

This book belongs to:

This patient guidebook is a great resource and an important tool to help you as you receive care. Please bring it with you to all of your appointments and treatments.

If found, please return to the clinic front desk.

Your health care team may have given you this information as part of your care. If so, please use it and call if you have any questions. If this information was not given to you as part of your care, please check with your doctor. This is not medical advice. This is not to be used for diagnosis or treatment of any medical condition. Because each person's health needs are different, you should talk with your doctor or others on your health care team when using this information. If you have an emergency, please call 911. Copyright © 10/2017 University of Wisconsin Hospitals and Clinics Authority. All rights reserved. Produced by the Department of Nursing. HF#3107

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Welcome

For more than 75 years, UW Health has been meeting health care needs of patients near and far. Our expert team of doctors, nurses, pharmacists, therapists, nutritionists, social workers and many more are among the finest in the world. They use their skills and expert knowledge to promote, maintain, and restore health.

UW Carbone Cancer Center – Cancer Care at Its Best

Established in 1973, the University of Wisconsin Carbone Cancer Center (UWCCC) is the *only* comprehensive cancer center in Wisconsin as defined by the National Cancer Institute (NCI). NCI supports research across the country to find the best way to prevent, diagnose, and treat cancer.

A vital part of the UW Medical School and UW Health, the UWCCC unites more than 300 doctors and scientists from across the UW-Madison campus. Together they are searching for ways to prevent this disease and treat it in its many forms.

Your UWCCC team provides care for more than 30,000 people each year. We diagnose, treat, and provide follow up care to people of all ages. Patients have access to a team of specialists whose expertise ranges from bone marrow transplantation to urology.

One of the UWCCC's greatest strengths is our commitment to cancer research. Clinical trials offer you the latest therapies and allow us to advance treatment possibilities for future patients.

Your Care

Within the UW Health system, there are more than 60 clinics. It is likely that much of your cancer care will occur in a clinic setting. Although you may be treated in one of our cancer clinics, there is also a chance that you could be seen in other clinics. (A complete list of the clinics is found on www.uwhealth.org.) If you are seen in more than one clinic, the doctors and staff strive to coordinate your care.

If You Need to be Hospitalized at UW Hospital

In our 505-bed teaching hospital, we see patients with a wide range of concerns. Cancer patients are hospitalized on our Hematology/Oncology unit, a pediatric unit, or on one of the surgical units. No matter where you receive your care, experts will manage your care to ensure the best outcome for you and your family.

National Recognitions:

- ***National Cancer Institute-designated Cancer Center***
- ***National Comprehensive Cancer Network member***
- ***Commission on Cancer Accredited***
- ***A Magnet Hospital for nursing excellence (American Nurses Credentialing Center)***
- ***Consistently ranked in the top 50 best hospitals for cancer care by U.S. News and World Report***

Parking

- **Let us park your car.** Valet parking services at the front entrance are free of charge. Tipping the valet staff is not allowed.
- **If you prefer to park your car,** patients and their families can park in the patient visitor ramp. Follow the signs on Highland Avenue to enter the ramp.
- **When you are here for a clinic visit,** bring your parking ticket in to have it stamped at the Clinics Information Desk. This will allow you to exit the ramp without paying.
- **Patients undergoing radiation treatments** should discuss parking with your radiation therapist on the day of your first treatment.
- **If you are hospitalized,** your family may receive a parking pass that will allow them to park free. This pass is limited to one per family. It can be picked up at the Main Information Desk.
- **RVs can be parked in a nearby lot for free.** Ask or call the staff at the Main Information Desk (608)-263-0315 for further details about this option.

Lodging

To learn more about lodging, talk with the Housing Accommodations Coordinator **(608) 263-0315** at the Main Information Desk. Staff can arrange for discounted rates at nearby hotels and/or talk with you about other options. For families of children being treated at UW Health, you may wish to stay at the Ronald McDonald House which is within walking distance.



Tips for Talking With Your Health Care Providers

You and your health care providers are working toward the same goal: your health. Health care providers can advise you and help treat health problems. Your good health depends on you. First, take advantage of clinic and hospital visits to learn how to best care for yourself. Second, become a partner in decisions that affect your health care. To form this partnership, talk with your provider and plan your care together.

- ✓ **Prepare for your appointment in advance.** You may want to jot down what you want to tell your doctor or nurse as well as any questions you may have.
- ✓ **You may want to bring someone with you.**
- ✓ **Be clear and direct when you describe your symptoms.** Here are some things you can be prepared to discuss: how long you've had the problem, what you have done about it, if it has changed, and what makes it better or worse.
- ✓ **If you have been treating yourself or if you have changed your prescribed treatment, tell your provider.** The health care team cannot make accurate decisions about your care unless they know how you have been treating your problem.
- ✓ **Ask questions.** Ask your provider to tell you what your diagnosis is, what caused it, what you should do about it, and when it will improve. Find out if you need to make a follow-up visit.
- ✓ **Make sure you understand any recommendations.** Repeat what you have heard to make sure you understand what was said. Also, make sure the instructions are right for you. If they aren't, let us know. Your health care provider may be able to alter the plan to better meet your needs.
- ✓ **Ask for more information if you need it.** If you do not understand something, ask us to explain it. Take notes or ask for a written handout if it would be helpful to you. Find out who to call if you have questions after you return home.

