

My Chemotherapy Treatment

Oncology & Hematology Care
VA Portland Health Care System
Portland, OR

VA



U.S. Department of Veterans Affairs

Veterans Health Administration
VA Portland Health Care System



Table of Contents

Chapter 1. About Cancer 1

Chapter 2. Welcome 3

Questions You May Have	4
Communication with Your Team	4
Office Hours & Appointments	4
Things to Remember	4
Getting to Your Appointment	5
Care After Hours	5
Prescription Refills	5
Telephone Calls	5
Your Medical Information	6
Laboratory & Radiology	6
Oncology & Hematology Provider-Patient Statement	7

Chapter 3. Your Chemotherapy & Other Treatments 9

What is Chemotherapy?	9
Your Chemotherapy Plan	10
What to Expect During Treatment	11
General Recommendations	12
Dental Care	12
Home Safety for Patients Receiving Chemotherapy	13
When to Call the Provider	14
What is Radiation Therapy?	15
Surgery	20
Biotherapy	20
Hormone Therapy	21
Complementary Therapy	21

Chapter 4. Laboratory Tests 25

The Effects of Chemotherapy on Your Blood Counts	25
Blood Transfusions	26

Chapter 5. Catheters & Ports	27
Venous Access Devices	27
Chapter 6. Side Effects	29
Taking Care of Yourself at Home	29
Appetite Changes	31
Constipation	32
Diarrhea	34
Skin & Nail Changes	35
Dry Mouth	36
Fatigue	37
Fever	38
Hair Loss	39
Mucositis	40
Nausea & Vomiting	42
Pain	45
Chapter 7. Eating Well	49
Taste Problems	49
Swallowing Problems	49
Increasing Oral Intake	50
Recipes	52
Chapter 8. Life Issues	55
Sharing the Diagnosis	56
Sharing Feelings	56
Coping Within the Family	56
When You Need Help	57
You & Your Self-Image	57
The World Outside	58
Living Each Day	59
The Years After	59
Coping with Your New Diagnosis	60
Spiritual Care of Cancer Patients	63

Chapter 9. Local Support Services	65
Oncology Social Work	65
Spiritual Care Resources	66
Tobacco Cessation Resources	67
Food Choices at the VA	68
Tips for Traveling to Portland	72
 Chapter 10. Additional Resources	 77
Advance Directives	77
VA Patient Rights & Responsibilities	80
 Chapter 11. Glossary	 85
 Chapter 12. Resources for Learning More	 91

How to Use Your Guide

This is your resource book. Feel free to make notes, highlight areas, write in the margins - whatever works for you! Many of the topics discussed in your appointments will be referenced in this book.



Image QR codes are found throughout this book. Use your smart-phone or tablet to scan them. This will take you directly to the website(s).



My Healthcare Team

My Cancer Doctor is _____

_____

My Nurse Practitioner is _____

_____

My Nurse Coordinator is _____

_____

My Cancer Navigator is _____

_____

My Social Worker is _____

_____

Who do I call?

Radiation Medical Support Assistant:

503-220-8262, ext. 56532

Medical Support Assistant:

503-220-8262, ext. 51169

Hematology Nurse Care Coordinator:

503-220-8262, ext. 51436

Oncology Nurse Care Coordinator:

503-220-8262, ext. 53408

If you need any new medications related to your cancer treatment call the nurse coordinator.

To Schedule Appointments for Chemotherapy:

503-721-7888, option 3

To Schedule Appointments for Medical Oncology:

Contact the Oncology/Hematology Facilitator

503-220-8262, ext. 51169

Prescription Refills:

Call before you run out

503-220-8262, option 4

For automated refills:

503-273-5201, option 2

Call at least 10-14 days before your prescription medications are needed. Refill information and instructions are found on your prescription bottles.

If you are starting oral chemotherapy it can take longer to get your first medications (2-3 weeks). Some of the oral chemotherapy can take time to special order. Refills need to be called in and can take 1-2 weeks to be delivered to your home.

Refill Online:

Go to MyHealtheVet and order your refills online. You will need to have a MyHealtheVet advanced account to access this feature www.myhealth.va.gov/



For Pharmacy Customer Service:

503-220-8262, option 1



Chapter 1. About Cancer

What is Cancer?

Cancer is the name given to a group of related diseases. Cancer is an abnormal growth of cells caused by injuries to certain genes. These injuries cause some of the body's cells to divide without stopping. Normal cells grow and divide to make new cells when the body needs them. Cancer cells will keep growing and are not needed by the body. Most cancers can spread to other parts of the body and can cause damage to the parts of the body where they grow. The spread of cancer is called metastasis.

What Causes Cancer?

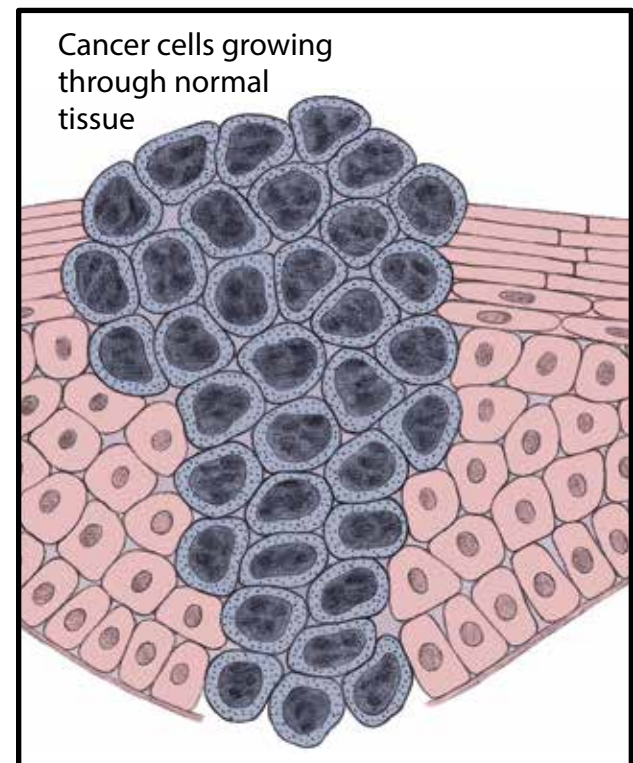
We don't know what causes cancer, but we do know that a number of things can cause the injury to genes that produce cancer. These are viruses, radiation, possibly other types of energy and chemicals. We are exposed to these things daily, which is why cancer is so common.

Is Cancer Hereditary?

Some forms of cancer may be passed on from family members through genes. This is called hereditary cancer. Most cancers are not hereditary. These families tend to have certain types of cancer, like breast, ovarian, and colon cancer in adults. Your doctor may direct you to genetic counseling to learn more.

Treatment Choices

Your treatment choices are defined by the type of cancer you have and the stage of the disease. What type of cancer you have depends on where the cancer started, and the type and look of the cancer cells. Staging is a way to describe the cancer growth. Staging will help the provider to customize your cancer treatment. Your health and the results of biochemical tests on your cancer cells will also guide your treatment. Almost all cancers will use staging, except for types of leukemia.



Chapter 2. Welcome to Our Office



The Veterans Health Administration Oncology and Hematology services and clinics are committed to providing advanced, quality healthcare that promotes and improves our Veteran's health and well-being. Our team has special training in cancer care (medical oncology and hematology). Your care team will include board certified physicians, nurse practitioners, registered nurses, a medical assistant, a patient-care coordinator, and a medical support assistant.

We want you to know that we are dedicated to you as our patient and will do our best to assist you and your family/friends through the treatment process.

Questions You May Have

You and your family may have questions about your diagnosis and treatment plan. Our health care team is here to help make sure you have the information you need.

Our nursing staff is trained in Oncology and Hematology (Cancer). They are available to help answer questions about your treatment and possible side effects.

Spokesperson

We suggest you appoint a spokesperson for your family. Your spokesperson will help you share information to the rest of your family and friends. This person would also be your contact, if you need one, between you and your health care team.

To Help You Communicate with Your Team

- » Bring a relative or friend with you to your appointment. You do not have to be alone, unless you choose to be.
- » You have a voice in decisions about your care.
- » Write down questions before your appointment. **All of your questions are important.**
- » Take notes during your appointment.
- » If medical terms or concepts are used that you do not understand, please ask us to explain them.
- » Please share. Something you may think is minor could affect your treatment. Something you think is serious could be easily treated.

Office Hours & Appointments

- » Office Hours are Monday through Friday from 7:00 am to 6:00 pm.
- » Same day appointments are open for urgent problems. Please call first.
- » **The length of your treatment may determine your appointment time.** Shorter infusion times will be scheduled in the afternoon.
- » Please arrive on time to help us keep appointments on schedule.
- » **Due to changes in the provider schedules or other conflicts, you may be asked to reschedule your appointment to a different day and/or time.**
- » Please call if you expect to be delayed. Late arrivals may need to be rescheduled.
- » A 24-hour notice is appreciated if you need to change or cancel an appointment.

At times we are delayed by emergencies or longer appointments with patients who are experiencing problems. Please know that we will make every effort to be on time or let you know when there is a wait.

Things to Remember

- » **Children:** Due to safety concerns and out of respect for all of our patients we ask you not to bring children into the exam area or leave children unattended in the waiting area. **Children under the age of 18 are not allowed in the infusion area.**

- » **Animals:** No service animals or other pets are allowed into the treatment area due to safety concerns.
- » **Fragrances:** Many patients develop an increased sensitivity to odor when receiving chemotherapy. Please do not wear any perfumes, body lotions, after shave lotions, or other lingering fragrances when you come to our office.
- » **Visitors:** You are welcome to bring a support person with you during your treatment. There may be times when visitors will need to wait in the waiting room. **Due to space limits, multiple visitors at the same time are discouraged.** This may be disruptive to other patients and make it difficult for staff to provide care.

Getting to Your Appointment

- » Parking in the patient parking garage can be challenging at times. Please allow time to find parking.
- » Public transportation is also available. For times and map locations contact Portland TriMet at www.trimet.org/ or 503-238-RIDE (7433).
- » There is also a VA shuttle service. To learn more call: 503-220-8262, ext. 57804.
- » If you need assistance with transportation to and from our clinic, please talk to your social worker. There may be other options available.
- » If you have been approved for travel assistance, please call 503-220-8262, ext. 55609.

Care After Hours

- » If you are having a medical issue or concern after hours (after 6:00 pm) please call 503-220-8262, option 5.
- » In case of an emergency, call 911.

Prescription Refills

- » **Plan ahead. Call at least 10-14 days before your prescription medications are needed.**
- » New prescriptions and refill authorizations are handled only during office hours.
- » For medication refills call the automated refill line at: 503-273-5201 or 1-888-400-8387.
- » Some narcotics require a written prescription, so please plan ahead.
- » If you are starting oral chemotherapy, it can longer to get your first medications (2-3 weeks). Some of the oral chemotherapy can take time to special order. Refills need to be called in and can take 1-2 weeks to be delivered to your home.
- » Check with your provider if you need to have any lab work done before starting a new refill.

Telephone Calls

- » Our healthcare team is trained to answer many of your medical questions. Please feel free to call during regular office hours.
- » If you need to speak to your provider, she/he will return your call or convey information through our staff as soon as they can, depending on their schedule.

- » Before calling your provider's office be ready to describe the problem you are having, when it started, what the symptoms are, what makes the problem better, or what makes the problem worse.
- » Have a pen and paper ready to write down instructions.

Your Medical Information

Your medical information will be kept strictly confidential. Information will not be released without written consent from you. We require your specific permission to discuss your care with anyone, including your relatives and friends.

Laboratory & Radiology

Lab Work

Lab work is usually done before most appointments and/or treatments. To get your lab work you may:

- » **Make an appointment:** call in advance to your local VA clinic or VA hospital to set up a lab draw appointment.
- » **Come to the Portland VA outpatient Lab Draw Clinic.**
  - Lab Draw Clinic is located on the 2nd floor of the main hospital building.
  - If you are planning on doing lab work the same day as your provider appointment, please plan on being at the lab at least 1 hour before your scheduled appointment time.
- » **Hematology and Oncology appointment:** If you have an appointment with a provider on Thursdays, between 9:15 am and

2:30 pm - you can get your blood work done before your appointment. The hematology and oncology phlebotomist is located next to where you check in for your provider appointment.

- » **If you are scheduled to only have treatment, your lab work may be done in our infusion clinic the same day, before starting treatment.**

Imaging

Imaging may be ordered by your provider and can be done at the Portland VA or your local VA hospital. Please call your patient-care coordinator for assistance with scheduling imaging appointments.

How can we help?

We appreciate the trust you have placed in us. We welcome your suggestions on how we can better serve you.



Oncology & Hematology Provider-Patient Statement

To best treat a serious illness, the patient and the provider should both be involved in the plan of care. A clear understanding of these shared expectations can enhance the treatment process.

Your Provider Will:

- » Give you information and education about your diagnosis and treatment alternatives available.
- » Encourage you to ask questions about your diagnosis and treatment, and to answer questions as clearly as possible. Our primary responsibility is to you. Your medical care will only be discussed with those people authorized by you.
- » Support your desire to get other professional opinions if you believe it to be in your best interest.
- » Provide you with information you request concerning professional training, experience, and philosophy.
- » Respect your desire to try treatment that might not be conventionally accepted. We will also give you our honest opinion about unconventional treatments.

We Hope That You will be Willing to:

- » Actively participate with our agreed-upon treatment plan.
- » Share with us about your needs and expectations.
- » Inform us if you desire another professional opinion.
- » Inform us of all forms of therapy you are involved with.
- » Attempt to coordinate the communication with your family and friends, through your designated spokesperson.

Chapter 3. Your Chemotherapy & Other Treatments



What is Chemotherapy?

Chemotherapy is an important part of the treatment of cancer. Chemotherapy means drug therapy, by mouth (oral) or in the vein (intravenous), muscle (intramuscular), artery (intra-arterial) or spinal fluid (intrathecal). Radiation therapy and surgery treat the cancer at its largest or primary site (local treatment).

Chemotherapy travels throughout the body where it can reach all the cancer cells, even the ones that can't be found by x-rays and blood tests.

Certain cancer drugs work well when given with others. Cancer chemotherapy usually consists of a combination of several drugs. This combination is given on a set schedule from a few months to several years. With

recent advances in chemotherapy, the drug treatment can often be given on an outpatient basis in our office.

What Can Chemotherapy Do?

Depending on the type of cancer and its stage of development, chemotherapy can be used:

- » To cure cancer.
- » To keep the cancer from spreading.
- » To slow the cancer's growth.
- » To kill cancer cells that may have spread to other parts of the body from the original tumor.
- » To relieve symptoms that may be caused by the cancer.

Which Drugs Will I Get?

Once the type of cancer has been determined, your provider will discuss treatment choices with you. To help you decide your treatment options, you will get information about the response rates, common side effects and alternatives. Your provider will discuss the exact drugs, doses, duration and the timing of chemotherapy after the chemotherapy treatment plan (protocol) has been decided. You will be given a written form that has information on what you need to know about your diagnosis and treatment. This form will be a reference for you when talking with providers involved in your care. Your provider may need to change your treatment plan based on blood tests, side effects, and how you are feeling. The protocols used in our practice are the same or very similar to the treatments used across the United States.

Some patients may be eligible for a research protocol. If so, this drug therapy will be according to the research study guidelines.

We want you to know as much as possible about the drugs you are receiving. We use both group and individual teaching. Once your treatment plan is identified, we will teach you what drugs you will get, the most common side effects, and how to manage those side effects if they happen. You will be given written information about the drugs and how to cope with the side effects. It's best to have a family member learn with you since they will be your support at home.

How Will I Know if My Chemotherapy is Working?

Your provider has several ways to how well your treatments are working. You will have physical exams, blood tests, scans and x-rays. Don't hesitate to ask the provider about the test results and what they show about your progress.

Tests and exams can tell a lot about how chemotherapy is working but side effects tell us very little. Side effects, such as nausea or hair loss, occur because chemotherapy harms some normal cells as well as cancer cells. Sometimes people think that if they don't have side effects, the drugs aren't working, or that if they do have side effects, the drugs are working well. Side effects vary so much from person to person, and from drug to drug, that having them or not having them isn't a sign that treatment is working.

Your Chemotherapy Plan

A customized treatment plan to meet your needs. The plan:

- » Sets flexible and realistic goals.
- » Includes a treatment schedule that is specific to your diagnosis.
- » Determines the type and amount of drugs needed to treat your specific type and stage of cancer.
- » Allows for possible emotional and physical side effects you may experience and gives you ways to help deal with these.

What is a "Cycle" of Treatment?

- » Chemotherapy may be given in cycles. This lets your body rest in between therapy.

- » Your chemotherapy cycle is created for you based on recommendations from research. It is important to follow the chemotherapy cycle and recommended administration times. This is done to help your body recover, build back up normal healthy cells, and increase your chances of killing off the cancer cells.

A Chemotherapy Plan Helps You

Your chemotherapy plan gives you an idea on what to expect during your treatment. The plan allows you to:

- » Help you and your loved ones know what to expect and stay on schedule to receive your specific chemotherapy routine.
- » Be proactive in preventing and treating side effects.
- » Reduce anxiety and fears.
- » Make sure you receive your full dose of chemotherapy. This gives the best chance of killing the cancer cells and preventing them from spreading or growing back.

What to Expect During Treatment

On the day of your first treatment, you may be seen by a nurse practitioner for an exam and to answer any questions you have. The nurse practitioner works closely with your medical oncologist. You will get an intravenous line (IV) and baseline blood tests may be done.

Your treatment will take place in a comfortable room with recliners. A family member or friend is welcome to stay with you during your treatment, if there is space. Treatment time is usually two to four hours. Because of the length of treatment,

you may want to bring something to do. Many patients read, sleep or visit with each other. If you will be getting treatment during lunch, you may want to bring either a sack lunch or a family member can purchase something in the hospital. Please be aware that strong food odors may contribute to nausea.

Thanks to new medications, most patients are able to spend their treatment without nausea. We will help you in any way we can to make your treatment experience as comfortable as possible.

You may want to have a family member or friend come with you on your first visit. It is helpful having someone else listen to what the provider tells you, and to have someone to drive you home. Some of the anti-nausea medicines can cause drowsiness and each person responds to treatment differently.

For safety, children under the age of 18 are not allowed into the infusion room. Please do not bring visitors with you if they are feeling sick or have signs of infection.

We recommend that you eat lightly before you come to the office for your first treatment. After your treatment, you will need to experiment with what works best for you. There are no set rules on what to eat. You may want to avoid foods that are heavy or hard to digest.

General Recommendations

There are many ways to keep yourself healthy during treatment. Here are a few things you can do:

1. Always wash your hands and practice good hygiene and mouth care.
2. Avoid exposure to contagious illnesses (colds, flu, etc.).
3. Maintain a well-balanced diet during treatment.
4. Try to keep fluid intake at eight to twelve 8 oz. glasses per day (two to three quarts per day).
5. Drinking alcohol should be kept to a minimum - an occasional single drink with dinner is OK.
6. Taking vitamins as part of your therapy is an individual choice.
7. Let your provider know about changes in medications you are taking (over-the-counter or prescription drugs).
8. Avoid taking aspirin or aspirin-containing products unless your provider has approved their use. When in doubt, ask your pharmacist if aspirin is part of your drug prescription.
9. Always use sunscreen and protective clothing. Avoid excessive sun exposure while receiving treatment.
10. Avoid hair coloring and perming while on treatment to decrease hair loss.

