusion and we are sure that his 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 child’s hematocrit is less than 25% or hemoglobin is less than 8.0, consultation with your doctor or a physical therapist is necessary to determine safe exercise options.
Fall Prevention

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

If your child has a history of confusion with any medications for nausea or pain control let your doctor 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 your child safe.

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 your child has a broken bone.
- Your child has fallen and hit her head, has low platelets, and/or is on anti-coagulant medications.

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

Important Signs and Symptoms
Report symptoms to your doctor or nurse during clinic hours today:
- If your child has fallen, even if you think that nothing is wrong.

What You and Your Child 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 your child puts her shoes on our exam tables and beds so that your shoes are always on to keep you safe. We don’t want your child 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, your child 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 your child to the bathroom.

- **Move around with care.** 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 your child uses 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 the clinic (like a spill on the floor), tell staff right away.

**Call for Professional Help When Needed Your Child:**
- Is groggy, dizzy, or feeling faint.
- Has fallen, let staff know RIGHT AWAY by yelling or asking anyone around you to help.
- Do NOT attempt to get up alone. You might hurt yourself trying to get up.

**What You and Your Child Can Do at Home**
- Think about the shoes your child wears. Have your child avoid wearing shoes such as slippery slippers, slippery socks, high heels, shoes without backs, or flip-flops. Wear sturdy, non-skid shoes such as tennis shoes. Wear them inside and outside the house. Avoid going barefoot, even inside the house.
- Move furniture so you have clear paths.
- Keep the floor, pathways, and stairs clear of objects. Remove things your child can trip over (like paper, books, clothes, and shoes) from stairs and halls.
- Never put small objects inside/outside your house, especially on the stairs.
- Fix loose or uneven steps.
- 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 the walking path.
- Remove small throw rugs or use double-sided tape to keep the rugs from slipping.
- Enhance/add to the existing lighting home. 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 your child has balance problems, consider having him use a shower seat or urinal for showering and dressing.
• Keep items that are used 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 your child doesn’t trip.
• Review medications regularly with your doctors to identify medicines that cause sleepiness, dizziness, or confusion so your child can be extra-safe after taking these medicines.
• Don’t drink alcohol if taking sedating medications.
• Talk to your doctor about seeing a physical therapist for mobility aid and balance and strengthening. Practice approved exercises regularly to improve your child’s strength, balance, and coordination.

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.

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 your child:
- Dizzy.
- Too tired to get out of bed or walk to the bathroom.

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

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

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

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

Goals
- Monitor the patient’s temperature. Seek professional help when the patient has a fever.

Urgent Signs and Symptoms
Go to Seattle Children’s Hospital Emergency Department (ED) NOW if:
- Temperature taken by mouth between 38-38.2°C (100.4-100.8°F) for one hour or more, or a temperature that is 38.3°C (100.9°F) or above. (added bold)
- 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. (added bold)
- Fever greater than 1 degree above normal when the patient is on prednisone or steroids. (subjective but maybe specific “above patient’s baseline” or “above patient’s normal temp” for clarity? I have question in to Dr Carpenter about this, too)
- Shaking chills (temperature may be normal).
- Cold symptoms (runny nose, watery eyes, sneezing, coughing).
- Note: Do not give Tylenol® (unless directed by the doctor or nurse).

For timely care and service at the ED, please follow these steps:
- If your child has a fever, always call the BMT team (clinic or inpatient BMT provider) before you go to the ED.
- When transporting a patient with chills, keep them warm and comfortable.
- The ED will then expect a call from the BMT provider with information about your child’s case. The Lobby Nurse will be informed that your child is on their way to the ED.

As soon as you arrive at the ED your child will be registered and checked in by the Lobby Nurse.
- If there is a wait line, quickly let the Security Guard (sitting at the computer next to the Lobby Nurse) know that your child is a BMT patient.
- The security guard will make sure that the Lobby Nurse puts your child at the top of the list to be seen.
- Once checked in and brought back to a room, a plan will be followed using best practices to manage fever and possible infection in BMT patients. (This will include expert monitoring, and receiving medications and resuscitation in a timely way)
In the rare event that your child needs to receive advanced life support, experts in our ED can best provide this care.

**Important Signs and Symptoms**

Report symptoms to a doctor or nurse during clinic hours today:

- Any new redness or swelling on the skin or at an intravenous (IV)/central line site.
- Cold symptoms (runny nose, stuffy nose, watery eyes, sneezing, coughing).
- New abdominal or back pain.
- Toothache.
- Cloudy or foul-smelling urine. Pain with going to the bathroom.
- Sinus pain.

**What You and Your Child 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.

**Where to Take Temperature**

The best way to take a temperature is to place the thermometer into the mouth under the tongue in the Sublingual pockets. The Sublingual pockets are in the lower jaw, under the tongue (see image below). If you have any questions, please ask your doctor or nurse.
Hand-Foot Syndrome

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

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

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

Just the Facts
Changes in memory and concentration are common throughout treatment. The changes may be temporary. Your child’s memory and concentration may improve as his treatment is completed and when he starts 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 your child may have good and bad days, you may want to use routine strategies to assist you when your child is having a bad day. It can be a frustrating and taxing problem.

Goals
- Learn how to cope with changes in memory and concentration.
- Get professional help when needed. Neuropsychologists evaluate memory.
- Ask your doctor to make sure that your child’s medications are not causing the problem.

Urgent Signs and Symptoms
Call the Clinic or the After Hours Clinic NOW if:
- Disoriented
- Confused

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

What You and Your Child 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 stress.
- Keep distractions to a minimum.
- Ask people to repeat things.
- Keep a list of questions for your doctor. Write the answers down.
- Tape record important conversations or conferences.
- Get important information in writing. Ask people to write it down for you.
- Place notes around the house to remind you of things.
- Keep an appointment calendar and one central memory book.
• Use a device to remind you to take your medications such as a watch or cell phone timer that can be programmed to go off at times when medications need to be taken.
• Keep things in a designated place, (for example: always keep your keys in the same place).
• Be understanding and patient with your child and know that these temporary changes are to be expected.
• Ask your doctor to review your medications.

How to Keep Minds Active?
Below is a list of resources you might want to utilize to enhance your child’s cognitive abilities. There are things you can do to regain some of your child's mental plasticity and prevent any further decline in 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. Have your child try writing and brushing her teeth with the opposite hand than she usually does.
• **Conversation**: Enjoy a conversation with a friend and discuss world events.
• **Languages**: Learn a new language. Rosetta Stone has CDs that you can purchase in various languages.
• **Read Books**: Join a book club, or attend a book reading. A couple of suggestions include:
  o *The Better Brain Book* by David Perlmutter and Carol Colman
  o *Whole Brain Thinking* by Jacqueline Wonder and Priscilla Donovan
  o *Carved in Sand* by Cathryn Jakobson Ramin (the story of her struggle with early onset memory loss).
• **Website Suggestion**: [www.positscience.com/](http://www.positscience.com/) is a website where you can try out a couple of the exercises from their Brain Fitness Program. This program has been used to help veterans with traumatic brain injuries recover some of their capabilities.
Get Professional Help When Needed
If problems persist or affect day-to-day living to a large degree, discuss the symptoms with your doctor or nurse. Ask your doctor or nurse about a Neuropsychological referral and Neuro-Rehabilitation Treatment.
Mouth Pain/Mucositis

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

Your child’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.

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 your child:
- Having difficulty breathing.
- Bright red in the mouth.
- Pain not controlled by medication.
- White patches or sores appear on gums or mouth.
- Difficulty swallowing food or fluid.

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

What You and Your Child 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 child’s gums and the tissue in his or her mouth.

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

• Take pain medication as instructed.

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

• For chapped lips apply lanolin creams, Chapstick® or Blistex® and lip balms that 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 nutrition and fluid intake.
• Warm fluids - try: chicken noodle soup, chicken broth, tea.
• Cool fluids - try: popsicles, slushies, sports drinks and Kool-Aid®.
Nausea & Vomiting

Just the Facts
Many patients experience nausea and vomiting at some time during the treatment process. It is one of the side effects of the chemotherapy and radiation. Contrary to what most people think, nausea and vomiting have little to do with your stomach. They are actions controlled by certain centers in your child’s 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

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

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

Urgent Signs and Symptoms
Call the Clinic or the After Hours Clinic NOW if:
- Having uncontrolled (constant) nausea and vomiting.
- Blood or “coffee ground” appearing material in the vomit.
- Medicine not kept down because of vomiting.
- Weakness or dizziness, along with nausea/vomiting.
- Severe stomach pain while vomiting.

Important Signs and Symptoms
Report symptoms to a doctor or nurse during clinic hours today if:
- Nausea persists without control from anti-nausea medications.
• Projectile vomiting.

What You and Your Child Can Do at Home
Prevent nausea and vomiting or manage symptoms well:
• Take your anti-nausea medicine as instructed before nausea starts.
• Before chemotherapy, lie down in a quiet place for 15-20 minutes and relax.
• Wear loose fitting clothes.
• Use distraction, relaxation, or deep-breathing techniques such as tapes, visualization, or hypnosis techniques. Try breathing through your mouth.
• Keep your mouth clean. Rinse with water often.
• Rest in a chair after eating, keeping head elevated.

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

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

Call for Professional Help When Needed
• If you notice that the anti-nausea medicine does not seem to control your child’s nausea, call your doctor or nurse. Additional medications may be used to better control your nausea.
• If the medicines seem to make your child nervous, jittery, or cause any unusual sensations, let your doctor or nurse know.
• Do not increase the amount of medicine without checking with the doctor, nurse, or pharmacist.
• Do not take any over-the-counter medicines without checking first with your doctor or nurse.
Pain

Just the Facts
Your child may experience pain during the course of his 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 his pain. On occasion your doctor may ask a doctor who specializes in cancer pain management to manage your pain.

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

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

Patient Rights and Responsibilities
As a patient of the SCCA, you and your child have the right to:
- Information about pain and pain management.
- Have your pain treated promptly.
- Have doctors and nurses who believe your report of pain.

As Healthcare Providers, we expect you to:
- Describe and rate your child’s pain.
- Ask about pain management.
- Discuss options with your doctor or nurse.
- Ask for pain relief when your child first experiences pain.
- Inform us if pain treatment is not working.
- Help us develop a treatment plan for your child.

Goals
- Report your child’s 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 Pain
Your child’s doctor or nurse will ask you to “rate” his pain using a simple method. Remember, only YOU know what and where your pain is, and YOU need to help us help you.

Your child’s doctor or nurse will ask her to “point” to the area of her pain. They will also ask the following questions:

- What will cause the pain?
- What do you think will get rid of the pain?
- What is the quality of your pain? (burning, radiating, throbbing, stabbing)

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

**How Can We Treat Your Pain?**

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

**Non-Drug Methods of Pain Relief**

- Hot or cold packs
- Massage/therapeutic touch
- Hypnosis
- Relaxation and music therapy

**Pain Medication May be Given Different Ways**

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

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

**Emergency Signs and Symptoms**

Call 911 IMMEDIATELY if you have:

- Severe chest/arm pain
- Severe squeezing or pressure in chest
- Severe sudden headache
Urgent Signs and Symptoms
Call the Clinic or the After Hours Clinic NOW if you have:

- New or uncontrolled pain
- New headache
- Chest discomfort / heart “flip-flop” feeling
- Pounding heart
- Painful central line site or area of “tunnel”
- Burning in chest or stomach
- Strong stomach pain
- Pain with infusion of medications or fluids into central line

What You and Your Child Can Do at Home

- Maintain your treatment plan-take medications as ordered. Do not increase your child’s dose of medication without talking to your nurse or doctor.
- Keep a pain journal.
- Use hot or cold packs.
- Find a relaxation technique that works for you such as meditation, guided imagery, hypnosis, massage, or therapeutic touch.
- Listen to relaxing music.
- Taking care of your child’s pain will help him sleep better, feel stronger, and be better able to cope with his illness.
- Continue activities that are meaningful to your child. These activities may help your child notice less pain or discomfort.
- Before taking pain medication/opioids, ask your nurse or doctor about ways to prevent constipation.
Peripheral Neuropathy

Just the Facts
Peripheral neuropathy is damage to nerves that can span from your child’s 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.

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

Emergency Signs and Symptoms
Call 911 IMMEDIATELY if:
- You cannot wake your patient.

Urgent Signs and Symptoms
Call the Clinic or the After Hours Clinic NOW if:
- Your child is unable to move his legs.
- Your child has fallen.

Important Signs and Symptoms
Report symptoms to a doctor or nurse during clinic hours today.
- Change in sensation symptoms: numbness, tingling, tremor, burning, loss of sensation, gait imbalance (unstable walking), sensitivity to touch, weakness, tiredness and heaviness.
- Movement Symptoms: lack of muscle control, falling, muscle twitching, cramping, foot drop, and muscle atrophy.
- Autonomic Symptoms: failure of the nerves to work correctly can result in abnormal blood pressure and digestive problems such as nausea, blurred vision, and dizziness.