Who should I call? Hematology Patients

Call 911 or your
local ambulance
OR
go to the nearest
emergency room.



EMERGENCIES

- Trouble breathing
- Heavy bleeding, or bleeding you can't stop
- Chest pain
- Fainting or passing out
- Anything else you think might be an emergency

Problems not related to
your cancer or treatment,
and refills of your other
medications.

Cancer and treatment symptoms

- Pain not relieved by medicine
- Fever over 100.8° F
- Shaking chills
- New or different pain
- Nausea and/or vomiting not relieved by medicine
- Uncontrollable diarrhea
- Mild bleeding
- Unable to eat or drink
- Symptoms getting worse
- If you are unsure whether a symptom is related to your cancer

Questions about your disease and treatment

Monday – Friday from 8 a.m. to 5 p.m., call **(608) 265-1700 or (800) 323-8942 and ask for 5-1700**. Select the number for your clinic, then select option 3, and ask to speak with a nurse.

All other times, call **(608) 262-0486 or (800) 323-8942** and ask to speak to the Hematology Fellow on call.

For issues related to **Radiation treatments, or if Radiation Therapy is your main treatment**, call **(608) 263-8500**, 24 hours a day, seven days a week.

To schedule a clinic visit or let us know you can't make it, call (608) 265-1700, choose option 1.

Your local health care provider

Name: _____

Phone: _____

Resources

Cancer Connect	608-262-5223
Emergency Department	608-262-2398
Physical Therapy Appointments <ul style="list-style-type: none"> • Rehabilitation Clinic • UW Hospital 	608-263-8412 608-263-8060
Radiation Oncology	608-263-8500
Registration/Insurance	608-261-1600
UW Hospital Information	608-263-8591
UW Carbone Cancer Center Nurse Triage and Scheduling	608-265-1700
UW Carbone Cancer Center Nutrition Appointments	608-265-1700
UW Carbone Cancer Center Pharmacy	608-263-7025
UW Health Billing	608-262-2221
UW Carbone Cancer Center Integrative Health (acupuncture, healing touch or a doctor consultation)	608-265-1700
UW Health Interpreter Services	608-262-9000
UW Health Patient Relations	608-263-8009
UW Health Radiology	608-263-9719
UW Health Smoking Cessation	608-263-0573
UW Hospital Wig Program	608- 265-0090
Wisconsin Tobacco Quit Line	877-270-STOP 877-270-7867



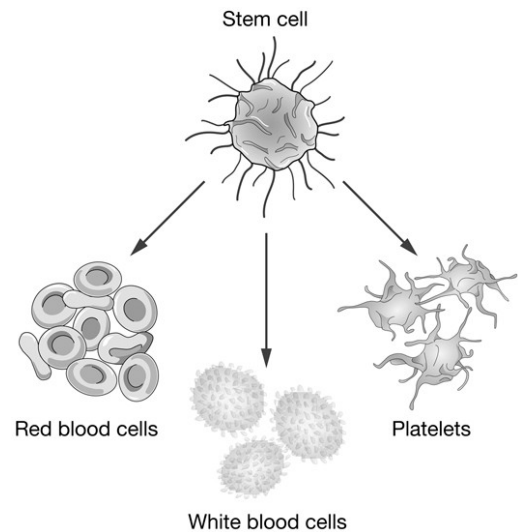
Understanding Cancers of the Blood

1. What are cancers of the blood?

Cancers of the blood develop when cells of the blood or lymph system grow in an abnormal way.

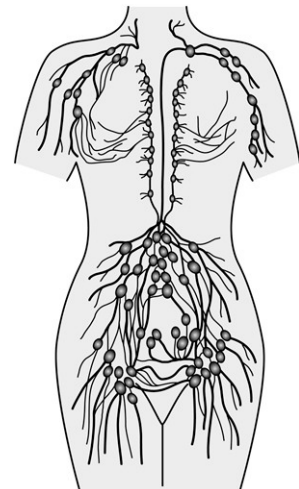
The Hematopoietic System

The bone marrow is the spongy tissue in the center of the bones where blood cells are made. A small group of cells, the stem cells, make all the blood cells including, red blood cells, white blood cells, and platelets. The stem cells divide and develop into the specific blood cells by a process of differentiation (going from an immature form to a mature form). This process is called hematopoiesis. When the cells are formed and able to function, they leave the marrow and enter the blood. The red cells carry oxygen to the tissues. Platelets help to stop bleeding. There are five types of white cells that fight infection and help in allergic reactions.



The Lymphatic System

The lymphatic system is made up of lymph nodes which are found throughout the body. Large groups of lymph nodes are found in the chest, neck, armpits, abdomen, groin, and pelvis. These nodes are joined by lymphatic vessels (tubes). Most of the cells in this system are lymphocytes, which are a type of white blood cell. Lymphocytes are made in the bone marrow, and either mature there, or in the thymus (a small gland at the base of the neck). Lymphocytes move between the blood and the lymph systems: from the marrow and the thymus, through the blood and lymphatic vessels to the lymph nodes and special tissues of the stomach, intestine, skin, and spleen.