11. Talk to your provider before dental work.

12. Good mouth care is important. Changes may happen during and after treatment. Look in your mouth every day for redness, soreness, and/or white patches. Avoid commercial mouthwashes, which may dry the mouth. Use a soft bristle toothbrush. Notify the office of any problems.



Don't forget to ask your doctor about receiving a flu shot!

More About Dental Care

Good dental care is always important, especially while receiving chemotherapy or radiation. Before starting treatment try to schedule a dental exam and cleaning.

It is best to avoid major dental work or teeth cleaning during the chemotherapy nadir period. The nadir period is when your white blood cell count is at its lowest. This period of time varies with treatment, but is often 7-14 days after you have received chemotherapy. A blood test (CBC) can determine if you are at the nadir. Please check with your provider to talk about the timing of dental care.



Home Safety for Patients Receiving Chemotherapy

You may notice that your nurse wears protective equipment (gloves, gown, etc.) when giving you your chemotherapy. This is done to protect the nurse from being exposed to the medications. You, your caregivers and family members must also protect yourselves against exposure. The below information will review how to safely handle chemotherapy medicines and your body waste when at home.

Handling Body Waste

Chemotherapy medication is released from the body through urine, stool, vomit and blood for 48 hours after your treatment has stopped. During that time, follow these steps:

- » After using the toilet, close the lid and flush twice. Men should urinate sitting down to avoid splashing.
- » After using the toilet, wash your hands well with soap and water. If any fluids splashed on your skin, clean the area with soap and water.
- » Wear gloves when cleaning the toilet or cleaning up any urine, stool or vomit or changing depends/incontinence pads.
- » Wash your hands with the gloves on, then remove the gloves, dispose of them in the trash, and wash your hands again.
- » If using a bedpan or urinal, wear gloves and dump contents into toilet close to the water to limit splashing. While wearing the gloves, wash the container with soap and water after each use.
- » Depends can be disposed of in the regular trash.

- » If you have an ostomy, wear gloves when emptying and wash the collection bag once a day with soap and water.

Handling Trash or Laundry

For 48 hours after treatment if you are touching trash or laundry that has come in contact with chemotherapy or body fluids:

- » Wear gloves when touching trash or laundry. Wash your hands with the gloves on, then remove the gloves, throw them in the trash and wash your hands again.
- » Contaminated trash can be placed in special bags if you have them. If not, double bag trash in plastic, leak proof bags.
- » If possible, wash contaminated laundry right away. If you can't wash it right away, put it in a leak proof plastic bag and wash as soon as you can.
- » Wash contaminated laundry separate from other laundry, using regular laundry detergent and warm or hot water.

Handling Spills

For 48 hours after treatment if chemotherapy or body fluids are spilled or splashed:

- » Wear gloves to clean up the spill/splash.
- » Wipe up the spill with paper towels.
- » Clean the area with soap and water.
- » Dispose of trash in specially marked containers (if you were provided with them) or double bag in leak proof plastic bags.

- » Wash your hands with the gloves on, then remove the gloves, throw them in the trash and wash your hands again.

Sexual Contact

Chemotherapy medications can also be excreted in body fluids, such as semen and vaginal fluid. To prevent exposure of these fluids for you or your partner:

- » Use condoms during oral sex and intercourse for 48 hours after treatment.
- » To prevent pregnancy effective birth control should be used throughout treatment and for several months or years after. Chemotherapy can have harmful side effects to the fetus, especially in the first trimester. In addition, menstrual cycles can become irregular during and after treatment, so you may not know if you are at a time in your cycle when you could become pregnant or if you are actually pregnant.

Safety for My Family

- » Hugging and kissing is safe for you and your partner or family members.
- » You can visit, sit with, hug and kiss the children in your life.
- » You can be around pregnant women. If possible they should not clean up any of your body fluids after you have treatment.
- » You can share a bathroom with others. If body fluids splash on the toilet, wear gloves and clean the area with soap and water before others use the toilet.



When to Call the Provider

Chemotherapy drugs are medications used to treat cancer. They are strong medications and may have side effects. There are some side effects that can be dangerous and need to be treated right away. There are some things you can do to reduce the side effects or discomfort you have from them.

Contact your healthcare team when you have questions or concerns related to your treatment and/or potential side effects.

These are examples of when to call your healthcare team (see next page).

Call Your Provider if You Have:

- » Fever greater than 100.4° F or chills, even without fever.
- » Severe headache or changes in your ability to think.
- » New chest pain or swelling in arm, neck, or chest.
- » Blood in your urine.
- » Blood (bright red, black, or coffee-ground-appearing) or pus in stools.
- » Any other unexplained bleeding or bruising, for example from the gums, nose or coughing up blood.
- » Changes in breathing or more difficulty breathing.
- » Redness, swelling, drainage, or pain with any vein or venous access device.
- » Diarrhea/loose bowel movements - more than 4 times daily.
- » Constipation - no bowel movement in 3 days.
- » Nausea - unable to eat or drink for more than 8 hours - or vomiting not controlled by prescribed medications.
- » Sore mouth that prevents you from eating.
- » Pain that is not being controlled.



What is Radiation Therapy?

If radiation therapy is a part of your cancer treatment plan, you will get your treatment at the Radiation Medicine Department at Oregon Health and Science University (OHSU). The OHSU staff is committed to giving you the best care available. We hope this information will provide you with a brief overview of their department, answer some common questions, and provide you with resources to learn more about your care. We welcome your feedback.

To Schedule, Cancel or Change an Appointment

Call 503-494-8756 between 8:00 am and 4:30 pm, Monday through Friday.

To leave a message for your doctor: Call 503-494-8756 between 8:00 am and 4:30 pm, Monday through Friday.

For EMERGENCIES ONLY: The Radiation Oncology Doctor on-call may be contacted by calling the OHSU operator at 503-494-8311, then asking for the Radiation Oncology Physician on-call.

Your Radiation Team Includes

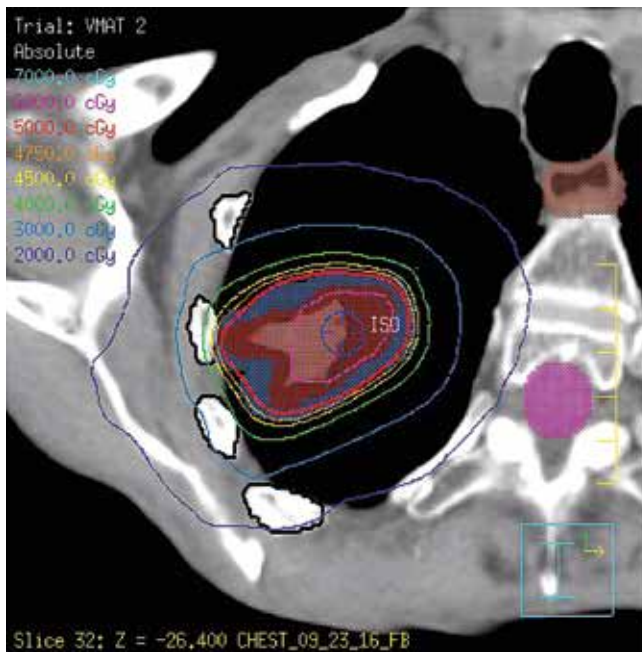
Radiation Oncologists: Doctors specially trained in radiation therapy for cancer.

Resident Physicians: Doctors who are receiving further training in the specialty of Radiation Oncology.

Radiation Therapists: Specially trained in administering the radiation treatments.

Radiation Oncology Nurses: Specialists in cancer care and education that can provide you with education about radiation treatment and its side effects.

Physicists: Experts trained in radiation



Stereotactic Body Radiation Therapy (SBRT) of lung

physics that make sure the radiation equipment is working properly and delivering the correct dose of radiation to you.

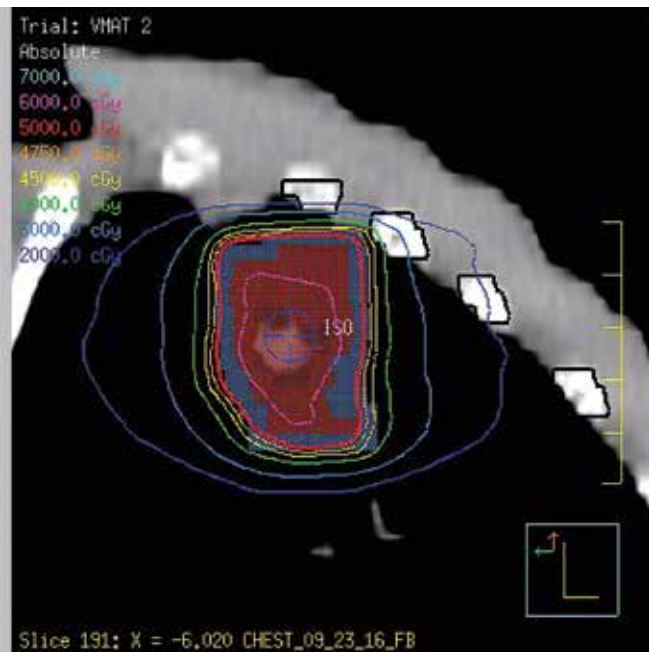
Dosimetrists: Experts in calculating and designing the planned radiation field correct for your tumor size, type, and location, as prescribed by the physician.

What is Radiation Treatment?

Radiation treatment uses high energy x-rays and/or electrons directed by a machine, called a Linear Accelerator, to very specific areas and depths in your body. The purpose is to destroy cancer cells within the treatment area. Normal healthy cells can also be damaged but many have the ability to heal after treatment is done.

How Do I Get Started?

You have been referred to a Radiation Oncologist (Radiation Cancer Doctor) by your regular physician, or by another one of your cancer doctors. Your first appointment is called a “consultation visit” and may last 1-2 hours. At this appointment, you may be



asked to watch an video about radiation. You will also meet the doctors and discuss with them what radiation therapy can do to help you. The doctors will review your medical records, including recent x-rays or scans that you have had done. They will perform a brief physical exam, and your vital signs will be measured. The doctors will talk to you about the treatment plan they recommend for you, and you will learn what the side effects from radiation may be - both short and long term.

At the completion of this visit, if you and the physicians agree that radiation therapy is a suitable treatment for you, you will be asked to sign a consent form. You will also be asked to make a series of appointments to begin the planning process. The next visit is called a simulation visit.

What is Simulation?

Simulation, or “Sim”, is a planning appointment. The purpose of this visit is to plan the best way to deliver radiation to the exact areas your Radiation Oncologist wants to treat.

You will be placed on a table lying in the most effective position for treatment and asked to lay as still as possible and to stay in this position, “the treatment position”, while they complete their planning. The therapist may create a special cushion, mold, or mask for you to be positioned in during treatments. These molds are called “immobilization devices”, and they help make sure you stay in the same position on the treatment table each time.

While in the treatment position, a CT scan of the treatment area will be taken. The Radiation Oncologist uses this scan to determine the exact location to be treated. Once the treatment “field” is determined, the therapists will make small marks, or tattoos, on your skin. These are small dots that look like freckles. Tattoo marks are used to line up the treatment field each time you come in. These tattooed dots are permanent. You will be asked to sign a brief consent form that lists the risks of the radiation treatment as explained by your radiation physicians.

For most patients, when you have completed the simulation visit, you will then go to the Radiology Department for a CT scan. The Radiation Oncologists use this CT scan to determine the exact location to be treated. Even if you have had a recent scan, you will need to undergo one that is only used for the purposes of planning your treatment. This CT scan will be done while you are positioned in the same way that you will be for each of your radiation treatments.

How Do I Know They Will Treat the Right Place?

The Radiation Oncologist, Dosimetrist and Physicist will review the CT scans and design the treatment field. They will design special shielding blocks that will form the radiation field specifically to your body shape. This will block the radiation from other parts of your body and will minimize damage to healthy tissue. The Radiation Oncologists will also use a special computer to design a plan that delivers the radiation to the right depth. They may also plan a “boost” dose of radiation that comes near the end of your treatment. A boost is a dose of radiation given to a smaller area within your treatment field. It is usually given for a few treatments. This targets an area that is at a higher risk for reoccurrence. An example would be a “boost” given to a lumpectomy site at the end of radiation to the whole breast.

How Many Treatments Will I Receive?

The Radiation Oncologist will develop a plan specific for you. Before starting radiation therapy, the team will coordinate with chemotherapy or surgery, if necessary. In most situations, you will receive radiation treatment once a day, 5 days a week (no treatment on Saturdays, Sundays, or some holidays). The treatments are individualized, and vary from 5 minutes to 30 minutes. Some types of treatment require one visit and some will require treatment for 5-7 weeks. Your Radiation Oncologist will determine the length of your radiation course after your consultation visit.



Pre and Post SBRT of lung

When Do I Start Treatment?

In most situations, you will be given a start time after your simulation appointment. Usual start days are 1 day to 4 weeks after your simulation. This time varies depending on urgency and coordinating factors, such as chemotherapy start date, if that applies to you.

What Happens During My Treatment?

At your first session, the therapists will check the accuracy and measurements of your treatment field. This includes a set of x-rays, often called “port films”. These x-rays do not tell us if your cancer is responding, they simply verify that your placement on the treatment table is the same from day to day, or week to week. A doctor must check the x-rays before you are treated. You should expect to be on the treatment table a few extra minutes the first day.

Radiation therapy does not hurt. It does require you to stay very still. Different

devices are sometimes used to help you lie still. Although the Radiation Therapist cannot be in the room when the machine is on, you are always monitored by camera and microphone. They can stop the machine and help you at any time. However, it is better to try to complete the treatment.

Once the treatment for the day is done, you can leave. Your treatments will continue Monday through Friday for the complete number of days prescribed by your plan. This schedule will be developed by you and the radiation therapists during your first treatment visit. The therapists will try to accommodate your needs, but please remember that many patients are treated each day, so you may not initially receive a daily treatment time that is at the most convenient time for you. We also try not to interrupt your treatment schedule, or “break” the treatment. Rarely, your health or a machine issue may delay your treatment schedule. In this case, the “missed” treatment day is added to the end of your radiation treatment schedule. For these reasons, we recommend you do not make travel plans that can’t be changed for a few days after your treatment plan is scheduled to finish.

You will see a Radiation Nurse and a Radiation Oncologist at least once a week while you are on treatment. This “doctor day” is usually the same day each week, but could change based on your Radiation Oncologist’s schedule. Expect to be in the radiation department longer on the day you see your physician. If you have side effects from treatment, let your provider know. You may need to be seen more often.

Am I Radioactive?

No. The type of radiation delivered in this department by the Linear Accelerator does not stay in your body. There is no need to avoid other people. Hugging, kissing, or sexual activity will NOT expose other people to radiation.

What Kind of Side Effects Can I Expect to Have?

Side effects are related to the specific area being treated and the total dose being delivered. Your Radiation Oncologist and Nurse will provide you with verbal, written, and sometimes video educational materials. Make sure you understand the information or tell us if you do not.

The two most common side effects of radiation treatment are fatigue and skin reactions. Except for feeling tired, side effects are related to the specific area being treated and the total amount of radiation that will be delivered. Most side effects do not develop right away, but may begin to be noticeable around your second or third week of treatment. Once your radiation treatment is complete, the side effects may take several weeks or longer to go away. Make sure that you understand or ask about any possible lasting effects from the radiation that may occur.

What Happens When My Treatment is Finished?

During the last week of your radiation treatment, you will meet with your Radiation Oncologist. They will tell you if you need any follow-up blood tests or x-ray studies. Since the maximum benefit of the radiation is not completed the day you finish your treatment, x-rays or other tests may not be done for several weeks to

months to evaluate what your response to treatment has been. Your Radiation Oncologist will usually have you return to the radiation department four to six weeks after your treatment is completed to monitor your recovery from the treatment.

Tips for Success During Radiation Therapy

Everyone is different. The best thing that you can do is to eat nutritious meals, drink 8-10 glasses of fluids daily, rest when you need to, and include some type of regular exercise or activity in your daily routine.

Your Radiation Oncologists and Nurse will check frequently and offer support to help with any side affects you may experience. Your radiation therapy team wants to help you make your treatment a successful one, so please do not hesitate to let us know if you are experiencing side effects, have questions about your treatment, or need help with other issues.

Special Concerns: If you are known to have an allergy to CT or PET scan contrast dye, please notify your radiation medicine team. If you are claustrophobic, or have anxiety when confined, ask your radiation medicine team about techniques or medications which may help.

You may also find it helpful to visit OHSU's website at: www.ohsu.edu/xd/health/services/cancer/getting-treatment/services/brain-cancer/treatment-options/radiation-therapy/





How is Surgery Used in Cancer Treatment?

Surgery is used in the diagnosis, staging, and treatment of cancer. A biopsy is often done to diagnose and stage the type of disease. A biopsy is when a small piece of tissue is removed. The extent of disease or stage is sometimes determined using surgical techniques. Surgery is also used to remove organs or tissues with cancer. This might be done as a single treatment or with radiation therapy or chemotherapy.

Why Do I Need Additional Treatment If I Already Had Surgery to Remove My Cancer?

Other treatments such as chemotherapy and radiation therapy are often needed because there may be cancer cells in the body that are not found by x-rays or blood tests. If only surgery is used, these cells may grow and the cancer will return.

Is Chemotherapy Done Before Surgery?

Yes, sometimes chemotherapy is done to shrink the tumor before surgery. This can make surgery easier.

Surgically Implanted IV Access Devices

Patients who will have chemotherapy get frequent blood tests and intravenous infusions. If starting an IV or drawing blood is difficult, a semi-permanent or durable intravenous line may be placed. These permanent lines (either implanted ports or catheters) are placed surgically in the chest area and can be left in for a week, a month, or years. The procedure is most often done as an outpatient and the line can be used right after placement. If you need one of these devices you will get more information on the procedure and the type of device that will best meet your needs. A referral to the surgeon will be set up for the procedure. For more information, see the section on Port/Catheters in this book.

Biotherapy

Biotherapy is a treatment that uses substances that naturally exist in the body to cause a desired response. There are two main types of biotherapies. One focuses on helping the body to destroy tumor cells. The other the other type focuses on helping the body to increase the numbers of a particular type of blood cell. Biotherapy is one of the newer methods to treat cancer and to help the body recover from the side effects of treatment.

Research in this area holds a great deal of promise for improved treatment methods. Drugs that fall within this category are interferon, interleukin, and colony stimulating factors like G-CSF and GM-CSF (granulocyte colony stimulating factors that increase the white blood cell count) and EPO (erythropoietin which increase the red blood cell count). If any of these drugs are

prescribed for you, you will get more information.

How are Biotherapy Drugs Given?

Biotherapies are given in a vein (intravenous or IV) or by an injection that goes under the surface of the skin (subcutaneous). Depending on the type of medication and the dose, it may be given in the hospital or in the provider's office. Many people are taught to give their own injections at home.

Hormone Therapy

A hormonally sensitive or hormonally dependent cancer is a type of cancer found in tissue, such as the breast, prostate, testicle, and endometrial lining. The tissues and the related cancer are dependent on the hormones naturally produced by the body for growth and function. Such cancers are often treated with hormone therapy.