What You and Your Child Can Do at Home
- You can meet with a physical therapist if your child is having problems with balance. Ask your team to schedule your child for a Physical Therapy appointment. Home equipment and/or devices to help your child walk independently may be recommended if he has mobility problems. Discuss with your doctor, nurse, and physical therapist safety measures you should put in place.
• Avoid extreme temperatures. Peripheral neuropathy may make areas of your body more sensitive to hot or cold.
• Have your child wear shoes, slippers, gloves, and other clothing to protect his skin from changes.
• Use extra care when using hot, sharp, or potentially harmful objects. Your child may be more at risk for clumsiness and prone to injury if he has reduced sensations.
• Avoid falls - review the Fall Prevention symptom sheet in this manual. If you have sensation changes, you are more at risk for falls.
• Check your feet every day, looking carefully at the bottom of your feet and toes for any changes.

For lack of sensation in your hands:
• Check temperatures with your inner forearms to avoid burns.
• Always use protective padding for cooking and rubber gloves for cleaning.
• Keep finger nails short to avoid tearing.
• Keep hands moisturized to avoid skin breaks from dryness.

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

Websites
www.neuropathy.org
Sexuality

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

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

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

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

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

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

Prevent Infection

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

Cope Creatively with Changes in Appearance

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

Keep an open mind about ways to feel sexual pleasure

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

Call for Professional Help When Needed
Women: Talk with your doctor or nurse if you notice signs of premature menopause, hot flashes, irritability, headaches, vaginal dryness, or less interest in sex. You may benefit from hormone replacement therapy (HRT) or a change in the dose or type of HRT you are using.
Men/Boys: Talk with your doctor or nurse if you experience loss of sexual desire, erection problems, trouble reaching orgasm, premature ejaculation, or pain. Your doctor will work with you to determine the cause (physical, hormone changes, or anxiety) and get you started on a therapeutic plan. Ask your doctor or nurse about medications.

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

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

What restrictions prevent me from resuming sexual activity?
- Sexual intercourse is restricted at times when platelet counts are less than 50,000. Sexual activity is also restricted when white blood counts are low (neutropenic-nutrophil count less than 500).
- Sexual activity is restricted when there is vaginal or rectal bleeding.
- If your partner has a sexually transmitted infection.*
* A Sexually Transmitted Infection (STI) is any contagious infection that can be spread by sexual contact such as chlamydia or herpes. You can get a sexually transmitted infection from sexual activity that involves the mouth, anus, vagina, or penis.

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

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

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

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

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

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

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

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

Will I be infertile after treatment?
- The type and dose of chemotherapy and or radiation you receive for treatment, your age, your previous chemotherapy and radiation exposures, and your gender can all influence your fertility.
- Women often stop ovulating for a period of time after treatment or may experience premature menopause.
- Men often stop making sperm completely or have very low sperm counts during cancer treatment and for several months after treatment. Not every male will resume normal sperm production and may be infertile as a result of surgery, chemotherapy, or radiation. It is best to see a fertility specialist to monitor fertility after cancer treatment.
- A small percentage of people, usually of younger reproductive age, do regain their fertility after treatment, but this may take months to years to occur and can be hard to predict for each person.
- Routine testing of sex hormones and sperm or ovarian function is often needed to see if fertility will be restored. However, as unexpected pregnancies have occurred, Discuss your birth control plan with your doctor to prevent unplanned pregnancy.
- It is recommended that all patients who are interested in preserving fertility have their options evaluated before treatment. This allows the time, and best chances, for storage of sperm, eggs, or embryos. If you are interested in options to preserve your fertility or to have your individual risk for infertility evaluated, talk to your doctor or nurse. A fertility specialist (Reproductive Endocrinologist)
can provide more information about your current fertility status and the fertility options available to you.

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

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

For women, the standard approach is to harvest eggs which are then fertilized by sperm and stored as embryos. Several weeks may be needed to allow for the harvesting of eggs and a partner or sperm donor is necessary. These embryos can be frozen for many years for use later. Similarly, eggs alone can be harvested and frozen without adding sperm. These eggs can be frozen for many years and used later to create embryos for implantation in the uterus.

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

Brochures - available in the SCCA Patient and Family Resource Center:

- “Sexuality and Cancer: For the Woman who has Cancer and Her Partner.” American Cancer Society
- “Sexuality and Cancer: For the Man who has Cancer and His Partner.” American Cancer Society
- “Managing Chemotherapy Side Effects: Sexual and Fertility Changes in Men.” NCI
- “Managing Chemotherapy Side Effects: Sexual and Fertility Changes in Women.” NCI

Books - Available at the SCCA Resource Center:


Other Suggested Books:


Website Resources

National Cancer Institute
www.cancer.gov
Search for “Sexuality”

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

University of Washington Reproductive Care
www.uwmedicine.org/search/locations

LIVESTRONG - Lance Armstrong Foundation
www.livestrong.org; Under Get Help, click on “Cancer Support.” Next click on “Learn About Cancer,” then click on “Cancer Support Topics,” and then on “Physical Effects of Cancer.”

Myoncofertility.com
www.myoncofertility.org; Discusses fertility issues before and after treatment

Fertile Hope
www.fertilehope.org

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

WebMD
http://women.webmd.com/tc/kegel-exercises-topic-overview
Sleep Problems

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

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.

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

Call for Professional Help When Needed
- If your child is not sleeping.
White Blood Cells

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

Goals
- Recognize signs of infection.
- Get professional help when needed.

Important Signs and Symptoms
Report symptoms to a doctor or nurse during clinic hours today.
- Shaking or chills.
- Cough.
- Temperature greater than or equal to 38.3°C (100.9°F), or a temperature of 38.0°C (100.4°F) for 1 hour.
- When taking an axillary (under the arm) temperature with children, call if the temperature is 37.9°C (100.3°F) or higher.
- Sore throat.
- A general feeling of tiredness or “flu-like” symptoms.
- Painful or frequent urination.

What You and Your Child Can Do at Home
Preventive measures:
- Look at your mouth and skin for signs of infection. Exercise excellent mouth care. See Mucositis information sheet.
- Have your child brush her 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 child’s skin clean and avoid cuts and scratches. Report any changes in skin including rashes, sores, and cuts.
- Wash hands frequently.
- Wear gloves when washing dishes.
- Shave with an electric razor.
- Use lotion for dry skin.
- If you have hemorrhoids, ask your doctor or nurse for advice before you self-treat.
- Check with your doctor or nurse regarding dental work.
Food Safety
A food-borne illness is any illness caused by eating a food that is contaminated with a bacteria, virus, mold, or parasite. Some organisms that can cause a food-borne illness are E. coli, Salmonella, and Listeria. Sources of food-borne illness or “food poisoning” may be the food handler, a work surface, or the food itself.

Bacteria and other organisms exist in most common foods. Most of these organisms are of little risk to an average person. However, persons undergoing chemotherapy, radiation, or a stem cell transplant are at increased risk for infections, including food-borne illness. By following safe food practices, you can reduce the risk of food-borne illness.

Follow the “Guidelines for Immunosuppressed Patients.” In addition, it is recommended that you follow the food safety guidelines discussed below. If you or your child has 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)
- Dilute bleach solution (for washing countertops, cutting boards, and other items): Mix $\frac{1}{3}$ cup unscented household bleach with $3 \frac{1}{3}$ cups water. This will make a total of $3 \frac{2}{3}$ cups of bleach solution.

Personal Hygiene
- Wash hands frequently with soap and warm running water, using a 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, after using restroom, handling garbage, or touching pets.
- Dry hands with a paper towel or cloth hand towel that is changed daily.

Kitchen Cleanliness
- Replace dish cloths and dish towels daily. Wash them on the hot cycle of your washing machine.
- Sanitize sponges daily in the bleach solution for five minutes, or heat them in a microwave oven on high for one minute, or run them through the dishwasher.
- Use liquid dish soap and hot water when hand-washing dishes, pans, and utensils. You may air-dry dishes instead of towel-drying them.
• Wash counters, cooking utensils, and can openers with soap and hot water right after use. After washing, they can be sanitized with dilute bleach solution.
• Keep the refrigerator clean. Clean spills immediately. Wash shelves and doors weekly using the diluted 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, without tasting, any bulging, leaking, or cracked cans, or any cans that are deeply dented.
• 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.
• Do not store any food supplies under the sink. Do not store chemicals or cleaning solutions over or near food supplies.

Cutting Boards
• Plastic or glass surfaces should be used for cutting raw meat and poultry. However, wooden cutting boards are safe if they are used exclusively for raw meat and poultry. Use a different board for cutting any other foods such as produce and bread.
• 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 wood and plastic cutting boards with the diluted 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 a week. Flood the surface with the bleach solution and allow it to stand for at least two minutes, then rinse and air-dry or pat dry with fresh paper towels.
• Replace worn cutting boards, including boards with cracks or grooves.

Safe Food Handling: From the Grocery Store to Your Home
• 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 the product is expired.
• 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 has not been properly handled.
• Avoid unpasteurized juice (unless prepared at home with washed produce).
• Choose shelf-stable salsa rather than salsa located in the refrigerated section of the grocery store.
• Avoid unpasteurized milk, yogurt, cheese, and other unpasteurized milk products, including Mexican-style cheese such as queso fresco.
• Do not use foods with any mold present.
• Avoid unrefrigerated, cream and custard-filled pastry products, such as fresh bakery cream pies, éclairs, cream-filled doughnuts and pastries. Commercial, shelf-stable items such as Danish pastries, Hostess Fruit Pies®, Twinkies® and Ding Dongs® are allowed. Follow the “Use By” date and store them according to the manufacturer’s guidelines after opening.
• 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 before consumption.
• Do not taste free, 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 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 it promptly.

Your 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 the “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.
• Children under one year should never consume honey or foods made with honey.

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 of the produce.

Use the following guidelines for handling all raw 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 important for produce that will not be cooked before 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. Rinse leaves of leafy vegetables, such as lettuce, spinach, cabbage, individually under running water. 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 from 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.
• Packaged salads, slaw mixes, and other prepared produce, even when marked “pre-washed,” should be rinsed again under running water; a 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, etc., 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 think a home-canned food may have been improperly processed because the lid bulges or the food has any bad odor or unusual characteristics after opening, THROW IT AWAY. Use home- canned foods within one year of canning, as chemical changes may occur.

Do Not Cross-Contaminate
• 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 for the cooked meat.

Keep Foods at Safe Temperatures
Proper Thermometer Use
• 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. Also, follow the manufacturer’s instructions.
• Test a thermometer’s accuracy by putting it into boiling water. It should read 212°F.
• Place a refrigerator thermometer on a shelf toward the back of the refrigerator. It should read 40°F or lower.

**Refrigeration**
• Keep the refrigerator temperature between 34°F to 40°F.
• Keep the freezer temperature below 2°F.
• Never leave perishable food out of the refrigerator for more than two hours. Throw away food left out of the refrigerator longer than two hours.
• Marinate foods in the refrigerator.
• Never thaw foods on the counter outside the refrigerator.
• 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, but 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, or three days. Date foods placed in the refrigerator to keep track of their age.
• Freeze foods that will not be used within two to three days.
• Never taste food that looks spoiled 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 below).
• 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 or lightly cooked eggs 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.

**Table 1. Recommended Minimum Cooking Temperatures**

<table>
<thead>
<tr>
<th>Product</th>
<th>Cooking Temperature or Visual Characteristics</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Eggs, Egg Dishes, and Casseroles</strong></td>
<td></td>
</tr>
<tr>
<td>Eggs</td>
<td>Cook until yolk and white are firm</td>
</tr>
<tr>
<td>Casseroles, foods with eggs, custards, and egg sauces</td>
<td>160°F</td>
</tr>
<tr>
<td><strong>Veal, Beef, Pork, Lamb, Rabbit, Goat, Game</strong></td>
<td></td>
</tr>
<tr>
<td>Whole pieces of 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>-----------------------------------------------------------</td>
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</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>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Ham</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Fresh (raw)</td>
<td>160°F</td>
</tr>
<tr>
<td>Pre-cooked (to reheat)</td>
<td>160°F</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Seafood</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Fin fish (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 (may be high risk food for people with low white count or immunosuppressed)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Leftovers, Hot Dogs and Luncheon Meats</th>
<th></th>
</tr>
</thead>
<tbody>
<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 Low White Blood Counts

* Low white blood cell count refers to a neutrophil count less than 1000

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).
- Drink fruit juices that 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 placemat, 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 reflect 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.
- Do not eat soft cheeses such as feta, brie, camembert, farmer’s blue-veined, stilton or Mexican-style cheese (queso fresco). Note: Cooked soft cheeses such as brie, camembert, feta, or farmer’s cheese may be acceptable, as the risk of contracting food-borne illness from cooked soft cheeses is low.
- Cut tofu into 1-inch cubes or smaller and boil five minutes in water or broth before eating or using in recipes. Note: This process is not necessary if using pasteurized tofu or aseptically packaged, shelf-stable tofu such as Mori-Nu® silken tofu.
- Avoid fresh fruit or vegetable salsas and salad dressing found in the refrigerated section of the grocery store. Choose shelf-stable salsas and salad dressing instead. Shelf-stable refers to unopened canned, bottled, or packaged food products that can be stored at room temperature before opening; the container may require refrigeration after opening.
- Do not consume raw honey or honeycomb. Choose grade A honey.
Water Safety Guidelines
Public water quality and treatment varies, so always check with the local health department and water utility about the safety of household and community tap water and ice for use by immunosuppressed persons.