Hormonal therapy is used to prevent the growth, spread, or return of hormonally sensitive cancers. This is done by blocking the cancer-stimulating effect of the body's natural hormones on the tissue or organ involved. Hormone therapy is delivered by injections or prescribed pills.

Complementary Therapy

A complementary therapy is not a cancer treatment. Complementary therapy can help you by easing the side effects and stress of cancer treatments. These therapies may help you tolerate and continue with the cancer treatment.

Complementary therapies include: massage, acupuncture, meditation, guided imagery, relaxation techniques, yoga, gentle exercise, and nutritional care. Tell



your provider before you start your treatment if you want to participate in these or other complementary therapies. A description of each of the treatments mentioned here is provided on the following pages.

Complementary therapies are different than alternative therapies. Alternative therapies often claim to be “safer,” “natural,” “secret,” or “miracle” alternatives to standard cancer treatments. Such alternative therapies are usually not tested and not proven to be safe or effective in cancer therapy.

Nutritional Care

Antioxidants: Are man-made or natural substances that may prevent or delay some types of cell damage.

Antioxidants are found in many foods, including fruits and vegetables. They are also available as dietary supplements. They reduces the damage caused by oxidation, such as the harm caused by free radicals. Examples of antioxidants include:

Beta-carotene	Vitamin A
Lutein	Vitamin C
Lycopene	Vitamin E
Selenium	



Vegetables and fruits are rich sources of antioxidants. There is good evidence that eating a diet with lots of vegetables and fruits is healthy and lowers risks of certain diseases. But it isn't clear whether this is because of the antioxidants, something else in the foods, or other factors.

High-dose supplements of antioxidants may be linked to health risks in some cases. For example, high doses of beta-carotene may increase the risk of lung cancer in smokers. High doses of vitamin E may increase risks of prostate cancer and one type of stroke. Antioxidant supplements may also interact with some medicines. Because of this, be sure to tell your health care team about any antioxidants you use.

Mind/Body Practices

Acupuncture: A key practice in traditional Chinese medicine, acupuncture is one of the oldest health customs in the world. The thinking behind acupuncture is that the life energy "Qi" (pronounced "chee") flows along meridians - or pathways - throughout the body. Acupuncture helps open up blockages in those pathways. Although acupuncture encompasses a family of practices, the one most associated is the use of fine metal needles inserted in the skin along the meridians, then stimulated either manually or with

electrical current. Acupuncture has been used to relieve chronic pain, and to help with a many different kinds of issues, from motion sickness to smoking cessation.



Acupressure: A similar practice to acupuncture in that it uses the handling (usually with fingers or hands) of various pressure points on specific areas of the body to allow the release of natural chemicals for healing. This is also known as "needleless acupuncture". One positive of this treatment is that no special equipment is needed and you can be trained to self-administer treatment. Without training, however, acupressure can lead to pain, bruising, nerve damage and internal organ damage.

Massage: Is the act or art of treating the body by rubbing, kneading, patting, or the like, to stimulate circulation and relax the individual, physically and mentally. Many different forms of massage exist:

Swedish massage: Most common type of body massage, uses long strokes, kneading, deep circular movements, vibration, and tapping.

Deep tissue massage: Used for long standing, deep muscular problems.

Neuromuscular massage: Used to balance the nervous system and the muscles.

Shiatsu: A Japanese form of bodywork, therapists use finger and palm pressure to restore balance in the body's natural energy flow, or Qi.

Aromatherapy massage: The use of essential oils during massage to activate the limbic system, which helps controls emotions and influences the nervous system and hormones.

Reflexology: Applied to points on the hands and feet with the aim of improving the health of other parts of the body.

Research supports the use of massage to minimize anxiety, depression, and pain; and help regulate blood pressure and heart rate. Massage in most forms is safe. However, depending on where you are in your treatment journey, you may want to proceed with caution. If you are receiving chemotherapy or radiation therapy for your liver cancer it is recommended to work with a therapist trained in oncology massage.

Oncology massage training will make sure your therapist will not:

- » Create lymphedema (fluid that collects and causes swelling in the arms and legs).
- » Mobilize a deep vein thrombosis (blood clot).
- » Compromise your possible immunosuppressed state.
- » Send chemotherapy through your body more quickly than intended.
- » Over-tax your already exhausted body.

Meditation: There are countless meditation techniques, some of which have been passed down through ancient traditions. Every technique has value; however, you don't need any special tools to meditate. Meditation is claimed to calm the body and spirit; people who practice it routinely say it can provide peace of mind and clarity. Some of the meditation types include:

Mindfulness meditation: Patients sit still in a comfortable position in a restful place. The idea is to gently keep bringing your mind back to the present moment whenever distractions or mind wandering occur.

Mindfulness based stress reduction (MBSR): Normally a programmed event which teaches mindfulness meditation to help you cope better and be more at ease in your life. Often run through a clinic or hospital, it includes sitting meditation (breath awareness, focused attention), body scanning (awareness of sensations in the body), mindful movement, walking meditation and insight meditation.

Focused meditation: This type of meditation involves focusing on something intently as a way of staying in the present moment and turning off your internal dialogue.

Visualization: Creating specific images in your mind for specific reasons. For example, thinking of a Pac Man gobbling up cancer cells during treatment.

Guided meditation: A teacher or recorded voice guiding a patient through a meditative process.

Transcendental meditation: Repeating a specific word or phrase (mantra) to focus

the mind, alleviate stress, and increase energy.

Prayerful meditation: The aim is to expand spirituality: opening up to the idea of a higher being or developing positive qualities such as compassion and wisdom.

Reiki: With this treatment, Reiki (pronounced ray-kee) healers place their hands lightly or just above a person to balance energy and promote healing. This therapy was developed in Japan in the early 20th century. There is a debate as to the usefulness of Reiki, however, people receiving chemotherapy who also received Reiki report feeling more relaxed, with less stress and pain. As a treatment, Reiki appears safe and without side effects. There are three levels of training for Reiki practitioners (sometimes called “Reiki Masters”). Only those who have achieved the 2nd and 3rd level of training are allowed to charge for their services.

Tai Chi & Qi Gong: Both tai chi and qi gong are ancient Chinese energy therapies that use mind/body practices combining gentle physical movements, mental focus, and deep breathing. Both practices embrace the Chinese concepts of yin and yang (opposing forces within the body) and qi (a vital energy or life force). Both practices are generally safe, but muscle strain can occur with overuse. Do not do tai chi and qi gong immediately after eating.

Yoga: Yoga began in India over 5000 years ago as a system of relaxation, exercise and healing. Yoga combines breathing, stretching, postures and meditation. The belief is experiencing these four practices create harmony between your mind, body and spirit which help clear your mind of any stress or confusion. People with cancer

who have done yoga report a sense of calm and better coping skills in dealing with their illness. They also said it helped with the side effects of their treatments (pain, being tired, sleep problems and depression).

The above section on integrative health practices have been taken from the VANJHCS Liver Cancer Patient Guide.

For a copy of the booklet, or to view online visit www.hepatitis.va.gov/products/liver-cancer-patient-guide.asp



Chapter 4. Laboratory Tests

The Effects of Chemotherapy on Your Blood Counts

Chemotherapy damages or wipes out rapidly dividing cells in the body. Even though the goal is to kill the cancer cells, there are many other rapidly dividing cells that may be affected by the chemotherapy. The most sensitive ones are the hair follicles, cells that line the gastrointestinal tract, skin cells, fingernails, toenails, and blood cells. Both chemotherapy and radiation therapy will affect the bone marrow which is the site where the blood cells are produced.

Most chemotherapy drugs will lower the blood counts within 7-10 days. These lower blood counts can last up to 14 days or longer. Your blood count is important as it helps you to fight infection during treatment. There are drugs that can cause the bone marrow to produce blood cells, which may be used in your care.

White Blood Cell (WBC)

White blood cells are the body's main defense against bacterial and viral infections. They are produced mainly in the bone marrow. White blood cells are rapidly dividing cells and have a short life span. They are very susceptible to chemotherapy.

There are many different types of white blood cells. The two most important are neutrophils and lymphocytes.

- » Neutrophils are your body's main defense against bacterial infections.
- » Lymphocytes make antibodies and are the main defense against viral infections.

A blood test can be done to check the percentage of neutrophils and lymphocytes. The blood test will check the percentage of cells and the absolute neutrophil count (ANC). The ANC is a measurement of the total number of neutrophils per cubic centimeter (cc) in your blood. The absolute neutrophil count is the number of white blood cells that are neutrophils. Your

provider uses this measurement to assess your risk of infection.

A normal WBC count is 4,000-10,000. While receiving chemotherapy your WBC and ANC counts may drop below normal. If your blood counts are too low to have chemotherapy, your medical oncologist will be notified. Your chemotherapy will be delayed and your provider will tell you when to recheck your ANC. This will tell you when you can safely continue your chemotherapy treatment.

Red Blood Cell (RBC)

Red blood cells carry oxygen to the body's cells and tissues. The oxygen is bound to a substance within a red cell, which is called hemoglobin (HGB). When your red blood cells are low, you are considered anemic. Anemia is when there is a low number of red blood cells to carry oxygen to your tissues and cells. You may get an injection to boost your RBC or a blood transfusion might be needed.

Platelets (PLT)

Platelets are small cells produced in the bone marrow. Platelets are cells in the blood that clot to keep us from bleeding. A normal platelet count is 150,000-450,000. Like red blood cells and white blood cells, chemotherapy drugs may affect platelets.

Other Laboratory Tests

Your provider may order other tests from the lab, such as chemistry profiles or tumor markers. The tumor markers are a broad category of substances produced by malignant cells or normal cells when there is cancer. Tumor markers may be found in body fluids (blood, urine, spinal fluid) or tissue specimens. These tests are sent to an outside laboratory. How long it takes to get the results will depend on the test ordered. You may get any of your laboratory results by asking your provider at the time of your visit. Your provider can also answer any questions you may have about your results.

Blood Transfusions

At some point during your treatment, you may need to have a red blood cell or platelet transfusion. Since chemotherapy can lower the body's ability to produce red blood cells and platelets, anemia or thrombocytopenia (a lack of platelets) may occur and a blood or platelet transfusion may be necessary.

To treat anemia (a deficiency of red blood cells), the type of transfusion usually ordered is in the form of packed red blood cells. This means the cells are separated from most of the plasma (the liquid part of the blood) and are infused like an "IV" over a period of several hours. Prior to your transfusion, you will need to have a blood

type and cross-match (lab test) done to be sure the transfusion you will receive will match your individual blood type. It is helpful to get this test done the day before your transfusion would begin. This additional time for the transfusion will require 4-6 hours. Your provider will help to find out how soon you will need to have the blood transfusion. This is based on your symptoms and your blood test results.

To treat thrombocytopenia, the platelets together with plasma are administered like an "IV". It usually takes 1 hour or less to give the platelet transfusion. Blood and platelet transfusions are currently done in our outpatient procedures unit.

For more information, ask your doctor or nurse or visit the National Heart, Lung, and Blood Institute web site www.nhlbi.nih.gov/health/health-topics/topics/bt



Chapter 5. Catheters & Ports

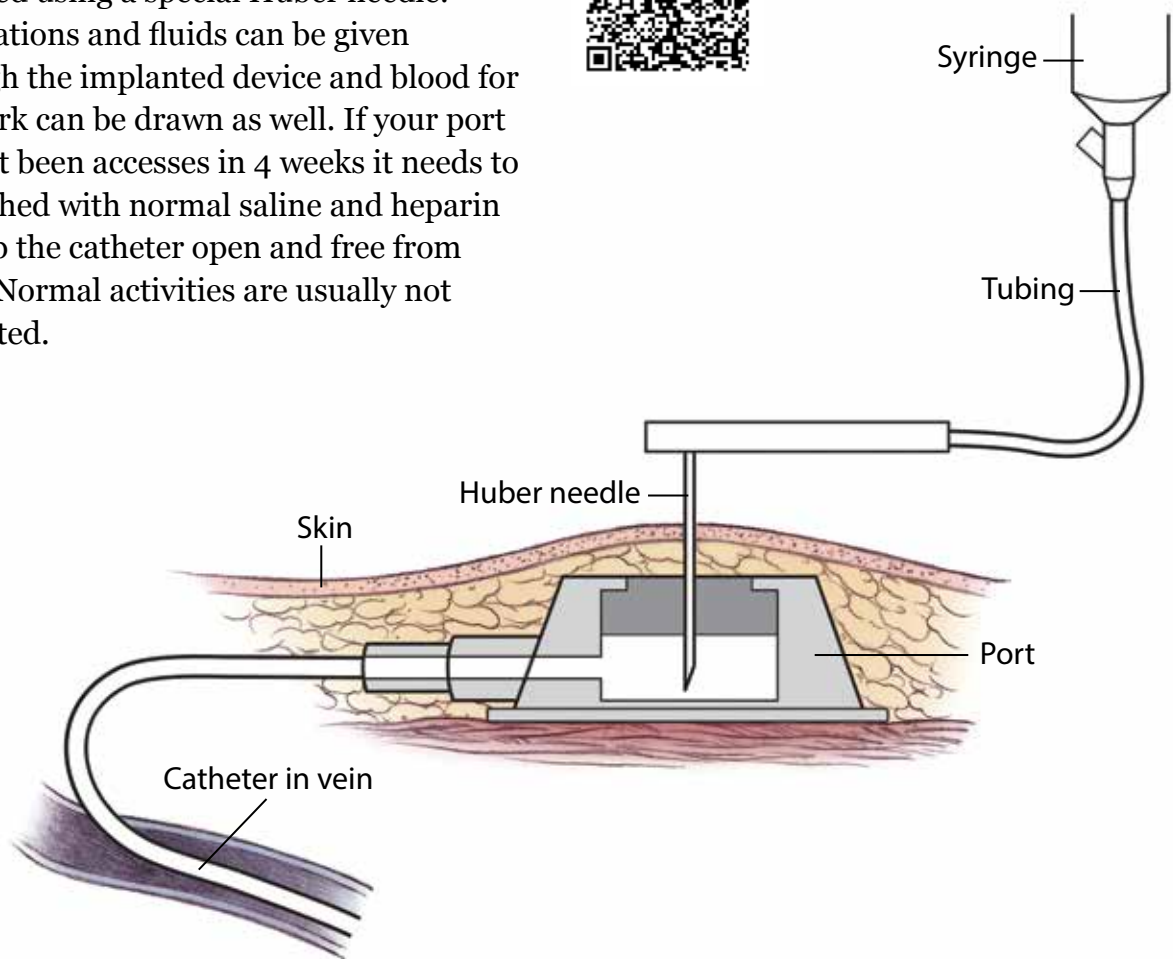
Venous Access Devices

Chemotherapy and other intravenous (IV) medications and fluids can be given into your veins. Depending on your treatment plan and your veins, the team might recommend that you get a venous access device. The two most common types of devices are an Implanted Port (sometimes called a portacath) or a Peripherally Inserted Central Catheter (PICC) line. These forms of access can be left in place for weeks, months, or even years.

Implanted Port

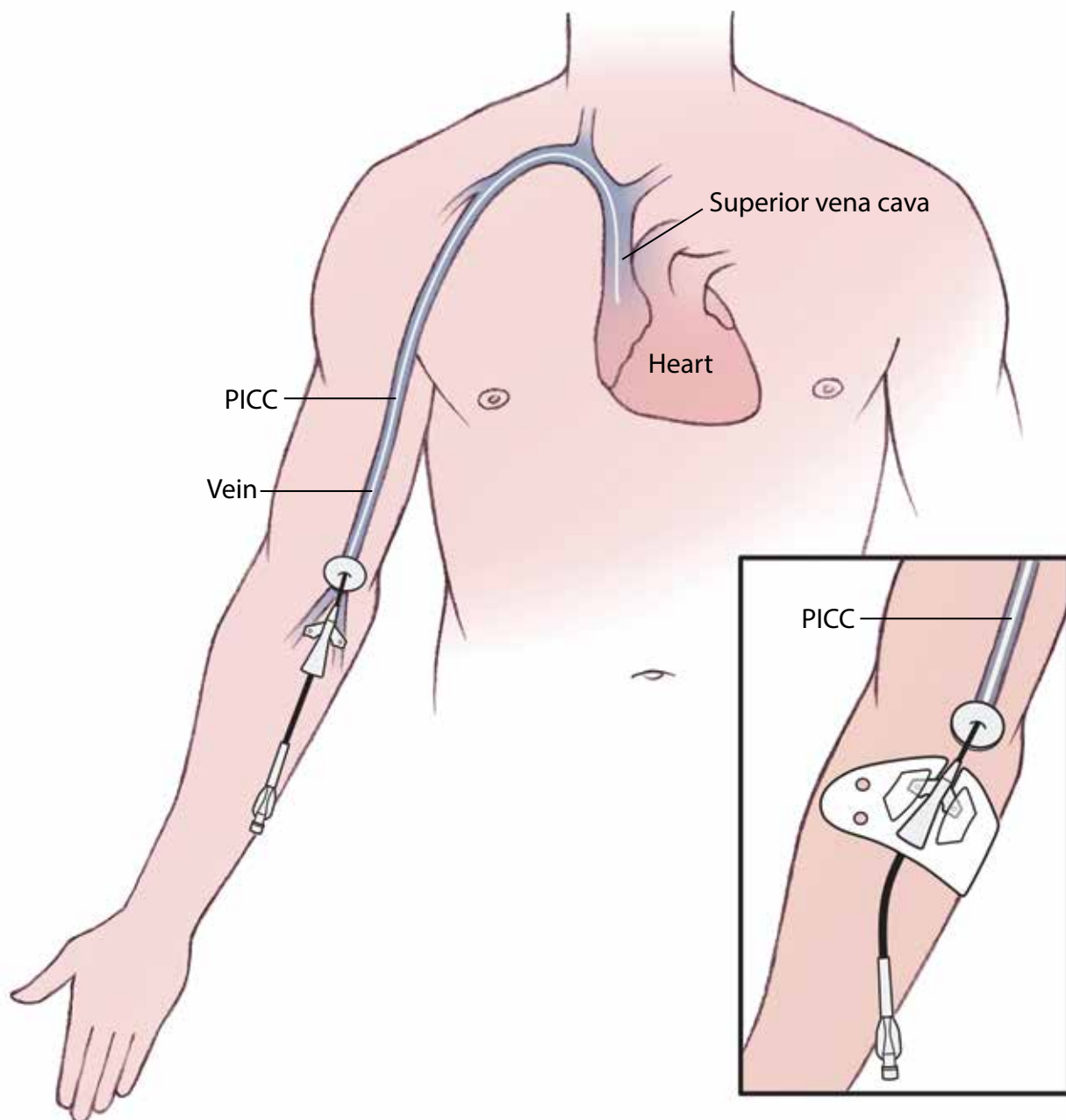
A radiologist will implant a port under the skin during an outpatient appointment. The port has two major parts: a small disc like chamber called a portal that has a catheter tubing that goes into a large vein in the chest and then connects to the portal. Your skin covers the entire device and is accessed using a special Huber needle. Medications and fluids can be given through the implanted device and blood for lab work can be drawn as well. If your port has not been accessed in 4 weeks it needs to be flushed with normal saline and heparin to keep the catheter open and free from clogs. Normal activities are usually not restricted.

For further information please visit this website: www.macmillan.org.uk/information-and-support/treating/chemotherapy/being-treated-with-chemotherapy/



PICC Line

A peripherally inserted central catheter (PICC) line is a long flexible tube that is placed in a large arm vein (near the bend of your arm or in your upper arm). The tip of this tube goes to a large vein right above the heart. The PICC line can be inserted by a PICC certified nurse or radiologist. The PICC can be used to put medications and fluids into your body, and to take blood for tests. A PICC line can stay in for many months and will require weekly flushing with saline and dressing change. This can be done in the chemo clinic. The insertion site should stay dry. You will not be able to go swimming. Baths are ok as long as the PICC line is kept dry. You can shower if the line is wrapped and waterproofed.



Chapter 6. Side Effects

Taking Care of Yourself at Home

The next section includes Symptom Management Information Sheets. These sheets will give you some ideas on how to take care of yourself at home and how to manage the side effects most common with chemotherapy treatment.



Common Side Effects of Chemotherapy Drugs

Infection	Hair loss or thinning
Bleeding	Changes in appetite
Nausea/vomiting	Changes in bowel patterns
Fatigue	Changes in sexuality

To Reduce Your Risk of Infection When Your White Blood Cell Count is Low

- » Avoid crowded areas, persons with colds, fever, or cough, children exposed to contagious illness or anyone recently vaccinated with a live vaccine.
- » Wash your hands often!
- » Urinate after sexual activity or avoid sexual activity if instructed by your provider.

To Reduce Your Risk of Bleeding When Your Platelet Count is Low

- » Avoid injury from bumps or falls.
- » Avoid or take care with knives and razors.
- » Avoid medications which contain aspirin, ibuprofen, Aleve, Anaprox (both are from the family of naproxen drugs), Orudis KT, Oruvail (both are from the family of ketoprofen drugs).

To Decrease Nausea & Vomiting After Chemotherapy

- » Take anti-nausea medicine as prescribed.
- » Avoid strong and unpleasant odors and fried or acidic foods.
- » Try frequent sips of fluid and small meals of crackers or other bland, room temperature foods.
- » Rinse mouth frequently.
- » Use distraction or relaxation strategies.

To Decrease Fatigue

- » Save your energy for what is most important to you.
- » Alternate activity with rest periods.
- » Avoid stress & use relaxation strategies.
- » Drink plenty of liquids and eat as well as you can.
- » Regular exercise at whatever level is tolerated.

To Cope with Hair Loss or Thinning

- » If you have long hair, consider cutting it shorter if hair loss is expected with your treatment.
- » Select a wig or other head covering before hair loss appears.
- » Avoid hair coloring and perms.

To Manage Changes in Bowel Patterns

Constipation

- » Drink plenty of fluids.
- » Eat food high in fiber such as: beans, grains, fruits, and vegetables, if you can tolerate them.
- » Use prunes, prune juice, hot tea, or hot lemon water to stimulate the bowels.
- » Regular exercise at whatever level is tolerated.

Diarrhea

- » Replace lost fluids with clear liquids, served cold or at room temperature. Examples include: water (plain, carbonated or flavored), fruit juices without pulp (apple or white grape), fruit-flavored beverages (fruit punch or lemonade), carbonated drinks such

as lemon lime soda, gelatin, tea or coffee without milk or cream, strained tomato or vegetable juice, sports drinks, clear, fat-free broth (bouillon or consommé), hard candy (lemon drops or peppermint rounds), ice pops without milk, bits of fruit, seeds or nuts.

- » Avoid milk products and caffeine.
- » Eat several small meals rather than three large ones. Add foods that decrease diarrhea such as: bananas, rice, applesauce, toast, mashed potatoes, eggs, fish, cottage cheese, and yogurt.
- » Avoid foods that cause gas, are very acidic, fatty, or fried.
- » Increase foods that contain potassium such as: apricots, peach nectar, bananas, mashed potatoes, or baked potatoes.

To Manage Changes in Sexuality

- » Talk about feelings and concerns with your partner.
- » Explore ways of touching and being held that can provide pleasure when sexual activities are limited.
- » Plan for uninterrupted time when your time and attention can be on one another.
- » Women may need water-based vaginal lubricants if dryness is a problem.
- » Avoid pregnancy during the time that either partner is receiving chemotherapy.

Symptom Management Information Sheet

Appetite Changes

Loss of appetite can be a serious problem, sometimes leading to malnutrition, weight loss, and poor healing. Your body needs good nutrition when fighting cancer. You need enough protein and calories to function at your best, to rebuild hair, muscle, and tissue, to provide energy, and to help reduce the effects of cancer and its treatment. Eating enough of the right kinds of foods can be tough when you don't feel like eating at all.

What to Do

- » Eat smaller and more frequent meals, especially if you tend to fill up before you finish a “normal” portion.
- » Talk with your provider, nurse, or dietician for nutritional supplements that can be eaten alone or added to milk, soup, or pudding.
- » Eat with family or friends when possible. Eating will seem less of a chore when it is a social event.
- » Take a walk before mealtime; mild exercise can wake up an appetite.
- » Eat a variety of foods. Spice up your recipes with herbs, spice, and sauces.
- » Use butter, bacon bits, croutons, special sauces, and marinades for extra flavor and variety.
- » If thirsty choose juice, milk, or other nutritious beverages.
- » Don't fill up on salads or “diet” foods. Eat vegetables, fruits, grains, meats, poultry, and fish to make sure you get enough calories and balanced nutrition.

Call Your Provider

- » If you haven't had the appetite or ability to eat solid meals in two or more days, despite trying the “what to do” suggestions.



- » If pain or nausea is decreasing your appetite.

Things to Avoid

- » Drinking a lot of liquids before a meal may fill you up leaving little desire for solid food. If you can't manage solid foods, try to drink nutritious beverages like milk, juice, or nutritional supplements (Ensure, Boost, etc.).

Symptom Management Information Sheet

Constipation

Constipation is the passage of irregular, infrequent, hard stools. Things that might lead to constipation are decreased food and fluid intake, decreased physical activity, and pain relieving drugs, especially opiates, which slow down the movement of food and fluid through the system. This results in the less frequent, often hard stool.

What to do to Help Prevent Constipation

- » Drink eight to twelve, 8 ounces glasses of fluid a day. Water and juice are best. Warm fluids may help.
- » Keep as active as you can. Walking is a great type of low impact exercise.
- » Increase fiber in your diet. High fiber foods include bran, whole grains, fruits, and vegetables as allowed.
- » If you are taking pain medication on a regular basis (daily) a stool softener or a combination stool softener/laxative should be taken daily. Colace and Senna-s are a two of the many brands of stool softeners available. Ask your pharmacist if you are having trouble making a selection.

What to do if Constipation is an Issue

- » Increase fluid intake to 2-3 quarts a day.
- » Increase fiber in your diet. Prunes (stewed, canned, dried or prune juice) can help.
- » Certain teas such as “Smooth Move” can be successful and well tolerated. These are generally found in the health food section of the grocery store.

- » Medications to prevent or decrease constipation: Call your doctor before taking any laxatives, or using suppositories, or enemas, unless prescribed by a provider.

Stool Softeners

These increase water and fat penetration in the colon and make it easier to have a bowel movement. Take one to three times daily. Available under brand names: Colace, Dialose, DC Softgels, Regulol.

Stimulant Laxatives

These act directly on the intestine by increasing motor activity. Available under brand names: Dulcolax, Fleet, Biscadodyl, Senokot. Take 1 tablet at bedtime or upon arising. You can use two if needed.

Bulk Laxatives

These move quickly through the bowel if there is enough fluid to make this happen. Brand names include: Fiberall, Konsyl, Metamucil, Reguloid, Serutan. Fluid is especially important when using this type of laxative. Milk of Magnesia is a saline type of laxative that acts by drawing fluid into the colon by osmosis. It is often mixed with Cascara, which is a chemical irritant. This can be taken when you wake up, followed by a warm drink.

Lubricant

These ease passage of stool by decreasing water absorption from feces. These should not be used for long-term therapy.

Lubricants may also be given as an enema to soften hard stool and make it easier to pass.

Suppositories

Glycerine suppositories are used to soften stool to make it easier to pass. Dulcolox suppositories stimulate and cause the lower colon and rectum to empty. If more than one day has passed without having a bowel movement, you may use a suppository to help clean out the lower colon and follow that with an oral laxative to move the waste through the bowel.

Swamp Juice

The recipe below has been successful, in spite of the title.

- Mix equal parts of orange, apple, and prune juice.
- When mixed this will keep refrigerated for 5 days.
- Drink 1-2 eight ounce glasses a day (warm or cold).

Call Your Provider

- » If you have not had a bowel movement for 3 days.
- » If you have abdominal pain, bloating or distension.
- » If you are vomiting.
- » If you have bleeding from the rectum.



Symptom Management Information Sheet

Diarrhea

Diarrhea is loose or liquid stool that occurs more often than normal. If you have liquid stools, call the office to report how many, how much, how often and what the stool looks like and any other symptoms. Contributing factors are chemotherapy, radiation therapy, food sensitivities, and emotional upset.

What to do About Dietary Modifications

- » Initially limit diet to fluids (flat carbonated beverages, fruit nectars, weak tea, water, Kool-aid, or other sports drinks).
- » Gradually progress to low residue, high calorie, and high protein diet; try bananas, applesauce, rice, mashed potatoes, dry toast, and crackers.
- » Increase fluid intake to 2-3 quarts a day to avoid dehydration including apple juice, bouillon, sports drinks, Jell-O, Kool-aid, non-carbonated beverages, and weak tea.
- » Drink beverages at room temperature and avoid foods that are either too hot or too cold.
- » Eat foods rich in potassium (baked potatoes, bananas, halibut, apricot, and peach nectars, citrus juices, Coca-cola).
- » Eat several small meals a day instead of 3 large meals.

What to do About Skin Care

- » Clean and lubricate the anal area after each stool.
- » Avoid toilet paper and use a clean, soft cloth and water for washing.

- » Gently pat area dry. Do not wipe.
- » Use cotton undergarments and change at least daily.
- » May use zinc oxide to protect intact skin.
- » May use witch hazel (Tucks) if skin does not sting and is intact.

Call Your Provider

- » Fever 100.4 °F or higher.
- » Moderate to severe abdominal cramping/pain/straining/bloating.
- » Dizziness.
- » Dark (concentrated) urine.
- » Dry mouth and skin.
- » Black stools or blood in stools.
- » Sudden rapid or irregular heartbeat.
- » If dietary measures and medication do not decrease the diarrhea.



Symptom Management Information Sheet

Skin & Nail Changes

Rough, red, flaky, itchy, and sometimes painful skin may be due to not enough oil and water in the layers or folds of the skin as a side effect of chemotherapy or radiation therapy. Your nails may darken, yellow, become brittle, or cracked. They may also develop vertical lines or bands.

What to do About Dry Skin

- » Use only warm water and mild soap to bathe, and do not take more than one tub bath or shower a day, unless you need to.
- » To “lock” moisture into the skin, add mineral or baby oil to bath water a few minutes after you have soaked. Apply unscented, water-based creams two or three times a day, especially after bathing.
- » Wear loose, soft clothing.
- » Keep room temperatures relatively cool (60-70°F) and well ventilated.
- » Drink as much fluids as allowed and tolerated.
- » Apply cornstarch as a dusting powder.

What to do About Nails

- » Keep nails clean and short to avoid scratches and possible infection.
- » Protect your nails by wearing gloves when washing dishes, gardening, or doing other work around the house.

What to do About Sunlight Sensitivity

- » Avoid direct sunlight, especially between 10:00 am and 4:00 pm when the sun’s rays are the strongest.

- » Use a sunscreen lotion with a skin protection factor (SPF) of 15 or higher to protect against sun damage.
- » Use lip balm with SPF.
- » Wear long-sleeve cotton shirts, pants, and hats with a wide brim to block the sun.
- » Even people with dark skin need to protect themselves from the sun during chemotherapy.

Things to Avoid

- » Scratching skin. If itchy, try rubbing the skin or using vibration to help.
- » Alcohol and coffee can increase skin blood flow and redness/itchiness.
- » Personal care products with fragrance or alcohol. These can increase redness/itchiness.

Call Your Provider

- » If your skin becomes yellow, red, and painful or if a rash, hives, or pus develops.
- » If skin remains itchy or painful for more than two days.



Symptom Management Information Sheet

Dry Mouth

Dry mouth is caused by the lack of saliva to moisten the mucous of the membranes. It can be caused by mouth breathing, medications, radiation therapy, chemotherapy, or as a result of dehydration.

What to do

- » Rinse mouth with a saline solution (pre-bottle or mix 1 tsp. salt in 1 quart of warm water) every two hours.
- » Drink fluids that are caffeine free.
- » Add sauces, gravies, broth, and dressings to foods.
- » Suck ice chips, popsicles, gum, or sugarless hard candies to keep the mouth moist. Include citric acid in your diet to stimulate saliva production. Citric acid is present in orange juice, lemonade, and sugarless lemon drops. You can also add lemon to tea, water, and soda.
- » Drink liquids with your meals.
- » Use artificial saliva (requires doctor's prescription).
- » Keep your mouth clean and fresh to decrease risk of infection and taste changes.

Things to Avoid

- » Eating dry food products such as bread products, crackers, or dry cake.
- » Eating or drinking very hot foods or beverages.
- » Licking your lips (this may increase drying or chapping).

- » Using any tobacco products.
- » Drinking alcohol.
- » Avoid alcohol-containing mouthwashes (alcohol is very drying to the mouth).

Call Your Provider

- » If dry mouth lasts for more than 48 hours.
- » If dry, cracked lips, or mouth sores develop.



Symptom Management Information Sheet

Fatigue

Fatigue is one of the most common problems for people with cancer. Fatigue is mental and physical exhaustion that does not get better with rest. People describe these symptoms in many ways: tired, weak, sad, bored, no energy, exhausted, depressed, and unable to concentrate. Many things can cause this: blood loss, bed rest or decreased activity, medicines, and sadness due to the diagnosis of cancer.

Fatigue is a common side effect during and after chemotherapy or radiation therapy. It can last a few weeks or even for several months. Fatigue can impact your life. Simple tasks such as shaving or brushing your teeth may seem impossible to do. Being flexible, planning, and understanding what is happening to you may make it easier to deal with fatigue. Using your energy wisely is very important.

Anemia can cause fatigue. Anemia is when there is a low number of red blood cells to carry oxygen to your tissues and cells. Your blood counts will be checked during your treatments by taking blood samples. If anemia is adding to your fatigue, a transfusion or medication may help.

Fatigue does not mean your cancer is getting worse or that your treatment is not working. Sometimes fatigue cannot be treated. When treatment is complete, your energy will slowly return. There can be many causes of fatigue, such as: *poor nutrition, stress, chronic pain, depression.*

What to do

- » Exercise daily as you are able to (walking).
- » Plan rest periods or naps to conserve energy for what matters to you. Rest when you are tired. Listen to your body.
- » Plan necessary activities throughout the day. Do the most important activities first, rather than all at once. Plan to slowly increase activities as your fatigue gets better.
- » Remember fatigue caused by treatment side effects is temporary and your energy should improve when treatment ends.
- » Eat well. Snack on high protein foods.
- » Try to do one special thing each day that you enjoy.
- » Ask for help with household and family activities.
- » Talking with others who are experiencing the same problem can help.

Call Your Provider

- » If you have an increase in shortness of breath.
- » If your fatigue gets worse.



Symptom Management Information Sheet

Fever

Fever is a body temperature of more than 100.4° F. Fever is usually caused by an infection. People receiving chemotherapy are more likely to get an infection because they may have lower number of white blood cells needed to fight infections. Fever can occur as a side effect of some drugs or may occur as a result of the cancer process.

Signs & Symptoms of Infection may Include

- » Temperature of 100.4° F or higher.
- » Shaking or chills.
- » Increased skin temperature.
- » Feeling warm or cold.
- » Feeling tired or listless.
- » Headache or body aches.
- » Confusion.
- » Skin rash.

What to do

- » Take your temperature tympanic (ear), oral (by mouth), or axillary (arm pit).
- » Drink more fluids, at least twelve eight ounce glasses per day.
- » Get more rest.
- » Take temperature every 3 hours.
- » Write down your temperature.
- » If temperature is over 100.4° F, call your provider.
- » If temperature is over 100.4° F, you may take acetaminophen (Tylenol).

Things to Avoid

- » Ice or alcohol baths in order to bring the fever down.
- » Taking rectal temperatures.

Call Your Provider

- » When you first notice a rise in temperature to 100.4° F or higher.
- » If you have two or more symptoms listed above under “Signs and Symptoms”.
- » If you develop a low-grade fever (less than 100.4° F) and it lasts for 24 hours.



Symptom Management Information Sheet

Hair Loss

Hair loss occurs because chemotherapy is a systemic drug. This means that it travels through the bloodstream and can affect cells all over the body, including hair follicles. Not all chemotherapy causes hair loss, and the effects on hair may vary. Not everyone will have hair loss, even when getting the same drug. If hair loss does occur, it usually begins within two weeks of the start of chemotherapy. Hair loss as a result of chemotherapy is temporary.

Radiation therapy to the head is a localized treatment. It can also lead to scalp hair loss. Depending on the dose of radiation received, hair may or may not re-grow.

What to do

- » Know that it is normal and healthy to worry about hair loss.
- » Buy a wig or toupee, before or at the start of treatment, so the color and texture of your hair can be matched before loss occurs. Check with your insurance company about wig coverage, it may be available with provider prescription.
- » Shaving your head completely gives some people a sense of style; others purchase hats and scarves to wear.
- » If you have long hair, consider having it cut shorter.

Things to Avoid

- » Excessive brushing.
- » Use of heavy barrettes or rubber bands.
- » Using heat-generating styling appliances such as: hair dryers, curling irons, or electric rollers.
- » Coloring or perming hair is discouraged.

Call Your Provider

- » If hair loss is impacting your daily life, please talk to your social worker. They may have some ideas and options that are available to help.



Symptom Management Information Sheet

Mucositis

Mucositis is the inflammation of the mucous membranes of the body. It is most common in the mouth, but may affect other areas lined with mucous membranes including the colon and rectal area, the vagina, the throat, and esophagus (the tube that leads from the throat to the stomach). Good hygiene is important during treatment to help prevent mucositis. Chemotherapy makes tissues dry, irritated, and less able to fight infection caused by the germs that normally live in those areas. When calling the office about a sore mouth (or any other mucous membrane), please try to look at the area so you are able to describe any reddened areas, white patches, blisters, or open sores that may be present.

What to do

Mouth Mucositis

- » Drink a lot of water and eat well (up to 2-3 quarts of water a day and a well-balanced diet).
- » Brush teeth gently with a soft bristle toothbrush 3-4 times daily (after every meal and at bedtime).
- » Rinse toothbrush thoroughly after each use and store it in a dry place.
- » Rinse mouth with a salt-water solution made by mixing 1tsp. of salt in 1 quart of warm water.
- » Use dental floss if platelet count is not low and you are not at risk for bleeding.
- » Use a lip lubricant or moisturizer.
- » Keep denture or oral appliances clean and remove them if they are causing irritation.