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

Well Water
It is not considered safe for persons who are immunosuppressed and at risk for infection to consume well water from private or small community wells unless the water is tested daily and found to be negative for coliforms and Cryptosporidium organisms. Examples of ways well water could become contaminated include:

- Construction occurring near the well
- Well depth is shallow
- Well is located near a dairy or large numbers of livestock
- Flooding has recently occurred in the well area

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

Private Wells and Small Community Wells: The water quality from these sources cannot be guaranteed unless it is tested daily and found negative for coliforms and Cryptosporidium organisms. It is recommended that you use other approved water sources, including boiled water or bottled water. The following are considered safe water sources, if your water is not from a city water or municipal well supply:

- Boiled Water: You can make safe water at home by bringing tap water to a rolling boil for 15-20 minutes. After boiling, store water in a clean, covered container in the refrigerator. Discard water not used within 48 hours (two days).
- Distilled Water: You can distill water using a steam distillation system. After distilling, store the water in a clean, covered container in the refrigerator. Discard water not used within 48 hours (two 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 specific 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. Members of the International Bottled Water Association (IBWA) follow stricter manufacturing practices in their water bottling process than those practices currently mandated by the United States Food and Drug Administration. Water bottled by a member of the International Bottled Water Association may be preferable to water produced by non-member bottlers.

**Not Considered Safe:** Common home water filtration devices do not remove bacteria or viruses. If well water is chlorinated per local health department guidelines, 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)
- Water filters (see below)

**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:

The filters must be designed to remove coliforms and Cryptosporidium. Any of the following are acceptable:

- Reverse osmosis filter
- Absolute pore size of 1 micron or smaller filter.
- Tested and certified by NSF Standard #53 for cyst removal

The water tap filter must be installed immediately before the water tap. 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”).
Nutrition Guidelines

If your child has a decreased immune functioning, they are at increased risk of developing a food-related infection. This diet is to help your child avoid foods that are more likely to contain infection-causing organisms, while allowing healthy food choices. You may want to discuss the safety of these or other foods with your dietitian. Follow this diet before and after all conditioning therapy. Your doctor 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.
- Before the end of these time periods, you and your child should talk to your doctor and dietitian about whether or not to continue any part of the diet.

<table>
<thead>
<tr>
<th>Food Groups</th>
<th>May Eat</th>
<th>Do Not Eat</th>
</tr>
</thead>
</table>
| **Dairy**   | Pasteurized grade A milk and milk products: eggnog, ice cream and ice cream bars, yogurt, frozen yogurt, sherbet, milkshakes, cream, cottage, ricotta, and processed cheeses. Dry, refrigerated, or frozen pasteurized whipped topping  
  Commercially packaged hard and semi-soft cheeses such as cheddar, mozzarella, parmesan, Swiss, Monterey Jack.  
  Cooked soft cheeses: brie, camembert, feta, farmer’s cheese. Though not risk-free, the risk of food-borne illness from these is low.  
  Commercially sterile ready-to-feed and liquid-concentrate infant formula. Avoid powdered formulas.                                                                                                                                                                           | Non-pasteurized or raw milk and milk products. Cheeses from delicatessens Cheese containing chili peppers or other uncooked vegetables Cheeses with molds: stilton, blue, roquefort, gorgonzola Mexican-style soft cheese, queso fresco, queso blanco |
<p>| <strong>Meat and Meat Substitutes</strong> | All meats cooked to well done. 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 can be used uncooked. Commercially-packaged salami, bologna, hot dogs, ham and other luncheon meats, heated until steaming Canned and shelf-stable smoked fish. Refrigerate after opening. Shelf-stable is unopened canned, bottled, or packaged foods, stored unopened at room temperature. Pasteurized or cooked tofu. Aseptically packaged, shelf-stable tofu and pasteurized tofu do not need to be boiled. Cut unpasteurized tofu into 1-inch cubes, and boil at least 5 minutes. | Raw or undercooked tofu meat, poultry, fish, game Raw or undercooked eggs and non-pasteurized egg substitutes; eggs over easy, soft-boiled, or poached. Meats and cold cuts from delicatessens Hard-cured salami in natural wrap Uncooked refrigerated smoked seafood such as salmon or trout labeled “lox,” “nova-style,” “jerky,” “lox” |</p>
<table>
<thead>
<tr>
<th>Food Groups</th>
<th>May Eat</th>
<th>Do Not Eat</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>five minutes in water or broth before eating or using in recipes.</td>
<td>“smoked” “kippered”</td>
</tr>
<tr>
<td></td>
<td>Refrigerated smoked seafood such as salmon or trout if cooked to 160°F or in a cooked dish or casserole</td>
<td>Pickled fish</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Tempe (tempeh) products</td>
</tr>
<tr>
<td>Fruits and Nuts</td>
<td>Well washed raw and frozen fruit; foods containing well washed raw fruits</td>
<td>Unwashed raw fruits</td>
</tr>
<tr>
<td></td>
<td>Cooked, canned and frozen fruit</td>
<td>Unroasted raw nuts</td>
</tr>
<tr>
<td></td>
<td>Pasteurized juices and frozen juice concentrates</td>
<td>Roasted nuts in the shell</td>
</tr>
<tr>
<td></td>
<td>Dried fruits</td>
<td>Non-pasteurized fruit and vegetable juices</td>
</tr>
<tr>
<td></td>
<td>Canned or bottled roasted nuts</td>
<td>Fresh fruit salsa found in grocery refrigerator case</td>
</tr>
<tr>
<td></td>
<td>Shelled, roasted nuts and nuts in baked products</td>
<td>Non-pasteurized items containing raw fruits in grocer’s refrigerator case</td>
</tr>
<tr>
<td></td>
<td>Commercially-packaged nut butters (such as peanut, almond, soybean butter)</td>
<td></td>
</tr>
<tr>
<td>Entrees, Soups</td>
<td>All cooked entrees and soups</td>
<td>All miso products: miso soup and miso paste</td>
</tr>
<tr>
<td>Vegetables</td>
<td>Well washed raw and frozen vegetables. Rinse under clean, running water before use, including produce that is to be cooked or peeled, such as bananas, oranges, and melon.</td>
<td>Unwashed vegetables, herbs</td>
</tr>
<tr>
<td></td>
<td>All fresh, frozen, canned vegetables, including potatoes</td>
<td>Fresh non-pasteurized salsa from the refrigerator case</td>
</tr>
<tr>
<td></td>
<td>Shelf-stable bottled salsa. Refrigerate after opening.</td>
<td>Non-pasteurized items with raw vegetables from grocer’s refrigerator case</td>
</tr>
<tr>
<td></td>
<td>Cooked vegetable sprouts, such as mung bean sprouts</td>
<td>All raw vegetable sprouts (alfalfa, clover, mung bean)</td>
</tr>
<tr>
<td></td>
<td>Fresh, well washed herbs and dried herbs and spices (added to raw or cooked foods)</td>
<td></td>
</tr>
<tr>
<td>Bread, Grain, and Cereal Products</td>
<td>All breads, bagels, rolls, English muffins, muffins, pancakes, waffles, French toast</td>
<td>Raw (not baked or cooked) grain products (such as raw oats)</td>
</tr>
<tr>
<td></td>
<td>Potato chips, corn chips, tortilla chips, pretzels, popcorn</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Cooked grains, grain products such as pasta, rice</td>
<td></td>
</tr>
<tr>
<td></td>
<td>All cereals, cooked and ready-to-eat</td>
<td></td>
</tr>
<tr>
<td>Beverages</td>
<td>Boiled well water</td>
<td>Unboiled well water</td>
</tr>
<tr>
<td></td>
<td>Tap water and ice made from tap water. If using a non-city water service use boiled or bottled water see “Water Safety Guidelines” in “Food Safety Guidelines”.</td>
<td>Cold-brewed tea made with warm or cold water</td>
</tr>
<tr>
<td></td>
<td>Commercially-bottled distilled, spring and natural waters See ““Water Safety Guidelines” in “Food Safety Guidelines” for approved bottled water treatments.</td>
<td>Non-pasteurized fruit and vegetable juices</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Mate’ tea</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Wine, unpasteurized beer</td>
</tr>
</tbody>
</table>
### Food Groups

<table>
<thead>
<tr>
<th>May Eat</th>
<th>Do Not Eat</th>
</tr>
</thead>
<tbody>
<tr>
<td>All canned, bottled, and powdered drinks</td>
<td>(Note: All alcoholic beverages should only be consumed following doctor’s approval.)</td>
</tr>
<tr>
<td>Instant and brewed coffee and tea; cold brewed tea made with boiling water</td>
<td></td>
</tr>
<tr>
<td>Herbal teas brewed from commercially-packaged tea bags</td>
<td></td>
</tr>
<tr>
<td>Commercial nutritional supplements, liquid and powdered</td>
<td></td>
</tr>
<tr>
<td>Commercially sterile ready-to-feed and liquid-concentrate infant formula. Avoid powdered formulas.</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Desserts</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Refrigerated commercial and homemade cakes, pies, pastries, and pudding</td>
<td>Unrefrigerated cream-filled pastry products (not shelf-stable)</td>
</tr>
<tr>
<td>Refrigerated cream-filled pastries</td>
<td></td>
</tr>
<tr>
<td>Cookies, both homemade and commercially prepared</td>
<td></td>
</tr>
<tr>
<td>Shelf-stable cream-filled cupcakes (Twinkies®, Ding Dongs®) and fruit pies (Poptarts®, Hostess® fruit pies)</td>
<td></td>
</tr>
<tr>
<td>Canned and refrigerated puddings</td>
<td></td>
</tr>
<tr>
<td>Ices, popsicles, and similar products</td>
<td></td>
</tr>
<tr>
<td>Candy, gum</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Fats</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Vegetable oils and shortening</td>
<td>Fresh salad dressings, found in the grocer’s refrigerated case, containing raw eggs or cheeses listed as “Do Not Eat” under “Dairy.”</td>
</tr>
<tr>
<td>Refrigerated lard, margarine, butter</td>
<td></td>
</tr>
<tr>
<td>Commercial, shelf-stable mayonnaise and salad dressings including Blue Cheese and other cheese-based salad dressings. Refrigerate after opening.</td>
<td></td>
</tr>
<tr>
<td>Cooked gravy and sauces</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Other</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Commercial pasteurized Grade A honey. Honey products are not allowed for any child less than one year old and or for children with SCIDS until 9 months post-transplant.</td>
<td>Raw honey; honey in the comb</td>
</tr>
<tr>
<td>Salt, granulated sugar, brown sugar</td>
<td>Herbal and nutrient supplement preparations Refer to Herbal and Nutrient Supplements.</td>
</tr>
<tr>
<td>Jam, jelly, syrups. Refrigerate after opening.</td>
<td>Brewer’s yeast, if uncooked</td>
</tr>
<tr>
<td>Catsup, mustard, BBQ sauce, soy sauce, other condiments. Refrigerate after opening.</td>
<td></td>
</tr>
<tr>
<td>Pickles, pickle relish, olives. Refrigerate after opening</td>
<td></td>
</tr>
<tr>
<td>Vinegar</td>
<td></td>
</tr>
</tbody>
</table>

### More Nutrition Tips

The chemotherapy your child will receive during his marrow or stem cell transplant will affect his nutrition in many ways. You may find that your child is not eating the way he normally does because of nausea, mouth and throat soreness, lack of appetite, or changes in the way foods taste. Use these tips to help you:
• Keep in mind that your child’s calorie needs are higher during your transplant. Keep your child’s body nourished even during the times you do not feel like eating.

• Your child will be using some medications that can be hard on his kidneys, so it is important to drink lots of fluids. Fluids include beverages, ice cream, sherbet, popsicles, Jell-O®, and soups. Your dietitian will give you a goal for daily fluid intake.

• Protein is needed for repair, growth, and fluid balance. Include high protein foods such as eggs, milk/dairy products, meat/poultry/fish, or medical nutrition supplements (such as Ensure®, Boost®, Scandi-Shake®, Instant Breakfast®, NuBasics® or Resource®) as much as possible each day. Other foods such as beans, nuts, and pasta can add protein to your child’s meals.

• Eat smaller, more frequent meals; snack often, and keep beverages handy at all times. Use a sports bottle to keep beverages close all day long.

• Foods will probably taste differently for a while. This will pass, but your child may need to make some adjustments to the way he eats. Eat foods that taste bland with those that taste good to you. Drink beverages with meals or snacks if your mouth is dry. And remember, what does not taste good today might taste good tomorrow.

• Tell your doctor or nurse if you child is having nausea, vomiting, diarrhea, constipation, heartburn, or mouth and throat pain.

• A dietitian can answer questions you might have or help you find the foods and nutritional supplements that will work for your child.

Shopping List
Below are some foods that may be easier to tolerate during and after chemotherapy. Circle the items your child enjoys and bring the list with you to the grocery store. If your child has high blood sugar (hyperglycemia), check with your dietitian or doctor to see which foods are right for your child.

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

Cereals/Breads
• Cream of Wheat®
• Cream of Rice®
• Cold cereals
• Muffins

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

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

**Fruits**
- Canned fruits
- Fresh melons
- Applesauce

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

*good protein sources

- Noodles*
- Gravy

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

Some foods to try:

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

Some foods to try:

<table>
<thead>
<tr>
<th>Beverages/Other</th>
<th>Proteins</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fruit-ades, Kool-Aid®, popsicles</td>
<td>Blenderized meats and casseroles</td>
</tr>
<tr>
<td>Slushies</td>
<td>Bland entrees: macaroni and cheese, soufflés, bland quiches, creamed chicken, spaghetti with cream sauce</td>
</tr>
<tr>
<td>Low-salt homemade or canned soups</td>
<td>Baby foods</td>
</tr>
<tr>
<td>Herbs for seasoning: thyme, basil, oregano, bay leaf</td>
<td>Milk</td>
</tr>
<tr>
<td></td>
<td>Eggnog</td>
</tr>
<tr>
<td></td>
<td>Cream pies, cheesecake</td>
</tr>
<tr>
<td></td>
<td>Custard, pudding</td>
</tr>
</tbody>
</table>

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

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

Some foods to try:

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

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

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

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

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

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

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

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

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

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

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

1. Interactions between preparations and prescribed medications may reduce the effectiveness of drugs routinely used during transplantation or chemotherapy.
2. Potential contamination of preparations derived from plants may cause bacterial, fungal or parasitic infections because of inadequate purification and sterilization. Even boiling water may not destroy some infectious organisms that can contaminate these products.
3. A few specific preparations have been repeatedly associated with serious toxic side effects to the liver, blood, kidneys, heart, and other body organs.
4. The production, distribution, and labeling of herbal preparations and nutrient supplements are not regulated by the U.S. Food and Drug Administration. As a result, the dosage may vary from the dose listed on the label. Also, the product might contain ingredients not listed on the label.

Herbal and Botanical Preparations

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

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

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

- Alfalfa
- Borage
- Chaparral
- Chinese herbs
- Coltsfoot
- Comfrey
- DHEA
• Dieter’s Tea (senna, aloa, rhubarb root, buckthorn, cascara, castor oil)
• Ephedra or MaHuange
• Groundsel or Life Root
• Heliotrope or Valerian
• Kava kava
• Laetrile (Apricot Pits)
• Licorice Root
• L-tryptophan
• Lobelia
• Maté Tea
• Pau d’arco
• Pennyroyal
• Sassafras
• St. John’s Wort
• Yohimbe and Yohimbine
Vitamin and Mineral Supplements and Antioxidants

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

<table>
<thead>
<tr>
<th>Micronutrient</th>
<th>Dietary Reference Intakes</th>
<th>Safe Upper Limits</th>
</tr>
</thead>
<tbody>
<tr>
<td>Vitamin A</td>
<td>2700 – 3000 IU/800 – 1000 RE or mcg</td>
<td>No more than 10,000 IU or 3,000 mcg</td>
</tr>
<tr>
<td>Vitamin C (Ascorbic Acid)</td>
<td>120 mg</td>
<td>No more than 500 mg</td>
</tr>
<tr>
<td>Vitamin D (Calciferol)</td>
<td>200 – 600 IU or 5-15 mcg</td>
<td>No more than 2000 IU or 50 mcg</td>
</tr>
<tr>
<td>Vitamin E (Tocopherol)</td>
<td>8 – 10 mg or IU</td>
<td>No more than 1000 mg or IU while on anticoagulant therapy No more than 800 mg or IU</td>
</tr>
<tr>
<td>ß-Carotene</td>
<td>No DRI</td>
<td>No more than 25,000 IU or 15 mg</td>
</tr>
<tr>
<td>Folic Acid (Folate)</td>
<td>400 mcg</td>
<td>No more than 1000 mcg or 1 mg</td>
</tr>
<tr>
<td>Vitamin B₃ Thiamin</td>
<td>1.1 – 1.2 mg</td>
<td>While high intakes of B-vitamins may not be toxic, talk with your dietitian to discuss your particular needs</td>
</tr>
<tr>
<td>Vitamin B₂ Riboflavin</td>
<td>1.1 – 1.3 mg</td>
<td></td>
</tr>
<tr>
<td>Niacin (mg of Niacin equivalents)</td>
<td>14 – 16 mg</td>
<td>No more than 35 mg</td>
</tr>
<tr>
<td>Vitamin B₆ Pyridoxine</td>
<td>1.3 – 1.7 mg</td>
<td>No more than 100 mg</td>
</tr>
<tr>
<td>Vitamin B₁₂ (Cobalamin)</td>
<td>2.4 mg</td>
<td>While high intakes of B-vitamins may not be toxic, talk with your dietitian to discuss your particular needs</td>
</tr>
<tr>
<td>Biotin</td>
<td>30 mcg</td>
<td></td>
</tr>
<tr>
<td>Pantothenic Acid</td>
<td>5 mg</td>
<td></td>
</tr>
<tr>
<td>Iron</td>
<td>12 – 15 mg</td>
<td>Iron supplementation is not recommended post-transplant.</td>
</tr>
<tr>
<td>Selenium</td>
<td>40 – 70 mcg</td>
<td>No more than 200 mcg</td>
</tr>
<tr>
<td>Calcium</td>
<td>1000 – 1200 mg</td>
<td>No more than 2500 mg</td>
</tr>
</tbody>
</table>
Recommended Vitamin Brands
Note: vitamin brands that contain Iron and/or extra C are not recommended.
- One-a-Day 50 Plus®
- Nature Made Mature Balance®

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

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

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

What is a Central Venous Catheter?
A central venous catheter, or central line, is a small flexible tube inserted into a large vein in your child’s chest. It is used to give your child fluid, nutrients, medicine, and blood products. It is also used to get blood samples without having to draw blood from your child’s arm. Many types of central venous catheters are available; they may be called tunneled catheters, central venous lines, and Hickman lines.

Central Venous Catheter Placement: What to Expect
The insertion of the central line is a minor surgical procedure. It is done in an operating room under general anesthesia (full sleep) and takes about one hour. The catheter is threaded through a “tunnel” under the skin and then placed into a large vein in the chest near the neck that returns blood to the heart. A small cuff on the catheter helps hold it in place in the tunnel, underneath the skin. This cuff also acts as a barrier to help prevent bacteria on the skin from traveling up the catheter tunnel and into the bloodstream. Your child will likely have a few sutures in place to help secure the line. Your child’s shoulder and chest area may be sore for a few days after insertion, for which a mild pain reliever will be prescribed. It is helpful for your child to move the shoulder and neck right after surgery to help keep the area from getting stiff.

Your child’s nurse will teach you how to care for the central line catheter by the day before it is inserted, and you will perform the first dressing change with the nurse’s help the day after the catheter is inserted.

How is the procedure done?
1. The doctor will make two small incisions—one in the upper chest near the neck, and the other on the lower chest.
2. Between these incisions, your child’s doctor will make a tunnel under the skin.
3. The catheter will be inserted in the lower incision on the chest and pulled through the tunnel.
4. The catheter is inserted into the large chest vein located near the neck (this vein returns blood to the heart).

Things to remember:
• Securing the line by dressing your child in a tight-fitting tank top or sports bra for at least one night after placement is recommended.
• Do not give your child aspirin, ibuprofen, or other over-the-counter pain medications without first checking with your child’s doctor or nurse.
• No heavy lifting for 72 hours.

Activity
Routine light exercise, sports, sleep, and travel are not limited by having a central line. The dressing is changed depending on dressing type or any time the dressing gets wet. Avoid swimming pools and hot tubs. Do not allow the blue caps of the catheter to float in bath water. Do not submerge any part of the catheter in bath water. The most important thing to remember about the line during activity is to always attach the catheter to skin, clothing or necklace to prevent accidental dislodgement. You may use a “bulldog” clamp to attach it to clothing or tape the catheter to the skin. Remember that the “bulldog” is an emergency clamp and should be kept with your child at all times.

Catheter Care at a Glance

<table>
<thead>
<tr>
<th>Dressing Options</th>
<th>Dressing Change</th>
<th>Flushing</th>
<th>Tape Tabs</th>
<th>Alcohol Wipe</th>
<th>Parafilm®</th>
<th>AquaGuard®</th>
</tr>
</thead>
<tbody>
<tr>
<td>Occlusive Dressing with or without Biopatch®</td>
<td>every 7 days</td>
<td>daily or with each use</td>
<td>daily</td>
<td>daily</td>
<td>with bathing</td>
<td>with bathing</td>
</tr>
<tr>
<td>Gauze and Tape</td>
<td>daily</td>
<td>daily or with each use</td>
<td>daily</td>
<td>daily</td>
<td>with bathing</td>
<td>with bathing</td>
</tr>
</tbody>
</table>

Fast Facts on Central Line Care: How to Protect Your Child’s Catheter

**DO**

- Keep dressing supplies dry—away from the bathroom and kitchen.
- Secure your child’s catheter and prevent accidental removal of the line. There are many ways to do this:
  - Place plastic tape tabs between clamp and cap on the catheter and change daily. Use the plastic tape tabs and bulldog clamp to secure the catheter to clothing or a necklace.
  - Place catheter in a clean, cloth pouch and secure the pouch with a bulldog clamp to clothing or a necklace.
  - Coil the catheter over the exit site and tape it to the skin.
- Place catheter clamps on the thick, reinforced area of the line, not too close to the hard plastic portion of the line.
- Change the dressing if it is wet, if it starts to come off, or if there is moisture underneath the dressing.
- Clean your child’s line once a day with alcohol swabs and replace plastic tape tabs.
- When bathing or showering, you should always cover the exit site of your child’s catheter with a plastic covering such as Aquaguard® or plastic wrap to prevent tap water from entering the catheter tunnel. The uncovered exit site should not come in contact with tap or bath water.
- Always securely wrap the Clave® end caps with Parafilm® to prevent water from entering the Clave® top or into the connection to the catheter.
- Change your child’s dressing if you notice moisture under the dressing when removing the plastic covering and Parafilm®. If you notice moisture under the Parafilm®, ask to have your child’s Clave® caps changed in the clinic.
- When changing your child’s dressing, if build-up is noted, you may first cleanse skin around the exit site with a sterile, saline-soaked gauze pad to remove ChloraPrep One Step® (chlorhexidine) and the no-sting barrier. Never use tap water to cleanse the exit site.
- Keep your child’s bulldog clamp with you at all times. The bulldog clamp is a safety clamp. Clamp the catheter close to their chest and call the clinic immediately if the catheter leaks, gets cut, or breaks.
**DON’T**

- Do not take the Clave® cap connectors off of your child’s catheter.
- Do not tape over the connection between Clave® caps and catheter.
- Do not let your child swim or use a hot tub.
- Do not allow Clave® caps, central catheter, or exit site to be submerged in bath water.
- Do not store catheter supplies in the bathroom or kitchen.
- Do not use scissors near your child’s catheter.

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**Daily Care: When to Flush and What Solution to Use**

- Flush each line of the catheter with normal saline followed by a heparin solution at least once each day and after each use.
- If your child is having a blood draw, both lines of the catheter will be flushed at that time unless the side not used for blood draw is connected to IV tubing.
- Flush the catheter at the beginning of an infusion with normal saline only.
- Flush the catheter at the end of an infusion with normal saline followed by a heparin solution.
- **If your child is receiving antibiotics:** Your doctor may recommend that they alternate infusing antibiotic doses between all lumens of the catheter. Please check with your child’s nurse if you have any questions.

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**Anti–Coagulation Therapy for Your Child’s Catheter**

**Heparin** is used to flush your child’s catheter to prevent clot growth within the central line. You will flush each lumen of the catheter with normal saline and heparin lock flush solution at least once a day. The daily heparin catheter flush is still required even if your child is on any of the oral or injectable blood thinners listed below to prevent or treat a blood clot.

In addition to heparin flushes, your child may also be required to take other medications to prevent clotting such as:

- **Warfarin (Coumadin®)** is given orally to prevent or treat clotting within or around your child’s central line or to treat blood clots that have formed in other blood vessels. Your child will have their Protime (PT) and International Normalized Ratio (INR) blood levels drawn throughout their treatment to make sure that the clots are treated appropriately.
- **Low-molecular weight heparin**, such as enoxaparin (Lovenox®), tinzaparin (Innohep®), and dalteparin (Fragmin®), or fondaparinux (Arixtra®; which is not a heparin or low-molecular weight heparin): Your child will be prescribed only one of the low-molecular weight heparin medications or Arixtra® at any one time. Your child will receive a shot/injection under the skin 1-2 times each day. Your child will have blood levels drawn periodically to check for anti-coagulation activity to ensure that they are treated appropriately.
Heparin “allergy” or history of heparin-induced thrombocytopenia (HIT): If you have ever been told that your child has an allergy to heparin, they should not use heparin or low-molecular weight heparin to prevent clots. This includes using heparin to flush the catheter. If your child has a heparin allergy, please ask about other flushing options. Please discuss with your child’s doctor or nurse if you are unsure if your child has a heparin allergy.