Tissues Other Than the Mouth

- » To prevent vaginal infection or cope with irritation:
  - Maintain good hygiene.
  - Wear cotton underwear.

- Wear pantyhose with a well-ventilated cotton lining.
- Don't wear tight slacks or shorts.
- Use cool sitz baths or cool compresses.
- Avoid intercourse or use a water-based lubricant.
- Notify doctor if vaginal infection is suspected.
- » To prevent anal/rectal irritation:
  - Clean area with mild soap after each bowel movement.
  - Use wet wipes when washing is not possible.
  - Keep area dry.

General Treatment

- » Use medications as prescribed (there are medicines available to relieve pain and treat infections that may develop).
- » Possible medications your provider may prescribe:
  - *Viscous Xylocaine*: This is a liquid that is swallowed, one tablespoon at a time and rapidly numbs the esophagus providing temporary relief. This is a thick fluid that may be diluted with an equal amount of water or antacid

(Maalox). Its effects may last approximately 10 minutes and may need to be repeated throughout the meal.

- **Pain Medication:** Your provider may prescribe a pain medication such as Vicodin, Percocet, or Oxycodone. In general, 1-2 tablets taken every 3-4 hours will help you control the pain. Some pain medications such as extended duration morphine (MS Contin) may be taken less often. These medications may make you sleepy and may affect your coordination; you should not drive or operate heavy equipment while taking these medications. An additional side effect includes constipation, and you may need to use laxatives or stool softeners, such as Milk of Magnesia. In some instances, pain medications may cause nausea. If this occurs, contact your provider.

- **Magic Mouthwash:** This liquid is usually used for pain control in the mouth and throat. It may be used either as a swish and gargle or swallowed. It can be taken up to 6 times a day, before, during, or after meals as needed.

- » Use pain medication before eating.
- » Eat food at room temperature or cold to prevent irritation.
- » Choose soft soothing foods:

ice cream	milkshakes
yogurt	bananas
applesauce	custards & pudding
baby food	gelatin
mashed potatoes	cooked cereals
macaroni & cheese	

soft-boiled or scrambled eggs	pureed foods
cottage cheese	fruit nectars
	watermelon

- » Cook foods until they are soft and tender.
- » Moisten foods with butter, margarine, sauces, and gravies.
- » Suck on ice chips, popsicles, or sugarless hard candy.
- » Dunk crisp or rough foods in liquids to soften them.
- » Use a straw to drink liquids.
- » If swallowing is hard try tilting your head back or moving it forward.
- » Rinse your mouth frequently with water.
- » Try nutritional supplements, such as Ensure, Boost, etc.

Things to Avoid

- » Avoid commercial mouthwashes that contain alcohol.
- » Avoid foods that are rough, acidic, salty, or spicy:

tomatoes	toast & crackers
raw vegetables	granola
citrus fruits	orange juice
salty snack foods (potato chips, pretzels, etc.)	lemonade

Call Your Provider

- » Call the office to report sore mouth or irritation of mucous membranes.



Symptom Management Information Sheet

Nausea & Vomiting

Nausea is a sick and queasy feeling in the stomach, as if you are going to throw up (vomit). A person can vomit even if he/she has not eaten anything and has not had any nausea. Radiation, certain chemotherapy drugs, some medicines such as narcotics or antibiotics, odors, and some foods may cause nausea and/or vomiting.

What to do

- » Eat and drink slowly.
- » Eat frequent small meals and snacks at bedtime.
- » Eat bland high carbohydrate foods.
  - Steamed white rice, mashed potatoes and boiled potatoes
  - Cream of rice or cream of wheat
  - Bananas or applesauce
  - Dry toast or crackers
  - Baby foods, soft pudding and yogurt
  - Noodles
  - Scrambled eggs
  - Smooth peanut butter
  - White bread
  - Skinned chicken or turkey, lean beef, boiled or baked fish
  - Cottage cheese
  - Peach and apricot nectar, grape or apple juice
  - Supplements such as Ensure, Sustacal, Isocal (if able to tolerate)
- » Drink clear liquids served cold (clear liquids are those that can be seen through when contained in a glass, and should not be alcoholic).
  - Gatorade, sports drinks, Kool-Aid, or popsicles
  - Clear soup or broth
- Ginger ale, sodas (but stir with a spoon or let them stand until the bubbles have gone away)
- Weak tea
- » Eat cold foods rather than warm foods since cold foods tend to have less food odor.
- » Rest for at least an hour after each meal, but do not lie down flat.
- » When nausea occurs, relax by taking slow deep breaths.
- » Perform good mouth care to keep your mouth fresh and clean.
- » Make sure you get your medicines to control nausea and vomiting.
- » Let your provider or nurse know if your drugstore does not have the medication or you cannot afford to pay for the medication.
- » Take anti-nausea medications as instructed. You may try taking your anti-nausea medications 30 minutes before meals or any activity that causes nausea. The key to control is to prevent nausea from developing.
- » Drink fluids between meals.

- » If you are not eating much, try a little low fat salty food like pretzels or bouillon because the salt helps your body hold onto its fluids.
- » Get rest and try relaxing activities as a distraction.
- » Try fluids 2 hours after vomiting.
- » Go outside of home for fresh air, taking in more oxygen may calm stomach.
- » Wear loose fitting clothes so as not to add pressure to stomach and throat.

Things to Avoid

- » Avoid certain foods:
  - Cooking areas where smells might be offensive
  - Spicy foods
  - Overly sweet foods
  - Foods with strong odors
  - High fat greasy foods
- » Drinking a lot of liquids with meals.
- » Drinking hot liquids.
- » If you need to rest after eating, sit or recline with your head elevated, don't lie flat on your back.

Call Your Provider



- » If you are having nausea or vomiting, you may need a prescription to prevent nausea and vomiting during treatment.
- » If your current anti-nausea medication is not helping, your provider may change medications.
- » If your medicine is helping your nausea and vomiting, but not as much as you would like, call your provider or nurse. Your medicine may need to be adjusted.
- » If you have vomiting and cannot take medicine.
- » If vomiting occurs more than three times in an hour.
- » If you are vomiting and you lose more than two pounds in a day.
- » If any blood or material that looks like coffee grounds appears in the vomit.
- » If you have nausea lasting more than a few days that keeps you from doing what is important to you.

Common Medications for Nausea & Vomiting

Your provider or nurse will instruct you on which ones to take,
and how to take them.

DO NOT mix medicines without approval from your provider.

Trade Name	Generic Name	Usual Dose	Comments
Compazine	Prochlorperazine	10 mg by mouth every 4 to 6 hours	May cause sleepiness or restlessness
Phenergan	Promethazine	12.5-25 mg by mouth every 4 hours	May cause sleepiness or restlessness
Kytril	Granisetron	1 mg by mouth per day	May cause headache or constipation
Zofran	Ondansetron	8 mg by mouth every 12 hours	May cause headache or constipation
Ativan	Lorazepam	0.5-1 mg by mouth every 4 to 6 hours	May cause sleepiness
Decadron	Dexamethasone	Variable dose	May cause irritation of stomach fluid retention May cause facial flushing May cause insomnia

Symptom Management Information Sheet

Pain

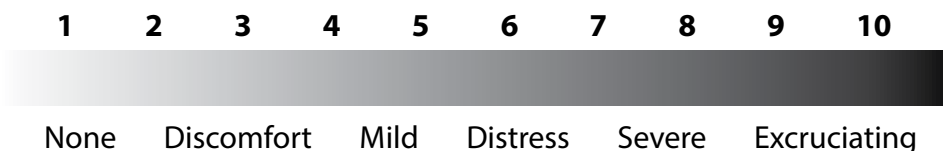
People with cancer may have pain. It may be due to the tumor, to the side effects of the treatment, or unrelated to the cancer or its treatment. Most cancer pain may be eliminated or significantly reduced. The person with the pain is the only one who knows how they are feeling. It is very important to tell your provider and nurses about your pain.



What to do

» Questions your provider may ask:

- Use the scale of 1-10 to rate the pain.



1. Where is the pain located?
2. When did the pain start?
3. How severe is it?
4. What makes the pain better?
5. What makes the pain worse?

- » Take the prescribed pain medicine:
  - Take the right amount of medicine at the right time. The medicine will be more effective if taken on a regular schedule, before the pain builds up. Continue taking the medication during the night, unless you are using a time-released capsule or patch.
- » Do not stop taking pain medication suddenly, if you have been on it for several weeks. Call your provider for information about tapering off your pain medication.
- » If you are having a procedure where you may not eat or drink talk to your doctor about whether to continue your pain medicines during this time.
- » A common fear for many people is becoming addicted to pain medicine; therefore they 'save it' for when their pain gets really bad. People who take narcotics for cancer pain take them to get relief from real physical pain. If you still have concerns about addiction, discuss it with your provider.
- » People who take pain medications over long periods of time may become tolerant to the medications effects. You might need more medication to help treat your pain. If you feel this is happening, call your provider.

» Common side effects of Pain Medication:

Constipation

- All narcotic pain medicines cause constipation.
- Increased fluids, fiber, and exercise (if appropriate) will decrease constipation.

- If you have been prescribed pain medications without being instructed to take laxatives, ask your provider for advice.

Dry mouth and nose

- Sip on water or suck on crushed ice.
- Suck on sugar-free hard candy.
- Avoid mouth-care products which contain alcohol.
- Use a room humidifier if available.
- Apply Vaseline to lips or nasal passages with a cotton swab.

Nausea

- Take pain medication with food unless instructed otherwise.
- If nausea persists talk with your provider. A different medication may cause you less nausea.

Drowsiness

- Expect drowsiness for a few days when pain medication is started or the dose is increased.
- A stimulating environment (i.e., music, lights, etc.) may help you feel more alert.
- If drowsiness persists after a few days talk with your provider.

» Additional ways to manage pain.

- Heat can relax muscles and give comfort. Use warm showers or baths, hot water bottles, warm washcloths, or heating pads. Avoid heating pads on skin that has been radiated or over medication patches, such as a fentanyl patch.
- Cooling can soothe pain, especially pain from inflammation or swelling. Use cool washcloths or ice packs.
- Positioning with pillows and cushions may help you be more comfortable.
- An adjustable bed or recliner may be more comfortable than a regular bed.
- Relaxation techniques may help relax muscles and reduce pain. Some techniques may be: deep breathing exercises, progressive muscle relaxation, meditation, or guided imagery.
- Massage areas that are sore due to pressure, muscle strain, or muscle tightness. It is not recommended to massage areas that are sore due to cancer.
- Activities that you enjoy will not stop the pain but may distract you and allow you to focus on something else for a time.

Things to Avoid

- » Withholding information on pain from your provider.
- » Taking pain medication in any way that has not been prescribed to you.

Call Your Provider

- » If any new pain occurs.
- » If pain continues or increases despite taking pain medicine as prescribed.
- » If pain increases when you lie down or if it occurs with headache, numbness, difficulty walking, or urinating.



Chapter 7. Eating Well

Cancer treatments may lower your appetite or change the way food tastes or smells. Talk with your health care team if you are not hungry or if you find it difficult to eat. This next chapter will give you ideas on how to get the nutrition you need while undergoing treatment.



Tips for When Your Sense of Taste Changes

Cancer treatments may change the way food tastes. Taste changes are common during chemotherapy. The exact reason for taste changes is not clear, although it is thought that it is a result of the damage to the cells in your mouth, which are especially sensitive to chemotherapy.

Take these steps to get the nutrition you need to stay strong during treatment.

- » If meats taste too bitter, substitute plain chicken and fish, mild cheeses, eggs, dairy products, tofu or peanut butter.
- » Marinate meats, chicken or fish in Italian dressing, lemon or pineapple juice, soy sauce or sweet-n-sour sauce.
- » Add sauces to meats.
- » Try spicy or highly seasoned foods, if you can tolerate them.

- » Eat more foods that are cold or room temperature.
- » If foods taste too sweet you can: avoid concentrated sweets, avoid sweet fruits, use sour fruit juices to mask sweetness.
- » Choose bland foods like eggs, cheeses and cottage cheese, hot cereals, puddings, cream soups, bread, potatoes, rice, pasta, and crackers since these are less likely to taste strange.
- » Remove strange tastes in your mouth by simply drinking water, tea, ginger ale or fruit juices mixed with club soda.
- » Chew sugar-free gums or suck sugar free hard candies to eliminate bad tastes.

Tips for When you Have Chewing & Swallowing Problems

Cancer and treatment can cause chewing and swallowing problems. When you run into swallowing and chewing problems, try different types of food and ways of eating. Find what works best. And remember to eat a nutritious diet. Your food should have enough calories, protein, vitamins, and minerals.

- » Moisten foods with gravy, sauces, broth, butter or margarine, mayonnaise or sour cream to make swallowing easier.

- » Serve soft moist foods such as:
  - Scrambled eggs, ice cream, macaroni and cheese, custard, soups, stews, and puddings (add fruit for extra nutritional value)
  - Mashed potatoes with gravy
  - Cereals cooked with extra gelatin made with soft canned fruit
  - Milk or cream cooked vegetables, cottage cheese
- » Take a sip of beverage with each bite of food.
- » Blended foods such as fruits and vegetables may be easier to swallow.
- » Cut food into small bites.
- » Soften hard foods such as toast by dunking in milk, cocoa, coffee or tea.
- » If you have dry mouth:
  - Chew sugarless gum or try sugar free hard candies (especially lemon) to stimulate salivation. (Candy and gum with sugar promote dental cavities and should be avoided).
  - If your mouth is not sore try sour pickles to stimulate salivation.
- » Drink plenty of fluids.
- » Ice chips or popsicles help relieve a dry mouth. You can make your own popsicles from fruit juices. They have more nutritional value than those you buy.
- » Avoid:
  - Dry, sticky foods such as peanut butter, hard dry foods such as crackers, nuts and popcorn; and raw vegetables.
  - Commercial mouth washes.



Tips to Increase Oral Intake

Cancer treatment may cause you to have trouble getting enough food and drink each day to keep you healthy. Below are some tips and tricks to help you increase the amount of food and drink you are able to eat and drink each day.

Dysphasia (trouble swallowing)

- » Soft or liquid foods are easier to swallow.
- » Food may have to be pureed.
- » Ground meats moistened with gravies or sauces, such as meatloaf and mashed vegetables decrease the risk of aspirations (choking).

Satiety (getting full early)

- » Eating 5 or 6 small meals daily is better than 3 large meals.
- » Nutritious snacks should be available throughout the day.
- » Food should be chewed slowly.
- » High-calorie foods should be added to menus.
- » Beverages should be taken 30 minutes before meals.

- » Beverages should be nutritious, such as juices, milkshakes or milk.
- » Greasy foods and rich sauces should be avoided.

Mucositis & Stomatitis (inflammation that leads to mouth pain)

- » Solid foods can be moistened with gravies or cream sauces to make chewing and swallowing easier.
- » Good oral hygiene is essential.
- » Soft toothbrushes prevent further damage to the mouth.
- » Local anesthetic solutions may be used prior to eating.
- » Soft, bland foods, such as yogurt, cream soups, and milkshakes, are less irritating and are often high in calories.
- » Frozen fruit juices or popsicles are cool and soothing.

Anorexia (loss of appetite)

- » Meals should be small and frequent.
- » Changes in diet and environment can stimulate appetite.
- » High-protein snacks, such as cheese and milk, should be eaten throughout the day.
- » Grains and nuts should be added to desserts.
- » Wine or a small glass of fruit juice before meals can stimulate appetite.
- » High-calorie foods, such as a cold chocolate protein drink, can be used to take medications.
- » Fatty foods should be avoided.

- » Four to six tablespoons of powdered milk can be added to cake and cookie recipes to increase protein content.

Nausea & Vomiting

- » Medicine to prevent nausea should be taken at least 30 minutes before eating.
- » Small, frequent meals reduce the incidence of nausea and vomiting.
- » Cooking and food preparation odors should be avoided.
- » Clear, carbonated beverages are advised.
- » Food should be served at room temperature and without beverages.
- » Very sweet, fatty, hot, or fried foods should be avoided.
- » Some medicines alter taste, so try a variety of foods.
- » Loose clothing is helpful.
- » Eating slowly and chewing food thoroughly should be encouraged.
- » Dry foods, such as toast and crackers, are advised, especially upon awakening.
- » Resting with the head elevated after meals is helpful.
- » Favorite foods should be avoided during chemotherapy to prevent food aversions from developing.

Taste Changes

- » Sweet marinades or soy sauce can be used with red meat.
- » Poultry, fish, eggs, and cheese can be substituted for red meat.

- » Chilled meat dishes, such as chicken salad or cold roast beef sandwiches, are advised.
- » Lemonade, tea with lemon, citrus fruits and drinks and pickled foods stimulate the taste buds.
- » Try new things. You might find that food you didn't like before, you now like.
- » Extra seasoning, spices, onions and garlic can be used.
- » Rinse your mouth with carbonated water before meals to clear the taste buds.
- » If you don't want to eat meats or protein foods, try to eat sweet, high-calorie, high-protein foods, such as milk shakes, puddings and ice cream.
- » For metallic taste - eat with plastic ware instead of silverware. Avoid foods from metal cans. Avoid cooking in metal pans.

Xerostomia (dry mouth)

- » Food should be moistened with gravies and sauces.
- » Artificial saliva preparations increase comfort and swallowing ability.
- » Pureed food is easier to swallow.
- » Food can be soaked in coffee, tea, milk, cocoa, or warm beverages.
- » Dry foods should be avoided.
- » A swallow of liquid with each mouthful eases swallowing.



Here are a few recipes that may be helpful to try if you are having trouble getting the calories and nutrition your body needs.

Fruit Frappe

Any frozen fruit or combination of:

Black cherries

Peaches

Raspberries

Ice cubes

Orange juice

1-2 bananas

Plain yogurt or yogurt ice cream

Make enough to fill blender, serve right away or freeze until next day. After frozen, will last 1 week in fridge.

1000 Calorie Shake

Whole milk

Whole milk ice cream

1/4 cup peanut butter

Banana or other fruit

1/4 cup oil

Any sauce (e.g. chocolate, butter
scotch)

Honey coated wheat germ (optional)

Make enough to fill blender, serve
right away or freeze until next day.
After frozen, will last 1 week in fridge.

Fortified Milk

1 quart whole milk

1 cup nonfat instant dry milk

Pour liquid milk into a deep bowl.

Add dry milk and beat slowly with
beater until dry milk is dissolved
(usually less than 5 minutes).

Refrigerate and serve cold.

Note: If it tastes too strong, start
with 1/2 cup of dry milk powder and
gradually work up to 1 cup.

Use fortified milk when making:

Macaroni and cheese

Puddings and custards

Cream sauces for vegetables

Mashed potatoes

Cocoa

French toast or pancake batter

Soup

Chapter 8. Life Issues - Cancer & Emotions



Exploring your emotions or feelings after a diagnosis of cancer is a road paved with hope, despair, courage, fear, humor, anger and constant doubt. Each person has to cope with cancer in an individual way. The following pages are meant as a guide - it is a collection of thoughts on how some people with cancer and their loved ones feel and the ways they found to deal with those feelings.