How to Flush the Catheter
Flush each line of the catheter at least once each day and after each use, first with saline, then with heparin. Supplies needed:
• Two -10 ml syringes with normal saline flush
• Two -5 ml syringes with heparin lock flush solution
• Alcohol wipes

1. Wash your hands.

2. Remove the syringe(s) from their package(s) by peeling the plastic downward.

3. Put on clean gloves. Vigorously scrub the top of the Clave® cap with an alcohol wipe for 15 seconds using a twisting motion as if you were juicing an orange. Allow the Clave® to dry completely for at least 5 seconds.

4. Hold the syringe with the cap on, pointed towards the ceiling, and remove the cap from the syringe. Carefully remove the air bubble by gently pulling back on the syringe to release pressure and then pushing up on the plunger until all air is removed from the syringe.

5. Insert the syringe into the center of the Clave® cap by pushing in and turning toward the right. Be sure not to touch the end of the Clave® cap or end of the syringe with your hand. The syringe tip should only touch the cleansed end of the catheter cap. If in doubt, please throw it out.
6. Unclamp the catheter.

7. Flush first with 5ml of normal saline followed by 2.5ml of heparin. Push the plunger on the syringe with alternating pressure and release (starting and stopping to create turbulence) to inject the fluid into the catheter. This keeps the catheter clean. Do not flush all of the fluid into the catheter. Only flush 5 ml of normal saline and 2.5 ml of heparin.

9. To create positive pressure in the line, clamp the catheter while injecting the last of the fluid before removing the syringe.

10. Remove the syringe. Discard in regular garbage can.

11. Repeat steps 2-10 on the other line. Use separate syringe for flushing each side of the central line.

**Daily Care: Cleaning the Catheter**
It is important to clean your child’s catheter every day. This helps to prevent infection.

1. Remove plastic tape tabs near Clave® caps.
2. Using two alcohol wipes for each line (one to hold the line and one to wipe it), start where line exits the dressing and wipe towards the end of the line. Take special care to thoroughly scrub around the connection between the line and the Clave® caps.
3. Replace plastic tape tabs near Clave® caps.
If you are using a baby bootie or cloth bag to hold your line, please be sure to use a freshly laundered bag after you clean your line. Make sure to change it daily.

Remember to clean your child’s catheter every day.

**When to Change Your Child’s Dressing**

- **If your child has a Biopatch® and Occlusive Dressing:**
  - Change the dressing every 7 days.
- **If your child has a Transparent Occlusive Dressing:**
  - Change dressing every 7 days.
- **If your child has a Gauze and Tape Dressing:**
  - Dressing should be changed daily.

**Additional Dressing Change Tips:**

- Both dressing and exit site should be looked at each day.
- Talk to the nurse if your child’s skin is sensitive to the dressing.
- The dressing should also be changed if:
  - The exit site cannot be seen because of drainage or moisture.
  - The dressing starts to come off.

**Dressing Change Supplies**

Wash your hands with soap and water. Assemble your supplies on a clean workspace:

- **If your child has a Biopatch® and Occlusive Dressing:**
  - 1 package 2x2 gauze
  - Biopatch®
  - 1 ChloraPrep One-Step® application
  - 2 pairs of clean gloves
  - Sterile saline flush
  - 2 alcohol wipes
  - 2 Cavilon No-Sting Barrier Film® foam pads
  - Transparent dressing (IV3000, Sorbaview, Tegaderm™ HP)
  - Plastic tape

- **If your child has a Transparent Occlusive Dressing:**
  - 1 package 2x2 gauze
  - Transparent dressing (IV3000, Sorbaview, Tegaderm HP)
  - 1 ChloraPrep One-Step® application.
  - *If allergic to Chlorhexidine, use 1 package isopropyl alcohol swab sticks and 1 package povidone-iodine swabs stick.
  - 2 pairs of clean gloves
  - Sterile saline flush
  - Plastic tape

- **If your child has a Gauze and Tape Dressing:**
• 3 packages 2x2 gauze (or 1 package 2x2 split gauze and 2 packages 2x2 gauze)
• 2 alcohol wipes
• Sterile saline syringe
• Skin prep
• Paper tape
• 1 ChloraPrep One-Step® application
  *If allergic to Chlorhexidine, use 1 package isopropyl alcohol swab sticks and 1 package povidone-iodine swabs stick.
• 2 pairs of clean gloves
• Plastic tape (for tape tabs)

**Dressing Change Steps**

1. Wash your hands with soap and water again.

2. Put on a clean pair of gloves.

3. Remove old dressing and throw away.

   □ **If your child has an occlusive dressing with Biopatch®:**
   - Remove the transparent dressing by starting at a corner, pulling “low and slow.”
   - When the Biopatch® is reached, continue to slowly pull back on the dressing to separate the Biopatch from the transparent dressing. **Do not use scissors.**

   □ **If your child has an Occlusive Transparent Dressing:**
   - Remove the transparent dressing by starting at a corner, pulling “low and slow.” **Do not use scissors.**

   □ **If your child has a Gauze and Tape Dressing:**
   - Remove the old gauze and tape dressing. **Do not use scissors.**

4. Remove plastic tape tabs near Clave® caps and throw away.

5. Open gauze pad and wet the pad with saline from the syringe. **Do not set a wet gauze pad on any surface or it will become dirty.**

6. Gently wipe skin in all directions around exit site with the saline-soaked gauze pad, allow to dry. This will remove any buildup of Chloraprep® and No-Sting Barrier® film and will also decrease skin irritation. Throw away gauze.

7. Report to your nurse if there is:
   - Bleeding or drainage at the catheter site.
   - Redness or swelling at the catheter site.
   - Pain or discomfort at the catheter site.

8. Take off gloves and throw them away.

9. Wash your hands again.

11. If crust is present, clean it from catheter exit site, using an alcohol wipe if necessary. If this is a scab, you do not need to remove it.

12. Clean around catheter exit site with ChloraPrep One-Step® swab using a back-and-forth motion across the exit site for 30 seconds. Allow to dry completely for 1-2 minutes. The Chlorhexidine used while cleaning the catheter exit site should be completely dry before applying the Cavilon No-Sting Barrier Film®.

*Alternate cleaning for Chlorhexidine allergy: Clean exit site in circular motion starting at the catheter and circle outward away from the exit site using one of the povidone-iodine swabs. Use the other two povidone swabs for a total of 3 cleanings at the exit site. Allow to air dry. Follow with 3 applications of alcohol swab sticks in the same pattern. Allow to air dry.

13. Open two alcohol wipe packages.
   - Using one alcohol wipe, hold the catheter near the exit site (near chest).
   - Using the second alcohol wipe, start where the line exits the skin and wipe the entire catheter.


15. Apply skin prep:
   - If your child has a Biopatch® and Occlusive Dressing:
     - Apply skin prep (Cavilon No-Sting Barrier Film®) to the area that will be under the transparent dressing. Avoid the exit site and the area that will be under the Biopatch®, as it will not be able to penetrate the skin and work to prevent an infection. Allow to dry completely for 1-2 minutes.

   - If your child has a Transparent Occlusive Dressing:
     - Apply skin prep (Cavilon No-Sting Barrier Film) to the site where the dressing will be placed.

   - If your child has a Gauze and Tape Dressing:
     - Apply skin prep to area where paper tape will be applied—allow to dry completely.

16. Apply new dressing:
   - If your child has a Biopatch® and Occlusive Dressing:
     - Place Biopatch® around catheter with the white side towards the skin (white to the bone, blue to the sky). The edges of the slit should touch each other to work best.
     - Do not place Biopatch® on top of catheter. If edges do not meet because catheter is too big or stitches are in the way, place the Biopatch® around the
catheter making sure the Biopatch® is in contact with the skin.

- To ensure easy removal, place Biopatch® so that the catheter rests on or near the slit.
- Place the transparent dressing over the catheter. Optional: make a loop with catheter to decrease the external length of the catheter.
- Paint the border of the transparent dressing with the Cavilon No-Sting Barrier® to create a seal between the dressing and the skin.
- Date the dressing with today’s date.
- If the Biopatch® becomes swollen with fluid, water, or blood, or the dressing starts to come off, the dressing should be changed more frequently. Talk to your nurse if your child’s skin is sensitive to the transparent dressing or if your child’s dressing needs to be changed more often than once every 3 days.

☐ If your child has a Transparent Occlusive Dressing:
- Place transparent dressing over central line exit site. Optional: make a loop with catheter to decrease the external length of the catheter.
- Paint the border of the transparent dressing with Cavilon-No Sting Barrier® to create a seal between the dressing and the skin.
- Date the dressing with today’s date.

☐ If your child has a Gauze and Tape Dressing:
- If using folded gauze: touching only the corner, remove one of the 2x2 gauze pieces, fold in half and place under the catheter.

- If using split gauze: Touching only the corners, place the 2 split gauze with the slits positioned horizontally (in opposite directions) around the central line as close as possible to where it exits the skin.
- Place the second 2x2 over the line and gauze.
- Secure gauze to skin with paper tape. Write the date and time on the dressing.
- Talk to your child’s nurse if the skin is sensitive to paper tape; an alternative tape may be suggested.

17. Secure the catheter by:
- Coiling it over the exit site and taping it to the skin,
- Placing in a clean cloth pouch and secure with a bulldog clamp.
- Using a bulldog clamp to attach the tape tab to your clothing or necklace.

Protecting Your Child’s Central Line When Bathing Or Showering

1. Wash your hands.

2. Place Parafilm® on Clave® caps and tubing connections.
• First stretch the Parafilm®.

<table>
<thead>
<tr>
<th>Problem</th>
<th>Solution</th>
</tr>
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</table>

• Then wrap it around the Clave® cap connection on each side of the catheter (stretching it makes it stick to itself).
• Then flip it over the end of the catheter to cover the Clave® cap, using your fingers to twist and mold it around the catheter, with a spiraling-down technique.
  • Wrap only around the thicker part of the end of the catheter. The Parafilm® will fit closely around the connector and will stick to itself. Make a tab on the end so it will be easier to remove.

3. Cover the entire dressing with a square of AquaGuard® (approximately 9x9). You may place the entire catheter under the AquaGuard®. If you do, the catheter tips must still be covered with Parafilm®. *Alternatively, plastic wrap may also be used in place of AquaGuard® and tape with paper tape on all sides.*

4. If your child takes a bath, the catheter should be kept above the water level at all times. If your child showers, the dressing should be kept out of the direct stream of water.

5. After bathing, dry off the plastic wrap or AquaGuard® with a towel, then remove it and throw it out.

6. Remove Parafilm® from Clave® caps — **DO NOT USE SCISSORS.**

7. Replace the dressing if there is moisture underneath or it has become loose.
| Line does not flush. | 1. Check to see if catheter is clamped or kinked.  
2. Contact the SCCA Clinic or After Hours Clinic for instruction. |
|----------------------|--------------------------------------------------------------------------------------------------|
| Fluid is leaking from the catheter. Do not use scissors near your child’s line. Catheter may be cut accidentally if dressing is removed with scissors. | 1. Immediately place a bulldog clamp on the catheter as close to the chest as possible.  
2. Check the catheter to find the break. It can be as small as a pinhole.  
3. Clean the break with an alcohol wipe.  
4. Wrap a sterile 2x2 gauze or an alcohol wipe around the break in the catheter and tape it in place.  
5. Notify the SCCA Clinic or After Hours Clinic immediately to get instructions. |
| Clave® cap comes off catheter. | 1. Immediately clamp catheter –DO NOT REPLACE CAP.  
2. Scrub catheter end with alcohol for 15 seconds and let dry 5 seconds.  
3. Place sterile saline syringe on end of catheter – DO NOT FLUSH.  
4. Notify the SCCA Clinic or the After Hours Clinic immediately to get further instructions. |
| Swelling around the exit site or fluid leaking from exit site. Swelling of the exit site, or bloody drainage or fluid leaking from the exit site can be a sign that the catheter is out of place. | 1. Stop any fluids running into the catheter.  
2. Place an ice pack on the swollen area, do not apply directly to bare skin.  
3. Notify the SCCA Clinic or the After Hours Clinic immediately to get instructions. |
| Swelling of the neck and face. Swelling of the neck and face can be a symptom of the catheter being out of place or that the vein is obstructed. | 1. Stop any fluids running into the catheter.  
2. Notify the SCCA Clinic or the After Hours Clinic immediately to get instructions. |
| Air in the catheter, the child is NOT short of breath. This could be caused by air being accidentally injected into the catheter or the Clave® cap falling off when the line is not clamped. | 1. Check the clamp to make sure that it is closed and then wash hands.  
2. Open two pre-filled saline syringes and one pre-filled heparin lock flush syringe.  
3. Scrub the end of the catheter cap with alcohol for 15 seconds and let dry 5 seconds.  
4. Attach one of the pre-filled saline syringes.  
5. Unclamp the line.  
6. Pull back on the syringe until blood appears.  
7. Clamp the line and discard the syringe.  
8. Scrub the end of the catheter cap with alcohol for 15 seconds and let dry for 5 seconds.  
9. Flush the catheter as usual, making sure to close the clamp at the end of the flush. If the clave cap is not on the line, leave the syringe attached.  
10. If your child becomes short of breath, call 911. Call Clinic if Clave® Cap is off. |
| Air in the catheter, and your child SUDDENLY becomes | 1. Have your child lie down on their left side so that their right hip is lifted above the level of the heart while checking the clamps on the catheter to |