Our bodies and minds are not separate. Your body can stay strong if you are able to cope well with the emotional turmoil of cancer. It is hard to think about dying, but it's important to focus on living. Remember, a diagnosis is not a death sentence; an increasing number of people with cancer are saved. Of the others, many will live well for a long time. Indeed, there are sunrises as well as sunsets to be enjoyed, so let us take a look at living - living with cancer and its treatment, but living nonetheless.

The following sections are excerpts from the Taking Time booklet from the National Cancer Institute, NIH Publication No. 92-2059
For a copy of the booklet, or to view online visit www.cancer.gov/publications/patient-education/takingtime.pdf



Sharing the Diagnosis

Cancer can be very lonely. No one should try to bear it alone.

Your family and friends usually learn the diagnosis sooner or later. Most find it easier for all if everybody can share their feelings instead of hiding them. This frees you to offer each other support.

People usually agree that hiding the diagnosis from them denies them the right to make important choices about their life and their treatment. Families say patients who try to keep the diagnosis secret rob loved ones of the chance to express that love and to offer help and support. Family members and intimate friends also bear great emotional burdens and should be able to share them openly with each other and the patient.

Even children should be told. They sense when something is wrong, and they may imagine a situation worse than it really is. You might want to tell the children directly; or it may be easier to have a close friend or loving relative do so. The children's ages and emotional maturity should be a guide in deciding how much to tell. The goal is to let children express their feelings and ask questions about cancer.

By sharing the diagnosis, yourself, family and friends build foundations of mutual understanding and trust.

Sharing Feelings

Some in the family are able to absorb the impact of the diagnosis sooner than others. This can create clashing needs as some wish to talk and some need to be private and introspective. Verbal and nonverbal clues help determine when is a

good time to discuss the illness and how each will learn to live with.

If family members cannot help each other, other emotional support systems are available in the form of groups or professional counselors. Then you have the right to set the timetable for when you ready to talk. Others can encourage that readiness through their love and continued presence. Talking may include expressing anger, fear and inner confusion. False cheeriness - the "everything will be all right" routine - denies you the opportunity to discuss fears and anxieties. Celebrating positive test results or good response to treatment is true support.

You need family or friends as a constant in a changing world. Your ability to hear from family and friends "I'm here," provides great support.

Coping Within the Family

Cancer is a blow to every family it touches. How it is handled is determined to a great extent by how the family has functioned as a unit in the past.

Problems within the family can be the most difficult to handle; you cannot go home to escape them. Adjusting to role changes can cause great upheavals in the way family members interact. Performing too many roles at once endangers anyone's emotional well-being and ability to cope.

Examine what tasks are necessary and let others slide. Consider hiring professional nurses or homemakers. Financial costs need to be weighed against the physical and emotional cost of shouldering the load alone.

Children may need special attention. They need comfort, reassurance, affection, guidance and discipline at times of disruption in their routine.



When You Need Help

When cancer develops, many people need to learn to ask for and accept outside help for the first time. These are some ways to begin:

- » Ask questions. Don't be afraid to your doctor, nurse specialists, therapists, and technologists the questions that come up.
- » Make a list of questions. Write out or tape-record the answers. Take someone else along as a second listener.
- » Ask your provider about treatments if you have questions about them.
- » Trust and rapport between patient and provider are important; you must be able to work together to treat the cancer most effectively.
- » Your healthcare team, hospital, library, the National Cancer Institute or other organizations are good sources of facts about cancer. Many can also provide the names of local support and service

organizations established to help you cope with the emotional stress of the disease.

- » Emotional support takes many forms. Counseling or psychiatric therapy for individuals, for groups of patients and for families often is available.
- » Many groups have been created by patients and their families to share practical tips and coping skills. One may be right for you.
- » Your minister, priest or rabbi, a sympathetic member of the congregation or a VA chaplain may be able to help you find spiritual support.

You & Your Self-Image

Each of us has a mental picture of how we look, our "self-image." Although we may not always like how we look, we're used to our self-image and accept it. But cancer and its treatment can change how you look and feel about yourself. Know you aren't alone in how you feel. Many others have similar feelings.

- » Fears and anxieties caused by cancer can affect a sexual relationship.
- » Treatment might make you feel uncomfortable about your body and sexually unattractive. Open discussion of these feelings with your mate is very important.
- » Personal qualities make up a great part of your attraction for your mate. These have not changed with treatment.
- » Spouses sometimes hesitate to initiate physical contact. Support, love and affection include hugs and caresses.

These may lead the partner with cancer to feel more comfortable about sexual intimacy.

- » Cancer is not contagious.
- » Cancer treatment can extend over weeks or months; side effects may come and go.
- » Side effects can sometimes make you feel poorly, even make you think the cancer has returned.
- » The known is less frightening than the unknown. Learn about your cancer, its treatment, and possible side effects and how to treat them.
- » Physical exercise improves body image and feelings of well-being.
- » Taking on new hobbies and learning new skills can bolster your good feelings about yourself.
- » Reconstructive surgery and well-made prostheses help some people overcome physical changes and emotional distress.
- » If you cannot find positive feelings about yourself, do seek professional counseling or therapy.
- » If your relationships are endangered by the stress of cancer, get professional help. You need the support of each other at this time.

The World Outside

- » Some friends will deal well with your illness and provide gratifying support.
- » Some will be unable to cope with the possibility of death and will disappear from your life.



- » Most will want to help, but may be uncomfortable and unsure of how to go about it. Help your friends support you:
  - Ask yourself, “Have friends deserted me or have I withdrawn from them?”
  - Ask for simple assistance - to run an errand, prepare a meal, come and visit. These small acts bring friends back into contact and help them feel useful and needed.
- » Another cancer patient or a group of other cancer patients can offer new friendships, understanding, support and companionship.
- » When you return to work, coworkers may shun you, support you, or wait for your cues on how to respond.
- » There are laws to protect you against job discrimination. If you think you have been discriminated against, call the Bureau of Labor and Industries.

Living Each Day

Each person must work through, in his or her own way, feelings of possible death, fear and isolation. Returning to normal routines as much as possible often helps. Give the pleasures and responsibilities of each day the attention they deserve. You are encouraged to continue pursuits that keep life meaningful; recreation keeps it zesty. Fill your life with both.

Remember the difference between “doing” and “overdoing.” Rest is important to both your physical and emotional strength. It is harder to bolster one’s will to live if you are alone; yet many have acted as their own cheering squad and have found ways to lead meaningful lives.

Family members should encourage your full participation in family life. Your family members should not equate physical incapability with mental failing. It is especially important that you continue to feel a necessary part of the family.

The Years After

Cancer is not something anyone forgets. Anxieties remain as active treatment ceases and the waiting stage begins. A cold or a cramp may be cause for panic. As six-month or annual checkups approach, you swing between hope and anxiety. As you wait for the mystical five year and ten year point, you might feel more anxious rather than more secure.

These are feelings we all share. No one expects you to forget that you have had cancer or that it might recur. Each must seek individual ways of coping with the underlying insecurity of not knowing the true state of his or her health. The best prescription seems to lie in a combination



of one part challenging responsibilities that command a full range of skills, a dose of activities that seek to fill the needs of others and a generous dash of frivolity and laughter.

You still might have moments when you feel as if you live perched on the edge of a cliff. They will sneak up unbidden, but they will be fewer and farther between if you have filled your mind with thoughts other than cancer.

Cancer might rob you of that blissful ignorance that once led you to believe that tomorrow stretched forever. In exchange, you are granted the vision to see each today as precious, a gift to be used wisely and richly. No one can take that away.



Coping with Your New Diagnosis

Cancer is one of those life crises that can provide new meaning and purpose in life. But that comes later. Awaiting the diagnosis and hearing the news can be the most emotionally difficult period of the entire cancer experience. Here are some suggestions and resources that can help you gather information and make decisions with presence of mind.

Know Yourself

There's no "right" way to cope with cancer. Each person handles the emotional challenges differently. Think about how you usually act in an emergency and expect to react the same way. It may help to understand the strengths that brought you through difficult times before. Who is your support that you can count on in trying times, including family, friends, spiritual advisors and mental health professionals.

Do what works for you. But if your usual reaction to crises might interfere with your ability to function at home or at work, and you are unable to make treatment, family or workplace decisions, reach out to traditional or new support systems now.

What Does Cancer Mean to You?

Cancer triggers a fear different from most other diseases, even though they may have worse consequences. Any sense of doom you may have probably comes more from this historic dread than from the current realities concerning your type of cancer and its treatment. Cancer is not a death sentence for most people. It does not necessarily lead to helplessness, pain, disfigurement, disability or the end of your career. Accept that these exaggerated fears are normal, but do not let them prevent you from having a worrisome lump or symptom checked out or from deciding to undergo recommended treatment. And do not believe that you will not have the energy or focus to pursue life goals. Most people find that their anxiety diminishes greatly once treatment begins and they are taking active steps to combat the disease.

Let it Out

Express your feelings, no matter how awful or embarrassing they may seem to you. Keeping them bottled up may stop you from moving beyond the distress. At work or at home, you may need to promote the image that you are in greater control than you may feel. In that case, you need to find a person you can trust or a safe place - at a support group, in a therapy session with someone who has had cancer - where you can vent your anger, fear, sadness and even those alternating hopeful and hopeless feelings. It may also help to find a quiet place to become aware of the full range of your emotions - by meditating or writing in a journal, for example - and to appreciate that you can get through this.

It's a Control Problem

Uncertainty and lack of control over your body and your future often underlie the anxiety that people experience at the time of diagnosis. People who have always felt in control of their futures, their careers and their families may have particular difficulty, as will those who find it difficult to deal with change. Becoming a medical patient and enduring the passive waiting that tests and treatments entail can provoke a feeling of loss of autonomy. Distinguishing between what you can and cannot control will help restore confidence and competence. For example, although you can't control the outcome of tests or treatments, you can collect information to understand the illness, choose doctors whom you trust, and participate in all decisions. On a smaller, day-to-day scale, although you can't always control waiting time, you can make it more comfortable by bringing a CD player and listening to your favorite music. Delegating essential daily chores to people you trust will also help you understand that you remain in charge of your life. At work, delegating tasks to trusted colleagues will help you - and them - to appreciate that you are managing your responsibilities during this personal crisis.

It's Not Your Fault

Resist blaming your personality, attitude, coping style, emotions, lifestyle or personal habits for your cancer. Cancer experts repeatedly emphasize that there is absolutely no scientific basis for these conclusions. The more you blame yourself, the less empowered you will feel to combat the disease.



Find Your Inner Warrior

Thinking of cancer as a battle to be won can help restore your self-confidence and self-esteem. People with a fighting spirit demand the best possible care for themselves. When confronted with a rigid bureaucracy, they insist on their rights. They don't take no for an answer. They are not necessarily "good" or "nice" patients. But if that's not your style, deputize someone to fight on your behalf.

Be Positive, But Be Real

Hopefulness and a positive outlook can be very motivating, but don't fake it or feel guilty when your spirits sink. Setting short-term goals can help to shore up your confidence. You have every right to feel lousy or dispirited even if other people pressure you to be more positive; there is no scientific research that links a positive attitude to recovery from cancer. But quality of life is directly affected by how you feel, and although it is normal to feel grief,

loss, sadness and fear from time to time, persistent anxiety and depression are not part-and-parcel of having cancer. Tell your doctor. Ask for help. You need your emotional energy to tackle the disease, not to mention all the other responsibilities that are important to your life.

Reach Out

Research shows that people who have strong ties to others deal with crisis best. Reach out to loved ones and close friends. Although some people may disappoint you - because of their own fear of cancer - be open to others who may unexpectedly offer concern and assistance. At home and at work, ask those you trust to help out with essential responsibilities and chores. During the period of uncertainty before treatment begins, cancer education programs and support groups can be sources of information as well as safe havens for emotional expression and understanding. Your healthcare team can provide information about cancer support groups. Cancer support chat rooms on the Internet can also help. Groups vary; if you don't feel comfortable in one, look for another.

Meeting one-on-one with someone with your type of cancer can help to validate your concerns.

Psychologists, social workers, nurses and psychiatrists trained in psychosocial oncology can be a help to people who are trying to manage the distresses associated with a cancer diagnosis. A previous history of depression or emotional problems may trigger a recurrence during this crisis. Your healthcare team can provide information.

Distract Yourself

Hard as it may be in the beginning of this journey, schedule some time off from thinking about your illness. Keep doing things you enjoy, including exercise, if you are up to it, and remember that there's life - plenty of it - beyond cancer. For some people, the workplace is where they best concentrate on their continuing competence and enjoy time away from the sick role.

Other Helpful Practices

» Gratitude:

Think about, what are you grateful for?

» Affirmations:

Use affirmations to restructure your thinking. For example, "I am strong. I am determined. I will survive."

» Mindfulness:

"Mindfulness means paying attention in a particular way; on purpose, in the present moment, and non-judgmentally."

John Kabat-Zinn

To learn more about mindfulness and to start your practice, talk with your provider or visit the VA Office of Patient Centered Care and Cultural Transformation. You will find instructional videos and audio files to help you begin: www.va.gov/PATIENTCENTEREDCARE/resources/multimedia/index.asp



Spiritual Care of Cancer Patients

Spirituality & Your Health

Spirituality is probably best understood as those beliefs and practices which bring meaning and value to one's life. For some it may be manifest in religion and attendance to a community. To others, it may be a sense of peace found while participating in activities in the forests of the surrounding area. What is important is that we take into account how those practices and beliefs may be impacted by our illness and how we might utilize those beliefs and practices to assist in coping with our treatment and prognosis.

How Can I Develop & Strengthen My Spirit?

A sense of meaning and purpose, a connection with one's community can help you to have a better quality of life during your illness and care. When persons have a sense of being spiritually connected to their world they have less anxiety, depression and pain. Spirituality may also allow one's problems in living to be held in a new perspective. Practices such as prayer, meditation and worship can often help and have a calming influence and restore one's sense of self. Many persons find support in spiritual communities where both practical and emotional help are provided. As a spiritual person, it is important to recognize that this journey is both an inward one and outward one. Learning what is meaningful and sacred can assist with the turmoil and chaos that a new diagnosis can bring and help you find strength and meaning in life.

What Are Some Practices I Might Try?

Take some regular time to pray or meditate. Developing this practice can frequently bring a sense of calm and stability.

Read spiritual writings such as the Bible, Koran, Bhagavad Gita or other sacred texts. Looking into these texts gives one a sense of being connected to an ancient source of strength and hope that have been a part of persons lives across cultures and traditions.

Seek the help of others. Have conversations about concerns you have, about practical aspects of your illness and don't be afraid of asking questions. We have found that all persons tend to experience many of the same feelings and thoughts. Realizing this often puts us in touch with that sense of community.

Some people find that journaling to express thoughts, feelings and memories is helpful. It also leaves a legacy to those who are important to you now.



Chapter 9. Cancer Support Services



Oncology Social Workers

Oncology Social Workers are an important part of our clinic care team and are available to assist you and your family at every stage of care including: diagnosis, treatment, and survivorship. Our social workers can provide emotional support and help you find resources to help you cope with a cancer diagnosis. They can also help you communicate with family members, friends, employers and members of your health care team. Social workers can help connect you with support groups.

Our social workers can also assist you in locating resources for:

- Transportation
- Hair loss and appearance
- Financial needs
- Insurance issues
- Employment/income issues
- Disability
- Referrals to community resources
- Support groups, classes & counseling
- Talking with children about a family member's cancer diagnosis
- In-home assistance
- Education resources about cancer
- Depression & Anxiety
- Integrative Medicine
- Stress Management
- Relaxation
- Guided Imagery
- Caregiver Respite

Our social workers are located on site and are available by phone to provide assistance. There is no fee to access social work services. Ask your doctor or nurse for assistance in contacting one of our social workers or call them directly. Please refer to My Healthcare Team page for your social worker's contact information.

Questions about Service Connected Disabilities?

For information on how to apply for service connected disabilities please talk to your Social Worker, Cancer Care Navigator, or local Veteran's Service officer for more information.

Visit these websites for more information:
www.benefits.va.gov/compensation/
www.publichealth.va.gov/exposures/agentorange/conditions/



Spiritual Care Resources at the VA Portland Health Care System

Chaplains are clinically trained caregivers who may assist you in the journey into your spiritual life. A sense of meaning and purpose, a connection with one's community can help you to have a better quality of life during your illness and care. Reflective conversations are frequently a great place to start the process of spiritual practice. Chaplains are available 24/7 to

provide assistance. Ask your provider if you need help in contacting chaplain service or call the hospital operator and ask to be connected to the chaplain. You may also call directly to 503-220-8262, ext. 57021.

Chaplain Services offer a variety of groups and services, including Midday Reflections, Guided Meditations, Jumma Prayer, Christian Worship and more are offered at the Portland Chapel. Call 503-220-8262, ext. 57021 to learn when these services and groups are offered.

Tobacco Cessation Resources

Trying to stop the tobacco habit can be difficult, but is always beneficial at any point in time. It helps the body's ability to heal. You may avoid problems that might occur related to surgery, chemotherapy, or radiation.

There are many different ways to try to stop smoking. Although some people are able to quit "cold turkey" once they've made up their minds, most people need assistance to be successful. The Center for Disease Control (CDC) recommends using a combination of three approaches when trying to stop smoking. The CDC recommends:

- » Nicotine replacement product, such as a patch or gum.
- » Specific smoking cessation drugs may be prescribed which helps keep nerves calm while decreasing the desire to smoke.
- » Participation in some type of support or counseling group help, with the day to day struggle of giving up a long-time addictive habit.

Resources

If you want to quit smoking and need help, talk with your health care provider and contact one of the following resources. They can help you with current information, advice, and suggestions for your smoking cessation.

For general information and resources from the VA, visit the Tobacco and Health information from VA Public Health www.publichealth.va.gov/smoking/



For support and ways to quit visit, specifically for Veterans visit: www.smokefree.gov/veterans



"U Can Quit 2" is a site to support service members who want to quit tobacco: www.ucanquit2.org



Mobile App Stay Quit Coach www.mobile.va.gov/app/stay-quit-coach



VA Tobacco Cessation Quitline

1-855-QUIT-VET (1-855-784-8838)

This telephone Quitline is from the National Cancer Institute and is for Veterans to help them quit tobacco products. The Quitline is free of charge and provides personalized counseling with Veterans. Hours of operation: Monday-Friday 5:00 am - 7:00 pm (PT). Once you call the Quitline, they will schedule follow up phone calls if you want support during your quit attempt.

VA Text Messaging Program, Smoke-freeVET. To sign up: Text the word VET to 47848 or visit: www.smokefree.gov/VET



VA Portland Health Care System Tobacco Cessation Groups

The VA offers in-person tobacco cessation groups to help you take the steps towards quitting. Many groups offer a medication prescription at the same visit and are held at different VA locations in the Portland area.

To see when Tobacco Cessation and other classes and groups are offered at the VA-PORHCS talk with your provider or visit the Veteran Education and Group directory online at: www.portland.va.gov/patients/patiented.asp



Food Choices at the VA & Neighborhood Area

It is important to take care of your body by eating well while you are being treated for cancer. Traveling away from home and going to one or more appointments during the day can make this hard.

Here are Some Resources for Meals During Your Stay in Portland

- » Food can be purchased at the Patriot cafeteria (canteen) located on the first floor of building 100, between 7:00 am and 3:30 pm. Options include items like yogurt, sandwiches, pizza and entrees like roast beef and mashed potatoes and range in price from \$1.00 - \$6.00 dollars.

- » There are multiple food and beverage choices at OHSU right across the bridge that connects VAPORHCS with OHSU. Choices include a full service cafeteria on the third floor, a café style sandwich and coffee shop on the ninth floor, and a seasonal farmer's market (June-October) every Tuesday.
- » There are also vending machines with soup, sandwiches and other convenience foods that can be purchased 24 hours a day for \$1.00 - \$4.00.

To learn more about the VA Canteen, including location and hours visit: www.portland.va.gov/visitors/canteen.asp



Meals at Oregon Health & Science University (OHSU)

There are multiple food and beverage choices at OHSU Marquam Hill Campus, right across the bridge that connects

Portland VA with OHSU. Choices include a full service cafeteria on the third floor, a café style sandwich and coffee shop on the ninth floor, and a seasonal farmer's market (June-October) every Tuesday.

You can almost always find food a few steps away at one of the following locations (see next page).

For the most up to date information about food choices at OHSU, visit www.ohsu.edu/xd/about/services/food-and-nutrition/where-to-eat/index.cfm
Marquam Cafe Menu Line: 503-494-FOOD, (503-494-3663)



Talk with Your Health Care Team

Side effects from your therapy may make eating difficult. If nausea, pain, or other issues are making it hard to eat, please tell your health care team.

If you are having trouble affording food or are eating less than two meals a day, please ask to speak to a social worker.

A cancer dietitian is available to give you individual counseling about ways to maximize your nutrition throughout your cancer treatment. Please ask your health care team if you think this would be helpful.

OHSU Marquam Hill Campus

Location	Floor	Café	Hours
OHSU Hospital	3rd	Café on Third	Always Open
OHSU Hospital	9th	It's All Good Natural Food Store	M-F, 8:00 am-7:00 pm Saturday, 9:00 am-4:30 pm
Hatfield Research Building	9th	Plaza Café	M-F, 6:30 am-2:00 pm
Child Development & Rehabilitation Center	2nd	Buffalo Café	M-F, 11:00 am-1:00 pm
Sam Jackson Hall	1st	Sam's Café	M-F, 6:30 am-4:00 pm
Multnomah Pavilion	1st	Pavilion Café & Coffee	M-F, 6:30 am-3:00 pm
Casey Eye Institute	1st	20/20 Café	M-F, 7:00 am-4:00 pm
Casey Eye Institute	1st	It's All Good @ Casey Eye Coffee Shop	M-F, 6:30 am-2:00 pm
Mackenzie Hall	1st	Mac Hall Bistro	M-F, 7:00 am-2:00 pm
Doernbecher Hospital	1st	Doernbecher Starbucks	M-F, 5:00 am-8:00 pm Weekends, 6:00 am-5:00 pm

South Waterfront Campus

Location	Floor	Café	Hours
Center for Health & Healing	1st	Daily Café	M-F, 7:00 am-5:00 pm Saturday, 9:00 am-2:00 pm
Center for Health & Healing	1st	Daily Café Coffee Bar	M-F, 6:30 am-4:30 pm

Grocery Stores in the Area



Photo courtesy of New Seasons Market

Large Grocery Stores

Safeway

1010 SW Jefferson St, Portland OR

503-205-1849

Fred Meyer

7555 SW Barbur Blvd, Portland OR

503-452-3000

Food Front Cooperative Grocery

6344 SW Capitol Hwy, Portland OR

503-546-6559

Market of Choice

8502 SW Terwilliger Blvd, Portland OR

503-892-7331

Neighborhood Markets

Swan Mart

4440 SW Barbur Blvd, Portland OR

503-227-5266

People's Food Co-op

3029 SE 21st Ave, Portland OR

503-674-2642

Ross Island Grocery & Cafe

3502 SW Corbett Ave, Portland OR

503-227-4531

Specialty Grocery Stores

Whole Foods Market

1210 NW Couch St, Portland OR

503-525-4343

Zupan's Markets

7221 SW Macadam Ave, Portland OR

503-244-5666

Zupan's Markets

2340 W Burnside St, Portland OR

503-497-1088

Hotel Tips

If your hotel does not have a kitchenette, buy high calorie foods that can be safely kept at room temperature. Some examples include:

- » Peanut butter, protein bars, instant soup.
- » Ensure or other nutritional supplements (less costly if purchased at the Patriot store).
- » Continental or 'Grab and Go' breakfasts are available for free at most hotels during certain morning hours. Ask at the front desk about what time the breakfast is available and where to find it.
- » Pack snacks to bring along when you will be away from your hotel room for very long. Some snacks that travel well include: bagels, pretzels, string cheese, jerky, dried fruit and nuts.

Tips for Traveling to Portland

How Will My Appointment get Arranged & Scheduled?

Your case may be reviewed by a VA Multidisciplinary team (also known as “Tumor Board”) which includes Oncologists from the Portland VA. If a consultation and/or potential treatment at the Portland VA would benefit you, your local Oncology providers will request a consult appointment for you at the Portland VA Health Care System.

More often than not, you will go for an initial consultation and then will return to your home while treatment plans are developed and preparations for treatment take place. When it is time for treatment to begin, you will return to Portland.

How Will I Get There?

If you meet the criteria below, you may be eligible for mileage reimbursement, or special mode transport in association with obtaining VA health care services.

You Qualify for Beneficiary Travel if:

- » You have a service-connected (SC) rating of 30 percent or more, or
- » You are traveling for treatment of a SC condition, or
- » You receive a VA pension, or
- » Your income does not exceed the maximum annual VA pension rate (\$12,652 for single person, \$16,569 with 1 dependent)*, or
- » You are traveling for a scheduled compensation or pension examination.

For more information on Qualification visit:
www.va.gov/HEALTHBENEFITS/vtp/Beneficiary_Travel.asp



*If your income was previously above pension rate but has changed (e.g. you are anticipating a significant reduction of income due to your illness and/or treatment needs), you may want to consider applying for a hardship consideration for travel assistance. You can apply for a hardship consideration at the Office of Enrollment & Eligibility (OEE) by writing a letter explaining your circumstances, and completing a Beneficiary Travel Waiver of Deductibles Worksheet form. Additional forms and information about what to include in your letter is available from the OEE or from a social worker.

What if I Don't Qualify?

If you do not qualify for beneficiary travel, and are unable to afford the costs of travel to Portland - please contact your local Social Worker, to discuss non-VA assistance programs (Angel Flight, American Cancer Society Air Miles Program, Angel Bus, etc.).

Where Will I Stay?

Accommodations will be arranged by the Travel Department - and you will not know for certain which hotel you will stay in until lodging is confirmed. Hotel rooms typically include an equipped kitchen, provide a continental breakfast, and provide limited shuttle services.

The three most frequently used hotels include:

Aladdin Inn
8905 SW 30th Ave, Portland OR
503-246-8241

Shilo Inn Beaverton
9900 Canyon Road, Beaverton OR
503-297-2551

Quality Inn Tigard
11460 SW Pacific Hwy, Tigard OR
503-245-6421

Lodging Unit (T51)

If you are staying at T51, your room will include a: kitchen, a stove, microwave, refrigerator, utensils, pots, pans, and a blender will be in your room. A volunteer may be available to take you to a nearby grocery store, or you may take the bus.

What to Bring

A caregiver (if needed). A caregiver can stay with you in the hotel during your short consultation visit. Once you begin treatment and are lodged in T-51 there is not a provision made for lodging your caregiver. If a caregiver is required, medical documentation as to why must be provided. Please be aware, that if you are admitted to the hospital for inpatient care, the VA will not continue to pay for a hotel room for your caregiver.

Prescription medications. Be sure to take enough medication to last the full length of your anticipated stay in Portland. The Portland VA cannot assist with filling prescriptions that are not yet due for refill.

Money for food, personal items, etc.

You are encouraged to limit your luggage and personal items. If you are admitted to the hospital, you will have to check out of your hotel room until you are discharged - so limiting the amount of luggage and belongings you have to move may make things easier.



If I Fly, How Will I Get from the Airport to the VA or to My Hotel?

Public Transit - Trimet

How do I use the light rail system (MAX) and the bus to get from the airport (PDX) to the VA?

The MAX light rail Red Line is the easiest way to travel to and from the airport.

Here are some quick facts:

- » The trip between the airport and downtown Portland takes about 38 minutes, and then the trip from

downtown to Marquam Hill by bus takes 15 minutes.

- » An adult ticket costs \$2.50 (Youth \$1.65, Honored Citizen \$1.00). MAX ticket machines return change in coins, so small bills are recommended.
- » You can roll your luggage on board.
- » The first train of the day arrives at PDX at 4:45 am. The last train departs PDX at 11:50 pm.
- » The MAX station and ticket machines at the Portland Airport are located on the lower level, next to the south baggage claim area (turn right at the base of the escalator).
- » Board the redline MAX train to Portland at the Airport. Get off at the Mall/SW 5th Ave MAX Station.
- » Board the #8 Jackson Park to Marquam Hill bus and get off at the US Veterans Hospital. The bus stop drops you off directly in front of the hospital.

For real time travel information and map locations please contact the Portland TriMet at www.trimet.org/ or 503-238-RIDE (7433)



VA Shuttle Service

For availability and more information, please call: 503-220-8262, option 1, ext. 57804.

Taxi Services

If you are traveling by plane you can take a taxi from the airport to your hotel or the Portland VA. If you are travel eligible, you may apply for cab fare reimbursement.

If You Drive

If you are traveling by automobile and are travel eligible, you may request travel reimbursement. To request the reimbursement, complete the form provided on the stand outside of the Enrollment office on the first floor, and drop it into the travel office drop box. Mileage reimbursement is at 41.5 cents per mile, and calculated from your home address to the facility where the appointment occurred.

Parking in the patient parking garage can be challenging at times, so please allow time to find parking.

Once at the VA, How Do I Get to the Sky bridge to OHSU?

(See map on facing page). Walk into building 100 (the main hospital), and board the patient elevators in front of you. Go to the second floor and when looking directly out the windows to the front of the building, turn right, and then make another immediate right. Follow the hallway to the sky bridge.



How Do I Get from the Sky bridge to Radiation at OHSU?

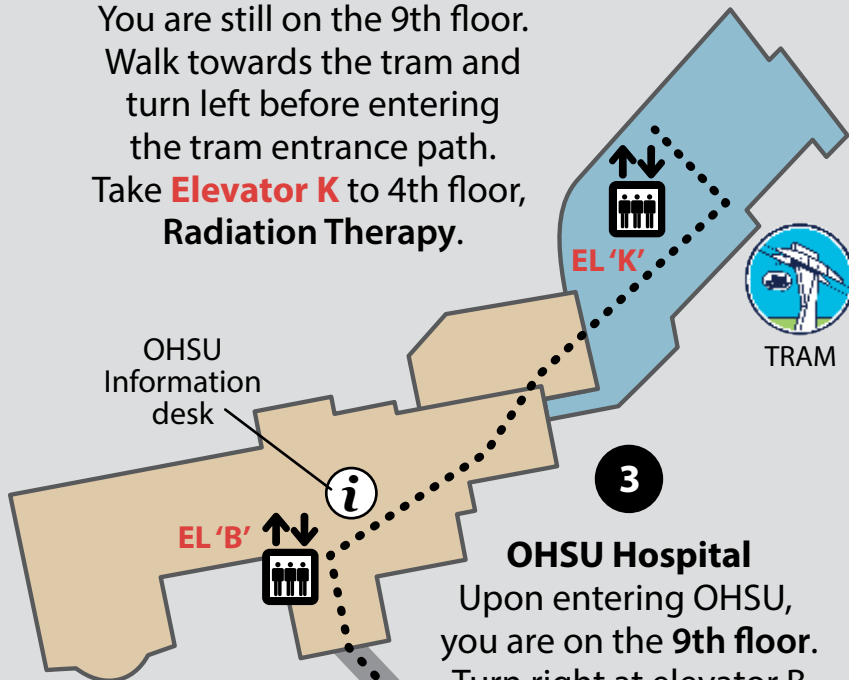
Walk over the sky bridge, once on the other side, go straight ahead until you reach a bank of 3 elevators (you will be on the 9th floor at OHSU). Turn right at the elevators and follow the hallway. At the end of the hallway are elevators for the Kohler Pavilion. Take the elevator to the 4th floor. Once out of the elevators, walk straight ahead. You will see the door for Radiation Therapy.



4

Kohler Pavilion

You are still on the 9th floor.
Walk towards the tram and
turn left before entering
the tram entrance path.
Take **Elevator K** to 4th floor,
Radiation Therapy.



3

OHSU Hospital

Upon entering OHSU,
you are on the **9th floor**.
Turn right at elevator B
and follow signs
to the tram.

2

Walk across
the Sky bridge
(660').

1

VA Portland Bldg. 100 (main hospital)

Take elevator to
the **2nd floor**,
follow signs to
the Sky bridge.



EL - Elevator

Chapter 10. Additional Resources



Advance Directives

What You Should Know About Advance Directives

As a VA patient you have a say in the health care you receive. When you are ill, your doctor should explain what treatments there are for your illness so that you can decide which one is best for you. But if you were too ill to understand your treatment choices or to tell your doctor what treatment you want:

- » Who would you want to make decisions for you?
- » What type of health care would you want?
- » What health care wouldn't you want?

Questions like these may be hard to think about, but they're important. That's why VA wants you to know about a legal form you can complete. It's called an advance directive.

What is an Advance Directive?

An advance directive is a legal form that helps your doctors and family members understand your wishes about medical and mental health care. It can help them decide about treatments if you are too ill to decide for yourself. For example, if you are unconscious or too weak to talk. There are two types of advance directives: durable power of attorney for health care and living will.

What is a Durable Power of Attorney for Health Care?

This form lets you name the person you trust to make health care decisions for you if you can't make them yourself - your "health care agent." He or she will have the legal right to make health care decisions for you. You can choose any adult to be your agent. It's best to choose someone you trust, who knows you well and who knows your values. You should make sure the person is willing to serve as your agent. If you don't choose an agent, your doctor will choose someone to make decisions for you in the following order: legal guardian (if you have one), spouse, adult child, parent, sibling, grandparent, grandchild, or a close friend. Your health care team, or a court, will make decisions for you in accordance with VA policy if none of the above is available.

What is a Living Will?

A living will is a legal form that states what kinds of treatments you would or wouldn't want if you become ill and can't decide for yourself. It can help your health care agent and your doctor make decisions the way you want them to. Writing down what kind of treatment you would or wouldn't want can help make it easier for those who



are asked to make decisions for you. Talk with your family, your health care agent, and your doctor about your wishes so they won't have to wonder what you want and if they're doing the right thing. If you don't have a living will, decisions will be made for you based on what is known about you in general and about your values. That's why it's important to discuss your wishes with your loved ones, your doctors, and your health care team.

Must My Health Care Agent Always Follow My Living Will?

Most of the time, yes. Your health care agent should try to respect your wishes. But it can be hard to imagine future health and say just what treatment you would want at that time, so sometimes your agent may have to interpret your wishes. In a VA advance directive, you can say if you want your agent to do just what your living will says, or if they may make the decision they think is best for you at that time, even if it isn't what you said you would want.

Should I Have an Advance Directive?

Yes, it's a good idea to have one. An advance directive helps protect your right to make your own choices. It helps make sure people respect your values and wishes if you can't speak for yourself. Your advance directive is used only when you aren't able to make decisions yourself.

For more information visit: www.portland.va.gov/patients/advance.asp



How Do I Complete an Advance Directive?

Fill out VA Form 10-0137, "VA Advance Directive: Durable Power of Attorney and Living Will." Or use any valid state advance directive form. Talk to a health care professional at your local VA health care facility. This might be a social worker or your primary care doctor. Or talk to your spiritual advisor or attorney. Your VA health care team can make your advance directive part of your medical record.

Do I Need to Fill out a Durable Power of Attorney and a Living Will?

No. Even though the VA form contains both, it's up to you whether you complete the durable power of attorney for health care, the living will, or both.

Can I Change My Advance Directive?

Yes, you may change or cancel your advance directive at any time. In fact, you should review your advance directive periodically, especially if there is a change in your health, to make sure it's up to date. If you change it, be sure to tell your health care team and have them put it in your health record. Share your new directive with your family members and other loved ones.

Patient Rights & Responsibilities

a. All patients have the following rights (these rights may be subject to restrictions as described in Paragraph b, Restrictions):

- (1) Patients will be treated with dignity, compassion, and respect as an individual. Consistent with Federal law, VA policy, and accreditation standards of The Joint Commission. Patients will not be subject to discrimination for any reason, including for reasons of age, race, ethnicity, religion, culture, language, physical or mental disability, socioeconomic status, sex, sexual orientation, or gender identity or expression.
- (2) Patients will be given information about the health benefits they can receive. The information will be provided in a way they can understand.
- (3) Patient medical records and all other information will be kept confidential unless disclosure is required or permitted by law or the patient consents to its release.
- (4) Patients of long term care or domiciliary programs have the right to perform or refuse to perform tasks in or for the organization as described in MCM 00-52, Organizational Code of Ethics and Ethical Behavior.
- (5) All patients have the right to:
  - (a) Information regarding patient rights and responsibilities; Patients will be given a copy of the Inpatient Handbook that contains written information about patient rights and responsibilities, ethics and other important information upon admission. Individual copies of patient rights and responsibilities are also available on request and rights are posted in key public locations such as in patient waiting areas.
  - (b) Be involved in the decisions about their care;
  - (c) Consent to or refuse recommended treatment and to be informed of the medical consequences of such refusal.
    - i. Patients have the right to receive adequate information to participate in care decisions and provide informed consent. Informed consent information is found in Medical Center Memorandum 11-40, Informed Consent and Refusal.
    - ii. Patients have the right to leave the hospital against the medical advice of the treating area if patient does not have significant psychiatric disease which would cause them to present a danger to him/herself or to others See Medical Center Memorandum 11-40, Informed Consent and Refusal for criteria of evaluating patient decision making capacity and role of surrogate decision maker. All adult persons whom appear competent to make decisions affecting their medical care will be allowed to make such decisions. Every reasonable effort should be made to convince the patient of the need for further medical care and evaluation, including the potential consequences of the decision to refuse further care. If the patient decides to leave, the patient treatment team should follow standard discharge process and provide patient with necessary information and services for continuity of care (see Medical Center Memorandum 11-11 Discharge Planning). The team should document discussions and discharge in patients permanent record and staff shall request the patient to sign a request for discharge against medical advice form (see Attachment A).
  - (d) Present grievances if they feel their rights have not been honored. Patient grievances

are addressed in MCM 00-48, Patient Grievance.

(e) Receive information about the cost of their care, if any, before they are treated;

Patients are responsible for paying their portion of the costs associated with their care.

(f) Complete advance directives; Advance directives help to protect their right to make medical choices that can affect their life. MCM 11-10, Advanced Directive, outlines policies and procedures related to advance directives. Patients also have the right to request assistance for ethical issues as explained in the Inpatient Handbook and outlined in MCM 00-52, Organizational Code of Ethics and Ethical Behavior.