143
### Troubleshooting Problems for the Central Venous Catheter

#### Overview of Medications

<table>
<thead>
<tr>
<th>Anti-Infectives</th>
<th>Description</th>
<th>Notes</th>
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</thead>
<tbody>
<tr>
<td><strong>Anti-Infectives</strong></td>
<td></td>
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<tr>
<td>ceftriaxone (Rocephin®)</td>
<td>Prevent and treat bacterial infections</td>
<td>Given intravenously</td>
</tr>
<tr>
<td>levofloxacin (Levaquin®)</td>
<td>Prevent and treat bacterial infection</td>
<td></td>
</tr>
<tr>
<td>ciprofloxacin (Cipro®)</td>
<td>Prevent and treat bacterial infections</td>
<td></td>
</tr>
<tr>
<td>Dapsone</td>
<td>Prevent pneumocystis pneumonia</td>
<td></td>
</tr>
<tr>
<td>Trimethoprim/Sulfamethoxazole (bactrim® or septra®)</td>
<td>Prevent pneumocystic pneumonia</td>
<td>May cause white blood cell (WBC) counts to drop</td>
</tr>
<tr>
<td>vancomycin (Vancocin®)</td>
<td>Treats bacterial infections</td>
<td></td>
</tr>
<tr>
<td>acyclovir/valacyclovir (Zovirax®, Valtrex®)</td>
<td>Prevents and treats viral infections</td>
<td>Taken for one year post transplant</td>
</tr>
<tr>
<td>fluconazole (Diflucan®)</td>
<td>Prevent fungal infections</td>
<td>Taken until day +75 or off prednisone</td>
</tr>
<tr>
<td>foscarnet (Foscavir®)</td>
<td>Treats cytomegalovirus (CMV)</td>
<td>May cause electrolyte imbalances and reduced kidney function needing intravenous fluids (IVF)</td>
</tr>
<tr>
<td>ganciclovir (Dhp) (Cytovene®)</td>
<td>Treats CMV</td>
<td>May cause WBC to drop</td>
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</tbody>
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<thead>
<tr>
<th>Anti-Nausea (Antiemetics)</th>
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<tbody>
<tr>
<td><strong>Anti-Nausea (Antiemetics)</strong></td>
<td></td>
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</tr>
<tr>
<td>diphenhydramine (Benadryl®)</td>
<td>Prevent and treat nausea</td>
<td>Also treats allergic reactions, causes drowsiness</td>
</tr>
<tr>
<td>granisetron (Kytril®)</td>
<td>Prevent and treat nausea</td>
<td>Used mostly with chemotherapy treatment</td>
</tr>
</tbody>
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**SHORT OF BREATHE, DIZZY, OR CONFUSED.**

1. Be sure they are closed.
2. Call 911 for emergency assistance.
3. Tell the medics to take your child to Seattle Children’s.
4. Call SCCA Clinic or After-Hours Clinic to tell them that your child is going to the ER via ambulance.
<table>
<thead>
<tr>
<th>Medicine</th>
<th>Effect</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>lorazepam (Ativan®)</td>
<td>Prevent and treat nausea</td>
<td>Also relaxes, causes drowsiness</td>
</tr>
<tr>
<td>ondansetron (Zofran®)</td>
<td>Prevent and treat nausea</td>
<td>Used mostly with chemotherapy</td>
</tr>
<tr>
<td>prochlorperazine (Compazine®)</td>
<td>Prevent and treat nausea</td>
<td></td>
</tr>
<tr>
<td>magnesium oxide (MagOx®)</td>
<td>Supplement magnesium</td>
<td>May cause loose stools</td>
</tr>
<tr>
<td>multivitamins</td>
<td>Supplement vitamins</td>
<td>Take when off TPN (Total Parental</td>
</tr>
<tr>
<td>potassium (k-dur® Klor-con®)</td>
<td>Supplement potassium</td>
<td>Nutrition)</td>
</tr>
<tr>
<td>amlodipine (Norvasc®)</td>
<td>Treat high blood pressure</td>
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<tr>
<td>atenolol (Tenormin®)</td>
<td>Treat high blood pressure</td>
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</tr>
<tr>
<td>conjugated estrogens (Premarin®)</td>
<td>Supplement estrogen in the body, control menstrual bleeding</td>
<td></td>
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<tr>
<td>medroxyprogesterone (Provera®)</td>
<td>Supplement progesterone in the body, control menstrual bleeding</td>
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<tr>
<td>heparin (Hep-Pak®)</td>
<td>Flush for Hickman catheter to prevent clotting</td>
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<tr>
<td>warfarin (Coumadin®)</td>
<td>Prevent blood clot from forming</td>
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<tr>
<td>enoxaprin (Lovenox®)</td>
<td>Prevent blood clot from forming</td>
<td>Given as an injection</td>
</tr>
<tr>
<td>lactase (Lactaid®)</td>
<td>Aids in digestion of milk products</td>
<td>Take before milk products</td>
</tr>
<tr>
<td>omeprazole (Prilosec®)</td>
<td>Decrease stomach acid production</td>
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<tr>
<td>ursodiol (Actigall®, Urso®)</td>
<td>Prevent liver problems</td>
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</table>

**Supplements**

<table>
<thead>
<tr>
<th>Supplement</th>
<th>Effect</th>
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<td>magnesium oxide (MagOx®)</td>
<td>Supplement magnesium</td>
<td>May cause loose stools</td>
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<tr>
<td>multivitamins</td>
<td>Supplement vitamins</td>
<td>Take when off TPN (Total Parental</td>
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<tr>
<td>potassium (k-dur® Klor-con®)</td>
<td>Supplement potassium</td>
<td>Nutrition)</td>
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</table>

**Additional Medications**
# Sample Transplant Outpatient Medication Schedule

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

<table>
<thead>
<tr>
<th>Medication</th>
<th>Dosage/Dosage</th>
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<th>10</th>
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<tbody>
<tr>
<td>[ ] Bactrim:</td>
<td>[ ] 1 DS tablet x 1/day</td>
<td>[ ] 50 mg x 1/day</td>
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<td>[ ] Dapsone:</td>
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<td>Discontinue Day – 2:</td>
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<td>Acyclovir:</td>
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<td>Begin Day –4:</td>
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<td>Fluconazole:</td>
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<td>Begin Day –4:</td>
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<td>Multivitamin</td>
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<td>Kytril:</td>
<td>1 mg</td>
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<td>Take Day 0, ½ hour before TBI:</td>
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Every 4 hours as needed: Ativan 0.5-2 mg  Benadryl 25-50 mg  Compazine 10 mg
Suggested Medication Schedule

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

<table>
<thead>
<tr>
<th>Medication</th>
<th>Dosage/Directions</th>
<th>6a</th>
<th>7a</th>
<th>8a</th>
<th>9a</th>
<th>10</th>
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Chapter 4- Long Term Recovery

“The actual BMT in the hospital was doable, the recovery is the hard part.”
-BMT survivor
How to Take Care of Your Child in the First Year

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

-BMT Survivor

What To Expect Moving Forward

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

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

In addition to the information in this manual, you and your child will receive information from doctors and nurses that will help you manage your child’s care when you leave the Clinic. If you wish to continue receiving transplant information, sign up for the quarterly Thriving newsletter included in your discharge packet. You can sign up for this newsletter online at www.seattlecca.org. Scroll down to “newsletter” in the bottom right hand corner of the page.

Take pride in your child’s journey through an intensive medical treatment, but remember that full strength and fitness will take several more months, or sometimes years, to achieve. Recovery is usually a gradual process. Remember rest, exercise, and good nutrition are the cornerstone to recovery.
Transition to Home
The Long-Term Follow-Up (LTFU) department offers telephone consultation services to you and your child’s primary doctor when you return home. Call your local doctor for everyday concerns. Call your oncologists for treatment related issues. LTFU consultation is available at SCCA if you or your doctor is concerned about transplant-related side effects or complications. It is a real possibility that your child may be readmitted to a hospital during her first year after transplant.

Self-Care Steps
You can play a proactive role in your child’s recovery by taking responsibility for the following self-care steps.

Doctor's Visits
These include physical exams, as well as labs and tests (such as blood counts and kidney and liver function tests). Our standard recommendations are:

- Weekly visits for the first month and every other week for the next 2 months. Then go once every 3 to 4 weeks, depending on your child’s progress. Your doctor will help you decide.
- A one year follow-up evaluation is necessary to assess disease status, late complications and to receive vaccinations. Call (206) 667-4415 to make your child’s one year follow-up appointment.

Skin Care
Note any of the following changes in skin, and report them to your doctor:

- Color changes
- Rash
- Lesions
- Scaly skin
- Texture changes and thickening
- Stiff or tight skin around joints

It is important to protect your child from UVA (Ultraviolet and UVB Radiation) and UVB to decrease the risk of skin cancer. Take the following steps to protect your child from harmful rays.

- Protect your child’s lips with SPF (Sun Protection Factor) 30 ChapStick®
- Use sunscreen: SPF 30 or greater is recommended for everyone, reapply every hour while outdoors
- Wear clothing with SPF protectant manufactured into the fabric such as Columbia®, Solumbra® and ExOfficio®
- Avoid long (over 1 hour) exposure to sun
- Apply sunblock or wear SPF clothing even on cloudy days, as they still result in exposure to ultraviolet radiation.

If dry skin is a problem, it is not necessary to bathe daily. It can also be helpful to:
• Use oil in bath water
• Use lotion
• Try natural soap for sensitive skin

Nail Care
Your child should not have manicure and pedicures if her immune system is still recovering and on antibiotics. Avoid fake nails and cutting of cuticles.

If your child’s ANC (absolute neutrophil count) is greater than 1500, without need for transfusions and she is off high dose steroids (greater than 1mg/kg), she can have a manicure or pedicure. Make sure a single basin is used, and equipment is sterilized after each person. Check the facility’s license: https://fortress.wa.gov/dol/dolprod/bpdLicenseQuery/ Choose “Cosmetologist, Barber, Manicurist, Esthetician”.

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

Of the patients who receive total body irradiation pre-transplant, 20% develop cataracts within 1 to 5 years after transplantation. Cataracts are also more common in patients who receive long-term steroids. Cataracts can be removed surgically and the lenses will be replaced. Discuss with your eye doctor whether it is appropriate to change the prescription for your child’s glasses. You may wait until your child is receiving less medication such as prednisone that can affect eyesight.

Daily Mouth Care
Careful flossing and brushing are important to maintain dental health and prevent infections. Continued use of saline rinses can help if your child’s mouth is dry, or if your child has excessive mucous, or if your child is being treated for oral fungus. Your child can rinse his/her mouth using ¾ teaspoon table salt in 1 quart of warm water.

Dental Visits
See a dentist six months after returning home for an exam to monitor for tooth decay and overall oral care. Routine dental cleaning and dental work should be postponed for at least 12 months after transplant, longer if your child is still on an
immunosuppressant. Your dentist should also monitor for oral cancer every 6 months. If dental work is necessary and your child is still receiving immunosuppressant medication you will need an antibiotic based on recommendations from the American Heart Association. If urgent dental care is needed in the first year or while your child is still on drugs that affect his immune system he should take oral antibiotics prescribed by your doctor, before dental work is done.

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

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

**Common Symptoms**

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

-BMT Survivor

**Cognitive Changes**
The issue of cognitive changes is receiving more research attention. Cancer causes biochemical changes that are now suspected of contributing to cognitive changes, even before any treatment. High-dose chemotherapy and radiation affect cognitive function. Studies show varying incidences of “chemo brain” among transplant patients. However, research indicates that the decrease in memory, multi-tasking ability and attention which characterize post-treatment cognitive changes resolve for a majority of people after about a year. People can return to their pre-transplant cognitive functioning anywhere from one to five years post-transplant. Some people will continue to have memory or fine motor difficulties. If your child is still having difficulties with cognitive changes after one year, ask your child’s doctor for a referral for neuropsychological testing so you know what his deficits are and what you can do about them. In the meantime, help your child’s memory by keeping a notebook where you put the things you want to remember. Make sticky notes about what you do not want to forget, like taking a medication before going to bed. Put the sticky note by something your child always remembers, like brushing teeth. Keep a basket by the door for the things you need to take with you like keys or glasses.
Sleep
Most people have difficulty with sleep at some point during and after transplant. It can be hard to get on a regular cycle of sleep and worry tends to increase as people lie in bed awake. Medication should be a short term solution, not a lifetime aid. Tips that help include keeping the bedroom dark and cool, and going to bed and getting up at the same time each day. It may be helpful for your child to get out of bed and do a relaxing activity like reading if she does not sleep after 30 minutes of trying. Learning relaxation skills to help your child’s body and mind to relax while lying in bed is also helpful.