(g) Be treated with dignity as an individual, with compassion and respect, with reasonable protection from harm, and with appropriate privacy;

(h) Receive, to the extent eligible, prompt and appropriate treatment for physical or emotional disorders or disabilities, in the least restrictive environment necessary for that treatment, free from unnecessary or excessive medication; Each patient has the right to be free from physical restraint or seclusion except in situations in which there is a substantial risk of imminent harm by the patient to self or others and less restrictive means of preventing such harm have been determined to be inappropriate or insufficient (see MCM 11-17, Restraint and Seclusion, for policies and procedures on restraint and seclusion).

(i) Be informed of any injuries caused during the provision of their medical care; Patients will be informed about how to request compensation for injuries. Refer to MCM 00-59, Patient Safety Improvement Program.

(j) Not be denied their legal rights while hospitalized (except where state law provides otherwise);

(k) Communicate freely and privately with persons outside the facility and to have or refuse visitors. There shall be reasonable access to public telephones for making and receiving calls.

(l) Receive unopened mail; If there is reason to believe the mail may contain contraband, then they will have to open the mail in the presence of an appropriate person.

(m) Patients will be afforded the opportunity to write letters and will be provided with assistance in doing so when necessary;

(n) Be allowed to wear their own clothes and to keep personal possessions, depending on their medical condition;

(o) Keep and spend their own money;

(p) Social interactions, as well as to regular exercise;

(q) Have the opportunity to participate in or abstain from religious worship, without coercion, or for the exercise of cultural and spiritual beliefs that do not interfere with the well-being of others or the planned course of the patient's medical treatment or therapy; and;

(r) Be informed of any human experimentation or other research/educational projects affecting their care or treatment.

b. Restrictions:

(1) A patient's rights may be restricted within the patient's treatment plan by a written order signed by the patient's medical or mental health care provider, if it is determined

that a valid and sufficient reason exists for a restriction, as defined below. The order imposing the restriction and a progress note detailing the indications for the restriction must be entered into the patient's permanent medical record. A valid and sufficient reason exists when, after consideration of pertinent facts, including the patient's history, current health condition and prognosis, the patient's medical or mental health care provider believes that the full exercise of the specific right would:

- (a) Adversely affect the patient's physical or mental health;
  - (b) Under prevailing community standards, likely stigmatize the patient's reputation to a degree that would adversely affect the patient's return to independent living;
  - (c) Significantly infringe upon the rights or jeopardize the health or safety of others; or,
  - (d) Have a significant adverse impact on the operation of the medical facility, to such an extent that the patient's exercise of the specific right should be restricted. In determining whether a patient's specific right should be restricted, the health or mental health professional concerned must determine that the likelihood and seriousness of the consequences expected to result from the full exercise of the right, are so compelling as to warrant the restriction.
- (2) The least restrictive method for protecting the patient's interests will be used, once it has been determined that a valid and sufficient reason exists for restricting any of the patient's rights. The Clinical Service Chief or the Chief of Staff must concur with the decision to impose such restriction. The order will be reviewed at least once every 30 days by the practitioner, and concurring executive for continued appropriateness. The patient must be promptly notified of any restriction and of the reason it was imposed.

c. Patient Responsibilities:

- (1) The patient and family are responsible for providing, to the best of their knowledge, accurate and complete information about present complaints, past illnesses, hospitalizations, medications, and other matters relating to the patient's health. They are responsible for reporting unexpected changes in the patient's condition to the responsible practitioner. The patient and family are responsible for asking questions when they do not understand what they have been told about the patient's care or what they are expected to do.
- (2) The patient and family are responsible for following the treatment plan developed with the practitioner(s) responsible for care, including following the instructions of nurses and allied health personnel charged with coordinating a plan of care and implementing the responsible practitioner's orders. They should express any concerns they have about their ability to follow the proposed course of treatment. In turn, staff will make every effort to adapt the treatment plan to the patient's specific needs and limitations. Where such adaptations are not recommended, the patient and family should understand the consequences of failing to follow the recommended course of treatment, or of using other treatments.
- (3) The patient and/or family is responsible for the health outcomes, if the patient or family refuses treatment or fails to follow the practitioner's instructions. Patient will assume all responsibilities and consequences that result from leaving against medical advice. Patients

are responsible to sign a request for discharge against medical advice from releasing VA Portland Health Care System, administration, personnel, and staff physicians from any responsibility.

(4) The patient and family are responsible for following the Medical Center's rules and regulations concerning patient care and conduct. They have a responsibility to:

- (a) Follow all of the Medical Center's safety rules and posted signs;
- (b) Try to be considerate and respectful of other patients and Medical Center personnel by not making unnecessary noise, smoking, exceeding the recommended number of visitors or visiting hours, or causing distractions, and by encouraging visitors to do the same; Patients and families are responsible for respecting the property of other patients and that of the Medical Center and for refraining from bringing alcoholic beverages, illicit drugs, or items which could potentially be used as weapons onto Medical Center grounds. If weapons are brought onto the grounds, they must be deposited with Police & Security staff upon arrival at the Medical Center.
- (c) Cooperate with treatment staff and to discuss any questions or disagreements about the treatment plan with the treatment staff;
- (d) Try to prevent injury to self, other patients, visitors, and staff members;
- (e) Be responsible for the safekeeping of clothing, money, and personal possessions the patient chooses to keep with him/her while hospitalized at this facility;
- (f) Keep scheduled diagnostic or treatment appointments on time and, when unable to do so, to notify Medical Center staff;
- (g) Avoid interfering with the treatment of other patients, particularly in emergency situations;
- (h) Assist by alerting staff when another patient is having any difficulty;
- (i) Be understanding and patient if delays are encountered; and
- (j) Assure that they understand discharge instructions, including discharge medications and how to take them, and know the dates of scheduled follow-up appointments.

(5) Nursing Skilled Care Unit residents or their guardians will provide written acknowledgement of an understanding of these rights and responsibilities.

d. Patient Discipline: Infractions of standards of patient conduct or violation of law, regulation, and/or Medical Center policies will be subject to review and possible penalty or disciplinary action, to include irregular discharge from the facility and/or legal action. All action taken will be in compliance with M-1, Part I, Chapter I, Section IV (Patient Conduct) and related policy, regulation and law.

Adapted from Rights and Responsibilities of VA Patients and Residents of Community Living Centers (CLC), IB 10-88, P91985.

For more information visit: www.va.gov/health/rights/patientrights.asp



Chapter 11. Glossary

Acute: Having a short and relatively severe course.

Adjuvant chemotherapy: Additional cancer treatment given after the primary treatment, usually surgery, to lower the risk that the cancer will come back. Adjuvant therapy may include chemotherapy, radiation therapy, hormone therapy, targeted therapy, or biological therapy.

Alopecia: The loss of hair from the scalp and/or body.

Anemia: A condition characterized by an abnormally low number of red blood cells; symptoms include shortness of breath, lack of energy, dizziness and fatigue.

Antibiotic: A drug used to fight bacterial infections.

Antibody: A protein produced by the body, in response to a foreign substance that fights the invading organism.

Antiemetic: A medicine to prevent or relieve nausea or vomiting.

Autologous transplant: A transplant in which the patient's own stem cells, rather than stem cells from a donor, are infused during transplant to provide the patient with a source of stem cells.

BMT: Initially, an abbreviation for "bone marrow transplant," now refers to blood and marrow transplantation.

Bacteria: Microscopic organisms that invade human cells, multiply rapidly, and produce toxins that interfere with normal cell function.

Benign: Used to describe a tumor that is neither cancerous nor capable of invading local tissue; for example, some types of moles or warts.

Benign tumor: A non-cancerous growth that does not spread to other parts of the body.

Biological therapy: The treatment by stimulation of the body's immune defense system.

Biopsy: The removal and microscopic examination of a sample of tissue to see if cancer cells are present.

Blood typing & cross-matching: Blood cells contain factors that are not the same in all people. Before being given a transfusion, blood samples from the donor and the patient are typed or classified (type A, B, AB, O) to match them. Once typed, the samples are cross-matched to double check that they are compatible.

Bone marrow: The inner, spongy tissue of a bone where red blood cells, white blood cells and platelets are formed.

Brachytherapy: Radiation from a source placed inside the body, or inside a body cavity.

CBC (Complete blood count):

Determines whether the proper number of red blood cells, white blood cells, and platelets are present in the patient's blood.

Cancer: A general term for more than 100 diseases that have uncontrolled, abnormal growth cells that can invade and destroy healthy tissue.

Candida: A type of yeast, common to the intestine that can cause infection in immune-compromised patients.

Carcinogen: Any cancer-causing substance or agent.

Carcinoma: Cancer that arises in the epithelial cells that cover external and internal body surfaces.

Carcinoma *in situ*: Cancer that involves only the top layers without invading deeper tissue.

CAT scan: Computerized Axial Tomography; special x-rays that produce computer images of organs and tissues, to detect tumors that regular x-rays cannot. Sometimes a "contrast medium" is used during CAT scans to better illuminate the body tissue being assessed. CAT scanning is performed in a small chamber or room and takes anywhere from 10 to 60 minutes.

Cell cycle: Sequence of steps that cells go through to grow and replicate.

CVC (Central venous catheter): A specially inserted, very thin, flexible catheter inserted into a large, "central" vein that provides repeated and painless access to the blood stream for infusion or medications, fluids and blood, and allows withdrawal of blood for laboratory tests. Different brands and types of CVCs include; Groshong, PICC, Broviac, and Hickman catheters. Insertion is usually in the upper, outer chest, or inner arm areas.

Chemotherapy: The treatment of malignancies and other diseases with chemical agents: use of cytotoxic chemicals to destroy rapidly dividing cancer cells throughout the body.

Chest x-ray: A view of the chest area, which includes the heart, lungs, and ribs.

Clinical trial: An investigation of the effects of materials or methods according to a formal study plan for a particular disease.

Colony stimulating factors: Proteins that stimulate the production of growth of certain types of blood cells. Also called CSFs or growth factors. Examples are Neupogen or Leukine.

Combination chemotherapy: The use of several drugs at the same time or in a particular order to treat cancer.

Culture: Samples taken of bodily fluids or tissues that are then allowed to grow in the lab to document the presence of an infection and identify the organism responsible.

Debulking: Surgery to decrease tumor size, which may improve the response to postoperative cancer treatment.

Diagnosis: A description of the cause, nature and expected effects of a medical condition.

Dysphasia: Difficulty swallowing.

Dyspnea: Difficulty breathing; shortness of breath.

Electrolytes (Lytes): Electrically charged particles found in the bloodstream. The correct level of each electrolyte is important for the overall functioning of the body. Examples are sodium, potassium, and magnesium.

Extravasation: A term used to describe chemotherapy escaping from the blood vessel into the surrounding tissue, which may result in tissue damage.

Febrile: When the body temperature is higher than what is considered standard or “normal” or feverish.

Gray: A measurement of absorbed radiation dose; 1 gray = 100 rads.

Histology: Examination under microscope of the structure, composition, and function of tissue.

Hospice: An organized service designed to provide supportive care to terminally ill patients and their families.

Immune system: The body’s defense network against infection and foreign particles.

Immunosuppression: A condition in which the patient’s immune system is functioning at a lower than normal level. (also called immunocompromised).

Immunotherapy: Treatment that is directed at producing immunity or resistance to a disease or condition.

Implant: A small container of radioactive material placed in or near a cancer.

In situ: Confined to the site of origin.

Infusion: The process of putting fluids into a vein by letting them drip slowly through an intravenous catheter.

Injection: The use of a syringe to “push” fluids into the body; often called a “shot”.

Interstitial radiation: A type of therapy in which radioactive substances are implanted into or close to the area needing treatment.

Intraoperative radiation: A type of external radiation used to deliver a large dose of radiation therapy to the tumor bed and surrounding tissue at the time of surgery.

Intrathecal chemotherapy: Special chemotherapy injected into the cerebral spinal fluid, thus entering the brain and central nervous system to treat cancer.

Intravenous: Into the vein; anticancer drugs are often given by IV injection or infusion.

Laser: A powerful beam of light that can develop intense heat when focused at close range. Used in some surgical procedures.

Leukemia: General term for a progressive cancer of the bone marrow, may be acute or chronic. There are several types of leukemia.

Lymphoma: A cancerous disorder of the lymphoid tissue, including Hodgkin's Disease. May be nodular or diffuse. There are several different types of lymphoma.

Malignant: Used to describe a tumor made up of cancerous cells.

Metastasis: The spread of cells from a primary tumor to a distant site. Usually transported via the blood or lymphatic system.

Metastatic: Spread of a disease from the organ or tissue to another part of the body.

MRI (magnetic resonance imaging): Uses a very strong magnetic field to visualize possible tumors in tissue with a high water or fat content, that cannot be easily studied by X-ray or some CAT scans. All metal items must be removed before testing, and your doctor, nurse, and the MRI technician must be aware of any metal items implanted in your body. The MRI machinery makes a thumping/clanking sound during the scan, and the scanning lasts anywhere from 10-60 minutes.

Mucositis: Irritation and/or sores in the mouth and esophagus caused by chemotherapy and radiation.

Nadir: The period of time when chemotherapy has its most significant effects on the bone marrow, typically ranges 7-21 days after chemotherapy is administered.

Nuclear scans: Creates images of tissues, organs, and bones to detect presence of tumors. Requires injection of very small amounts of radioactive material to pinpoint areas of possible tumor. Nuclear scanning is performed on a very firm platform and lasts anywhere from 10-30 minutes.

OCN (oncology certified nurse): A registered nurse who has practiced oncology nursing for several years, and has passed the national comprehensive oncology nursing examination.

Oncologist: A physician trained to treat patients who have cancer.

Oncology: Study, science, or treatment of neoplasms (cancers) and tumors.

PCA (patient controlled analgesia): A pump used to administer IV pain medications in which the patient has the option to administer his/her own doses.

PRBC (packed red blood cells): A transfusion of red blood cells that you may receive when the red blood cell count is low.

Palliative therapy: A treatment that may relieve symptoms without curing the disease.

Peripheral blood stem cell transplant: A procedure in which the patient's own peripheral blood stem cells are removed, stored, and returned to the patient after high-dose chemotherapy to restore bone marrow function. This may also be called peripheral blood stem cell rescue or support.

PLTs (Platelets): Small cells in the blood that are important in blood clotting and help to prevent bleeding.

Polyp: A growth or mass protruding from a mucous membrane, such as the lining of the intestine. Usually a benign overgrowth of normal tissue, sometimes polyps can be true cancerous tumors.

Port-a-cath: A vascular access system implanted completely under the skin, usually in a convenient, but inconspicuous location on your chest or arm. Medications and fluids can be delivered directly into the bloodstream with the ease of simple injection through the skin.

Protocol: A standardized treatment plan.

PFTs (Pulmonary function tests): A non-invasive breathing test to determine the efficiency of the lungs.

Rad: Abbreviation for “radiation absorbed dose”. A measurement of the amount of radiation absorbed by tissues. (100 rads = 1 gray)

Radiation: Energy carried by waves or a stream of particles.

Radiation therapist: A person specifically trained to tune the equipment that delivers radiation treatment. Sometimes called a “radiation technologist”.

RBCs (Red blood cells): Blood cells that transport oxygen throughout the body.

Regression: Shrinkage or abatement of cancer growth.

Relapse: Recurrence of disease following treatment.

Remission: Reduction of a clinically detectable disease for as long as possible, even though the disease may not have been eliminated.

Risk factor: A component of behavior, genetic makeup, or exposure to a known cancer-causing agent, which increases a person’s chance of developing a particular form of cancer.

Sarcoma: A general term for often rapidly growing, highly malignant tumors originating from connective tissue (such as bone, cartilage, muscle, blood vessel, or lymphoid tissue). There are several different types of sarcoma.

Sepsis: The presence of infectious organisms in the blood.

Shunt: A device used to establish an artificial passage by which body fluid is diverted from one circulatory path to another.

Simulation: A process involving special X-ray pictures that are used to plan radiation treatment so that the area to be treated is precisely located and marked for treatment.

Staging: Methods used to establish the extent of a patient’s disease.

Stem cell: “Mother” or “primitive” blood cell from which all other blood cells originate.

Survival: Usually expressed as the ratio of those who survive a disease per number of persons diagnosed with the disease in a given amount of time.

Synergism: Cooperative effects of two agents giving a total effect greater than the sum of the two agents taken independently.

TPN (Total Parenteral Nutrition): Fluid infused into a central venous catheter, which provides calories, vitamins, and minerals that would normally be received from food. (Also called hyperalimentation).

Thrombocytopenia: Decreased platelet counts.

Transfusion: An infusion of blood products, usually red blood cells or platelets, to support the body while waiting for stem cells to grow.

Ultrasound: A non-X-ray, radiologic imaging technique where deep structures of the body are visualized by recording the reflections of ultrasonic waves into the tissues. Commonly used in abdominal/pelvic tissue to detect masses and tumors.

Vascular access device: A specially inserted catheter or device into a large vein. It provides repeated and relatively painless access to the bloodstream for injection of medications and fluids, also withdrawal of blood for laboratory tests. There are several different types. This includes tunneled catheters, such as the Groshong brand. (typically placed in the upper, outer chest). The PICC catheter, (inserted in the inner arm fold); and an implantable port, such as the port-a-cath brand, (often placed in the upper outer chest).

Virus: Very small organisms that cause infections by invading other cells.

WBCs (White blood cells): The blood cells that help the body fight infection, and mount immune responses.

Xerostomia: Dryness of the mouth, due to side effects of some medication, or removal or damage of the salivary glands due to surgery or radiation. May be temporary or permanent.

Chapter 12. Resources for Learning More

Federal Resources

National Cancer Institute

www.cancer.gov
www.nci.nih.gov

Veterans Health Library

www.Veteranshealthlibrary.org

Private/Nonprofit Organizations*

Lung Cancer Alliance

www.lungcanceralliance.org

American Cancer Society

www.cancer.org

American Lung Association

www.lungusa.org

American Institute of Cancer Research

www.aicr.org

American Society of Clinical Oncology

www.asco.org

Cancer & Careers

www.cancerandcareers.org/

Cancer Care

www.cancercare.org

Cancer Legal Resource Center

www.disabilityrightslegalcenter.org/cancer-legal-resource-center

Cancer Research & Prevention Foundation

www.preventcancer.org

Cancer Care Resources

www.cancercarerresources.org

International Cancer Alliance

www.icare.org

International Myeloma Foundation

www.myeloma.org

Lymphoma Information Network

www.lymphomainfo.net/index.html

MacMillian Cancer Support - Information & Support

www.macmillan.org.uk/information-and-support/index.html

National Ovarian Cancer Coalition

www.ovarian.org

Patient Advocate Foundation - Guide to Disability Process

www.patientadvocate.org/requests/publications/Guide-To-Disability-Process.pdf

Prostate Cancer Foundation

www.pcf.org/

Susan G. Komen Breast Cancer Foundation

www.komen.org

University of Pennsylvania - OncoLink

www.oncolink.com

*Please note, the VA does not endorse these organizations and is not liable for quality of the care or product/content.



[illegible]

[illegible][illegible]

Oncology & Hematology Care

VA Portland Health Care System
3710 SW US Veterans Hospital Rd
Portland, OR 97239

503-220-8262

800-949-1004