Depression and Other Feelings
“People are entitled to their feelings. And they’re entitled to them at every stage of treatment and survivorship. We know from the science of emotion that the most harmful way, the most damaging way, to manage emotions is to try to dictate them.”

-Dr. Karen Syrjala (in Surviving Survivor Stereotypes by Curtis Pesmen)

Your child may continue to experience significant distress following transplant. Sometimes, this can lead to feelings of sadness or depression and associated symptoms such as worry, anger, and fatigue. Distress can also lead to changes in sleep and eating patterns. Even post-traumatic stress can happen. We recommend making time and saving energy to participate in activities that your child enjoys, so life is not entirely about health. Spend time with friends and family. If these symptoms continue for more than a couple of weeks, it is important to discuss them with your doctor or nurse. Some people find that talking to a therapist after transplant is very helpful. There is so much that most people have been through and have to cope with after treatment. Talking with a therapist can help your child reclaim his life and make sense of what he has gone through.
Fatigue, Weight and Exercise  
“Some problems such as fatigue can begin during therapy and may continue indefinitely, though the duration and severity differs greatly between individuals.”  
- Rabiya Tuma, PhD, Treatment Aftershocks  

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

Adequate immune function takes approximately one year after transplantation to recover. During this time your child is still vulnerable to infections. Symptoms such as fever, chills, coughing, difficulty breathing, severe diarrhea or vomiting should be promptly reported to your doctor.

Cytomegalovirus (CMV) Monitoring

Your child may need weekly CMV monitoring after treatment. At discharge you will receive specific recommendations to take to your local doctor.

Exposure to Others

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

Hand Washing

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

Temperature

Take your child’s temperature if she is feeling ill, has shaking chills or if you suspect that she has a fever. Note time and circumstances. Notify your doctor promptly if your child has a:

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

Rash

Notify your doctor promptly if any rash develops.

Animals and Plants

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

Sexual Activity
Limiting the number of sexual partners is advised. Condoms should be used for protection against sexually transmitted infections (STIs). Normal cleanliness should be observed. Birth control should be used as necessary to prevent pregnancy, as your child may not be sterile. Discuss with your doctor and nurse. If dryness is a problem, a lubricant may be helpful. Drugs used for impotence should be avoided while on an immunosuppressant, and should not be used without a cardiac evaluation.

**Swimming**
Swimming may expose your child to microorganisms capable of causing infections. You should measure the benefits of your child swimming against the potential risks of these infections. If swimming or water aerobics is the preferred or recommended method of exercise, it should be done in a well-maintained pool with adequate chlorination. Your child’s face should not be submerged under the water. Never swim with a central line in place. Also, your child should not swim for the first 6 months after the transplant. Hot tubs should not be used for the first 6 months after transplant.

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

Many patients travel home within the first 6 months after transplant. As with any activity involving risk, weigh the specifics of your situation. To minimize risks when traveling:
- Take a copy of your child’s critical medical records with you.
- Seek medical care promptly for new symptoms.
- Control your environment by avoiding crowds and maintaining infection precautions.
- If you fly, ask to be moved if you are seated near someone with respiratory symptoms. Carry hand sanitizer and wipes.

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

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

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

If you do not return for your child’s one-year follow up, ask your doctor to contact the Long-Term Follow Up department about immunizations. If a household member receives the Varicella (chickenpox) vaccine, your child should be taking acyclovir. If a household member develops lesions (or pox), your child needs to be isolated while their lesions are present.
Medications

Your child’s medications are important to help her maintain general health. Please give them as prescribed.

- **Bactrim® (sulfamethoxazole-trimethoprim):** This is a broad spectrum antibiotic specifically for the prevention of pneumocystis pneumonia and for prevention of certain types of bacterial infections (Streptococcus pneumonia and Haemophilus influenza).
  - Take this medication if prescribed for at least 6 months after transplant, or longer if continued on immune suppression medications.
  - **Always take Bactrim® (or an alternate drug) when taking immunosuppressive medications.**

- **Acyclovir or Valacyclovir:** These drugs are antiviral agents used to prevent varicella zoster (shingles). If one of these is prescribed, it should be taken for the entire first year, and should be given concurrently while on immunosuppression and for six months after completion of taper.

- **Hormones:** Hormones may be prescribed for women in premature menopause due to the effects of conditioning therapy.

- **Immunosuppression:** Keep accurate records of dates when stopping or restarting immunosuppressive medications (prednisone, cyclosporine, MMF, tacrolimus, rapamycin). Immunosuppressive medications may require that blood levels be checked.
Secondary Cancers

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

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

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

Helpful Hints to for Your Child to Remember

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

Relationships

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

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

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

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

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

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

   -Sharon Bober, PhD

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

-Kathy Latour, Getting Through Survivor Guilt

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

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

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

To my family and friends:

I am recovering from a Blood or Marrow Transplant (BMT). I am able to return home, but my recovery from this procedure can take months. Here is a list of things you should know about my recovery:

**My Risk for Infection Continues:** It will take at least ____ months for my immune system to recover. It’s possible that it could take even longer, depending on what medications I will need or what complications might arise. I am at a higher risk for infection and will need to pick activities that minimize my risk of infection.

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

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

**Fatigue:** I will have both good and bad days. I would like to see you; however, short visits will be better for me. Some days I might not be up for long conversations or involved activities. Exercise can help with fatigue. I might ask you to join me on a walk.

**Memory and Concentration:** The treatment and medications I take can affect my memory and ability to concentrate. Don’t be surprised if I forget something you tell me. I expect this to improve as I recover.

**My Caregiver:** ________ had a lot of responsibility while we were away from home. Now that we are home, ________ will still have caregiver responsibilities along with all the usual home and work routines. If you would like to help, here is a list of suggestions:

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

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

Sincerely,
Survivorship Resources and Websites

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

Be the Match
Bethematch.org

Bone Marrow Transplant Forum, BMT-TALK: To subscribe to the mailing list, send an email to listserv@listserv.acor.org. Write only “SUBSCRIBE BMT-TALK” in the message body along with your first and last name.

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

Recommended Tests and Procedures
Center for International Blood & Marrow Transplant Research
www.cibmtr.org

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

Help with Post-Transplant Medication Costs
Patient Access Network Foundation
www.panfoundation.org/

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

Fred Hutchinson Cancer Research Center
www.fredhutch.org

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

Seattle Children’s
www.seattlechildrens.org

Insurance and Employment Rights
Cancer Advocacy Now
www.canceradvocacynow.org
Employment Rights Cancer and the Americans with Disabilities Act
www.eeoc.gov/facts/cancer.html
The Job Accommodation Network
http://askjan.org

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

National Organizations

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

National Cancer Institute

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

National LGBT Cancer Network
www.cancer-network.org

American Cancer Society
www.cancer.org

National Coalition for Cancer Survivorship
www.canceradvocacy.org

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

Pediatric
American Childhood Cancer Organization
www.acco.org

Candlelighters® Childhood Cancer Family Alliance
www.candle.org

Children’s Oncology Group
www.survivorshipguidelines.org

Human Growth Foundation
Hgfound.org

Skin Care
Skin Cancer
www.skincancer.org
Sun Safety
www.fda.gov Search “Sun Safety”

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

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

National Women’s Health Network
www.nwhn.org/

Health Insurance Pamphlet ACS

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

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

Long-Term Follow-Up Physician Program Guidelines:

Fred Hutch Long-Term Follow Up:
Click on “Information for Patients.”

Contact Information for LTFU
Phone number: (206) 667-4415
Toll Free Fax: (206) 376-8197
Fax: (206) 667-5619   Email: LTFU@seattlecca.org
## Common Infection Control Questions

<table>
<thead>
<tr>
<th>Questions Often Asked</th>
<th>Time after Transplant</th>
</tr>
</thead>
<tbody>
<tr>
<td>The general guidelines below may not apply to your case. You must discuss these rules with your physician to assess if they apply to you. See key at the bottom of the table for numbered footnotes.</td>
<td>From 1-6 Months</td>
</tr>
<tr>
<td><strong>Pediatric patients:</strong> Discuss with your physician when restrictions may continue to apply to your child’s care after one year post transplant.</td>
<td>From 6 months to 1 year</td>
</tr>
<tr>
<td><strong>Animals, Birds, Reptiles, Fish</strong></td>
<td></td>
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<tr>
<td>Small cage rodents (gerbils, rabbits, hamsters, guinea pigs, hedge hogs, prairie dogs, ferrets) <strong>Do not handle.</strong></td>
<td>No</td>
</tr>
<tr>
<td>Small cage rodents (gerbils, rabbits, hamsters, guinea pigs, hedge hogs, prairie dogs, ferrets) <strong>Do not handle.</strong></td>
<td>Ok</td>
</tr>
<tr>
<td>Reptiles and amphibians (snakes, turtles, frogs, lizards, iguanas, etc.)</td>
<td>No</td>
</tr>
<tr>
<td>Reptiles and amphibians (snakes, turtles, frogs, lizards, iguanas, etc.)</td>
<td>No</td>
</tr>
<tr>
<td>Farm animals (pigs, horses, cows, llamas, etc.) <strong>Do not handle; stay out of barns full of hay</strong></td>
<td>No</td>
</tr>
<tr>
<td>Farm animals (pigs, horses, cows, llamas, etc.) <strong>Do not handle; stay out of barns full of hay</strong></td>
<td>Ok</td>
</tr>
<tr>
<td>Wild &amp; game animals (deer, elk, squirrels, bear, etc.) (exotic animals, i.e., monkeys, etc.) <strong>Do not handle.</strong></td>
<td>No</td>
</tr>
<tr>
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<td>No</td>
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<tr>
<td>Zoos &amp; petting zoos</td>
<td>No</td>
</tr>
<tr>
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<td>No</td>
</tr>
<tr>
<td>Public aquariums (3) <strong>Do not touch marine life in handling tanks.</strong></td>
<td>No</td>
</tr>
<tr>
<td>Public aquariums (3) <strong>Do not touch marine life in handling tanks.</strong></td>
<td>Ok (3)</td>
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<tr>
<td>Animal trophy mounts in the house</td>
<td>Ok</td>
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<tr>
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<td>Ok</td>
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<tr>
<td>Fishing (fresh &amp; salt water) <strong>OK to handle fish if wearing gloves; do not bait hooks</strong></td>
<td>Ok</td>
</tr>
<tr>
<td>Fishing (fresh &amp; salt water) <strong>OK to handle fish if wearing gloves; do not bait hooks</strong></td>
<td>Ok</td>
</tr>
<tr>
<td>Hunting (wild game and birds) and sport shooting (2) (Wear latex gloves when handling game; do not clean game with a venous catheter device)</td>
<td>No</td>
</tr>
<tr>
<td>Hunting (wild game and birds) and sport shooting (2) (Wear latex gloves when handling game; do not clean game with a venous catheter device)</td>
<td>Ok (2)</td>
</tr>
<tr>
<td>Horseback riding <strong>Stay out of barns full of hay.</strong></td>
<td>No</td>
</tr>
<tr>
<td>Horseback riding <strong>Stay out of barns full of hay.</strong></td>
<td>Ok</td>
</tr>
<tr>
<td>Cats/dogs (not sleeping with pets, no feeding pets, no bathing or grooming pets)</td>
<td>Ok</td>
</tr>
<tr>
<td>Cats/dogs (not sleeping with pets, no feeding pets, no bathing or grooming pets)</td>
<td>Ok</td>
</tr>
<tr>
<td>New pets in patient’s household</td>
<td>No</td>
</tr>
<tr>
<td>New pets in patient’s household</td>
<td>No</td>
</tr>
<tr>
<td>Cleaning feces, litter boxes, utensils, or cages/tanks, etc.</td>
<td>No</td>
</tr>
<tr>
<td>Cleaning feces, litter boxes, utensils, or cages/tanks, etc.</td>
<td>No</td>
</tr>
<tr>
<td>Domestic birds (parakeets, parrots, etc.) <strong>Not if you have respiratory problems.</strong></td>
<td>No</td>
</tr>
<tr>
<td>Domestic birds (parakeets, parrots, etc.) <strong>Not if you have respiratory problems.</strong></td>
<td>Ok</td>
</tr>
</tbody>
</table>
### Questions Often Asked

The general guidelines below may not apply to your case. You must discuss these rules with your physician to assess if they apply to you. See key at the bottom of the table for footnotes.

**Pediatric patients**: Discuss with your physician when restrictions may continue to apply to your child’s care after one year post transplant.

<table>
<thead>
<tr>
<th>Time after Transplant</th>
<th>From 1- 6 months</th>
<th>From 6 months to 1 year</th>
</tr>
</thead>
<tbody>
<tr>
<td>Poultry &amp; wild birds (pigeons, baby chicks, chickens, ducks, geese, other wild birds, etc.)</td>
<td>No</td>
<td>No</td>
</tr>
</tbody>
</table>

### Other Activities

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

**Key:**

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

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

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

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

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

6. Avoid all public hot tubs.
Chapter 5- Appendix
Overview
The Fred Hutchinson Cancer Research Center (FHCRC), University of Washington (UW), and Seattle Children’s have integrated their adult and pediatric oncology-related patient care services into a separate, jointly governed Seattle Cancer Care Alliance (SCCA). SCCA creates a highly integrated approach to cancer research and treatment. SCCA does not discriminate against any patient or patient’s family member on the basis of race, color, religion, creed, national origin, sex, age, disability, marital or veteran status, sexual orientation, gender identity. If you feel you experienced discrimination as a patient at SCCA, please contact SCCA Patient Relations at (206) 606-1056.

SCCA Purpose and Principles
The Alliance was formed to:
- Provide state-of-the-art, patient-focused cancer care.
- Support the conduct of cancer clinical research and education.
- Enhance access to improved cancer interventions and advance the standard of care, regionally and beyond.
- Collaboration across the care delivery system.

Inpatient Services
Pediatric inpatients receive care at Children’s, and adult inpatient services are provided at the University of Washington Medical Center (UWMC).

Outpatient Services
Outpatient services for the Alliance are located at the SCCA Clinic on the Hutchinson Center’s Lake Union campus at 825 Eastlake Avenue East. If you have any questions regarding the Alliance, feel free to ask your doctor or nurse.

SCCA Patient Rights and Responsibilities
The SCCA respects the rights of all our patients equally and individually.

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

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

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

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

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

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

Patient Responsibilities

As a patient at SCCA, you share in the responsibility for your care. You have the responsibility to:

- Participate in decisions involving your care;
- Provide complete information about your health, symptoms, and medications;
- Ask your provider questions when you do not understand the planned treatment, care, or what is expected of you;
- Follow the treatment plan, which you and your provider have agreed upon;
- Keep appointments or let us know if you cannot make them;
- Take responsibility for the outcomes if you do not follow the treatment plan;
- Be considerate of the rights of other patients, personnel, and property;
- Follow SCCA rules and regulations;
- Provide accurate and timely information about sources of payment and your ability to meet financial obligations;
- Promptly meet any financial obligation agreed to with the SCCA;
- Let your providers know if you have concerns or complaints about any aspect of your care. SCCA encourages you, the patient, to talk with your healthcare team initially. Your nurse or social worker can be an advocate for you. If this course of action does not meet your needs we encourage you to speak with Patient Relations at (206) 606-1056. You may also make complaints to the Washington State Department of Health at 1-800-633-6828 or to the Joint Commission by calling 1-800-994-6610 or online at www.jointcommission.org, or by e-mailing your concerns to complaint@jointcommission.org.

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

Personal Valuables

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

Weapons and Illegal Substances

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

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

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

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”)

**SCCA Clinic**
825 Eastlake Avenue East
Seattle, WA 98109-1023
(206) 606-7222
Parking at SCCA is $4.00 with validation

**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.
# Charts and Records

## Axillary (Under the Arm) Temperature Conversion Chart

<table>
<thead>
<tr>
<th>°F</th>
<th>°C</th>
<th>What to do:</th>
</tr>
</thead>
<tbody>
<tr>
<td>96.8</td>
<td>36.0</td>
<td>This is “normal” temperature range.</td>
</tr>
<tr>
<td>97.8</td>
<td>36.6</td>
<td>CALL DOCTOR for shaking chills.</td>
</tr>
<tr>
<td>98.0</td>
<td>36.7</td>
<td></td>
</tr>
<tr>
<td>98.2</td>
<td>36.8</td>
<td></td>
</tr>
<tr>
<td>98.4</td>
<td>36.9</td>
<td>Do not take Tylenol®.</td>
</tr>
<tr>
<td>98.6</td>
<td>37.0</td>
<td>Re-check in 30-60 minutes for a temperature in this range taken under the arm.</td>
</tr>
<tr>
<td>98.8</td>
<td>37.1</td>
<td>CALL DOCTOR for shaking chills.</td>
</tr>
<tr>
<td>99.0</td>
<td>37.2</td>
<td></td>
</tr>
<tr>
<td>99.2</td>
<td>37.3</td>
<td></td>
</tr>
<tr>
<td>99.4</td>
<td>37.4</td>
<td></td>
</tr>
<tr>
<td>99.6</td>
<td>37.6</td>
<td>CALL DOCTOR for a temperature of 37.5-37.7°C (99.5-99.9°F) taken under the arm, that continues for one hour.</td>
</tr>
<tr>
<td>99.8</td>
<td>37.7</td>
<td></td>
</tr>
<tr>
<td>100.0</td>
<td>37.8</td>
<td>CALL DOCTOR for a temperature greater than or equal to 37.8°C (100°F) taken under the arm.</td>
</tr>
<tr>
<td>100.2</td>
<td>37.9</td>
<td></td>
</tr>
<tr>
<td>100.3</td>
<td>37.9</td>
<td></td>
</tr>
<tr>
<td>100.4</td>
<td>38.0</td>
<td></td>
</tr>
<tr>
<td>100.6</td>
<td>38.1</td>
<td></td>
</tr>
<tr>
<td>100.8</td>
<td>38.2</td>
<td></td>
</tr>
<tr>
<td>101.0</td>
<td>38.3</td>
<td></td>
</tr>
<tr>
<td>101.2</td>
<td>38.4</td>
<td></td>
</tr>
<tr>
<td>101.4</td>
<td>38.6</td>
<td></td>
</tr>
<tr>
<td>101.6</td>
<td>38.7</td>
<td></td>
</tr>
<tr>
<td>101.8</td>
<td>38.8</td>
<td></td>
</tr>
<tr>
<td>102.0</td>
<td>38.9</td>
<td></td>
</tr>
<tr>
<td>102.2</td>
<td>39.0</td>
<td></td>
</tr>
<tr>
<td>102.4</td>
<td>39.1</td>
<td></td>
</tr>
<tr>
<td>102.6</td>
<td>39.2</td>
<td></td>
</tr>
<tr>
<td>102.8</td>
<td>39.3</td>
<td></td>
</tr>
<tr>
<td>103.0</td>
<td>39.4</td>
<td></td>
</tr>
<tr>
<td>103.2</td>
<td>39.6</td>
<td></td>
</tr>
<tr>
<td>103.4</td>
<td>39.7</td>
<td></td>
</tr>
<tr>
<td>103.6</td>
<td>39.8</td>
<td></td>
</tr>
<tr>
<td>103.8</td>
<td>39.9</td>
<td></td>
</tr>
<tr>
<td>104.0</td>
<td>40.0</td>
<td></td>
</tr>
<tr>
<td>104.2</td>
<td>40.1</td>
<td></td>
</tr>
<tr>
<td>104.4</td>
<td>40.2</td>
<td></td>
</tr>
<tr>
<td>104.6</td>
<td>40.3</td>
<td></td>
</tr>
</tbody>
</table>
## Oral Temperature Conversion Chart

<table>
<thead>
<tr>
<th>°F</th>
<th>°C</th>
<th>What to do:</th>
</tr>
</thead>
<tbody>
<tr>
<td>96.8</td>
<td>36.0</td>
<td>This is “normal” temperature range. CALL DOCTOR for shaking chills.</td>
</tr>
<tr>
<td>97.8</td>
<td>36.6</td>
<td></td>
</tr>
<tr>
<td>98.0</td>
<td>36.7</td>
<td></td>
</tr>
<tr>
<td>98.2</td>
<td>36.8</td>
<td></td>
</tr>
<tr>
<td>98.4</td>
<td>36.9</td>
<td></td>
</tr>
<tr>
<td>98.6</td>
<td>37.0</td>
<td></td>
</tr>
<tr>
<td>98.8</td>
<td>37.1</td>
<td></td>
</tr>
<tr>
<td>99.0</td>
<td>37.2</td>
<td></td>
</tr>
<tr>
<td>99.2</td>
<td>37.3</td>
<td></td>
</tr>
<tr>
<td>99.4</td>
<td>37.4</td>
<td></td>
</tr>
<tr>
<td>99.6</td>
<td>37.6</td>
<td></td>
</tr>
<tr>
<td>99.8</td>
<td>37.7</td>
<td></td>
</tr>
<tr>
<td>100.0</td>
<td>37.8</td>
<td></td>
</tr>
<tr>
<td>100.2</td>
<td>37.9</td>
<td></td>
</tr>
<tr>
<td>100.3</td>
<td>37.9</td>
<td></td>
</tr>
<tr>
<td>100.4</td>
<td>38.0</td>
<td>Do not take Tylenol®. Re-check in 30-60 minutes for a temperature in this</td>
</tr>
<tr>
<td></td>
<td></td>
<td>range taken by mouth or under the arm. CALL DOCTOR for shaking chills.</td>
</tr>
<tr>
<td>100.6</td>
<td>38.1</td>
<td></td>
</tr>
<tr>
<td>100.8</td>
<td>38.2</td>
<td></td>
</tr>
<tr>
<td>101.0</td>
<td>38.3</td>
<td></td>
</tr>
<tr>
<td>101.2</td>
<td>38.4</td>
<td></td>
</tr>
<tr>
<td>101.4</td>
<td>38.6</td>
<td></td>
</tr>
<tr>
<td>101.6</td>
<td>38.7</td>
<td></td>
</tr>
<tr>
<td>101.8</td>
<td>38.8</td>
<td></td>
</tr>
<tr>
<td>102.0</td>
<td>38.9</td>
<td></td>
</tr>
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<td>102.2</td>
<td>39.0</td>
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<td>102.4</td>
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</tr>
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<tr>
<td>104.4</td>
<td>40.2</td>
<td></td>
</tr>
<tr>
<td>104.6</td>
<td>40.3</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>CALL DOCTOR for a temperature greater than or equal to 38.3°C or 100.9°F.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

CALL DOCTOR for a temperature greater than or equal to 38.3°C or 100.9°F.
### Blood Counts

**Day __________________**

**Date __________________**

<table>
<thead>
<tr>
<th>Parameter</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>WBC</td>
<td>4 - 10</td>
</tr>
<tr>
<td>ANC</td>
<td>3.2 - 4</td>
</tr>
<tr>
<td>Polys</td>
<td>2 - 7.5</td>
</tr>
<tr>
<td>Bands</td>
<td>0 - 1</td>
</tr>
<tr>
<td>Lymphs</td>
<td>1 - 4.5</td>
</tr>
<tr>
<td>Monos</td>
<td>0 - 1.4</td>
</tr>
<tr>
<td>Eophils</td>
<td></td>
</tr>
<tr>
<td>Basophil</td>
<td>0 - 0.3</td>
</tr>
<tr>
<td>Metamyelo</td>
<td>0</td>
</tr>
<tr>
<td>Myelocyte</td>
<td>0</td>
</tr>
<tr>
<td>Platelet</td>
<td>150 - 400</td>
</tr>
<tr>
<td>SGOT</td>
<td>&lt;50 / 78</td>
</tr>
<tr>
<td>Creatinine</td>
<td>0.7 - 1.5</td>
</tr>
<tr>
<td>BUN</td>
<td>4 - 22</td>
</tr>
<tr>
<td>Bilirubin</td>
<td>&lt;1.2 / 0.3</td>
</tr>
<tr>
<td>Cyclosporin</td>
<td>300-1200</td>
</tr>
<tr>
<td>RBC</td>
<td>4 - 5.3</td>
</tr>
<tr>
<td>HGB</td>
<td>12 - 15</td>
</tr>
<tr>
<td>HCT</td>
<td>36 - 45</td>
</tr>
<tr>
<td>MCV</td>
<td>81 - 100</td>
</tr>
<tr>
<td>MCH</td>
<td>27 - 35</td>
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<td>MCHC</td>
<td>32 - 37</td>
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<tr>
<td>RDW</td>
<td>0 - 15.1</td>
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<tr>
<td>Magnesium</td>
<td>1.5 - 2</td>
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<tr>
<td>Sodium</td>
<td>136 - 145</td>
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<tr>
<td>Potassium</td>
<td>3.5 - 5.5</td>
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<tr>
<td>Chloride</td>
<td>95 - 110</td>
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<tr>
<td>CO₂</td>
<td>23 - 31</td>
</tr>
<tr>
<td>Glucose</td>
<td>60 - 110</td>
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## Daily Food Intake Sheet

<table>
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<tr>
<th>Time</th>
<th>Served (ml)</th>
<th>Eaten (ml)</th>
<th>Code</th>
<th>LIQUIDS</th>
<th>Time</th>
<th>Served</th>
<th>Eaten</th>
<th>Code</th>
<th>SOLIDS</th>
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Bowel Movement Record
Please answer these questions at the end of the day.

Date ______________________

• How many bowel movements (stools) did you have today? ______________________
• How many times did you vomit today? ______________________

Please circle the number which best depicts your bowel movements today.

1. Watery
2. Liquid, creamy
3. Very loose, mushy, semi-liquid
4. Loose, soft
5. Formed with some liquid
6. Soft, formed
7. Normal, formed
8. Hard
9. Hard, dry