2. How are cancers of the blood diagnosed?

How your cancer is diagnosed depends on your symptoms and physical exam findings. Some symptoms that a patient may present with are fatigue, fevers, unexplained pain, and/or weight loss without dieting. More specific symptoms may be frequent infections, change in well-being, unusual bruising, or lymph node swelling. A routine blood count test may show abnormal findings. Patients who may have a cancer of the blood are referred to a Hematologist (a doctor who treats diseases of the blood) for further work up and testing.

Tests for workup and diagnosis

Procedures and tests may be needed. This depends on your symptoms and blood test results.

- **Physical exam-** is done to evaluate your general health. This will include checking lymph nodes and abdominal organs.
- **Blood and/or urine tests-** tell us about your blood and the function of organs such as your liver and kidneys. Some diseases make special proteins that can be measured in the blood and/or urine. Frequent blood tests are often needed.
- **Biopsies-** of tissues may be needed to find out the type of disease and the best treatment. This may be done in surgery, in a clinic or patient's hospital room, or during a special x-ray guided procedure. It depends on where the tissue is located.
- **Bone Marrow biopsy-** gives more specific details about the blood cells and the health of the bone marrow. In this procedure, a small amount of marrow and a small core of bone are removed from the pelvic bone with a special needle. This may be done in a clinic or in a patient's hospital room.
- **Cytogenetics-** is a test that may be done with blood, bone marrow, or other tissues such as lymph nodes. It analyzes the number and shape of the cells' chromosomes, or genetic material. These findings are used to diagnose, plan treatments, and track your response to treatment.
- **Lumbar puncture-** may be needed for some of the blood diseases to find out if abnormal cells are present in the cerebral spinal fluid. The cerebral spinal fluid surrounds the brain and spinal cord. A small needle is inserted in the low back (lumbar region) to collect fluid and sometimes to give chemotherapy. This may be done in a clinic, in a patient's hospital room, or in radiology.
- **Ultrasounds, CT, MRI, PET, X-Rays, and other imaging studies-** are used to determine the amount of disease.

Other tests may be ordered. Again, this depends on your physical complaints and exam. Echocardiogram, EKG, and pulmonary function tests may be needed to obtain a baseline function and guide the treatment plan.

3. Is there a name for my cancer of the blood?

Cancers of the blood may occur in any of the blood cells. The cancer you have, or are suspected to have, is:

- | | |
|---|--|
| <input type="checkbox"/> Acute Myelogenous Leukemia | <input type="checkbox"/> Multiple Myeloma |
| <input type="checkbox"/> Acute Lymphocytic Leukemia | <input type="checkbox"/> Hodgkin's Lymphoma |
| <input type="checkbox"/> Chronic Myelogenous Leukemia | <input type="checkbox"/> Non-Hodgkin's Lymphoma |
| <input type="checkbox"/> Chronic Lymphocytic Leukemia | <input type="checkbox"/> Myelodysplastic Syndrome |
| <input type="checkbox"/> Hairy Cell Leukemia | <input type="checkbox"/> Myeloproliferative Disorder |

Further handouts will be given to you to explain your specific cancer.

4. How do cancers of the blood spread?

Cancers of the blood are often found in only the bone marrow or lymphatic system. When cancers of the blood spread to other areas, it is often through the blood or lymph vessels.

5. What is a tumor grade?

Cancers of the blood are not usually assigned a grade like solid tumors such as breast or lung cancer. Subtypes of non-Hodgkin's lymphoma are considered to be low, intermediate, or high grade. In this case, the structure of the cell and the cell type determine the grade, and are a measure of the aggressiveness of the cancer.

6. What is staging?

Staging is sometimes used to describe the extent and type of the disease, and to guide treatment plans. While leukemia and myelodysplastic syndromes are not staged, they have subtypes, which describe specific features of the disease. Since there are many differences between how types of blood cancers are staged, or categorized, you will be given more detailed information for your specific disease.

My cancer of the blood is staged or categorized as:

7. What are the treatment options for cancers of the blood?

The treatment options differ. This depends on the specific disease. Chemotherapy is often the primary treatment for leukemia, though treatments vary based on the subtype. Treatment for lymphoma and multiple myeloma will change based on the specific stage, and may include, chemotherapy, radiation therapy, and/or surgery. Treatment for myelodysplastic syndrome, like leukemia, is dependent on the subtype.

About My Cancer of the Blood

Name and location: _____

Cell Type: _____

Stage/Subtype: _____

Grade: _____

Other notes: _____



Facts about Surgery for Cancer

For people with certain types of cancer, or whose cancer is found early, surgery may be the best choice for treatment. Some people only have surgery. Others have chemotherapy or radiation therapy before or after their surgery.

Often, people are afraid of surgery. Your team of doctors, nurses, social workers, and others can answer questions and counsel you to help you make the choices that are right for you.

If your doctor suggests surgery for your cancer, and you decide to have it, a team of experts will work with you before and after your surgery to make sure you are comfortable.

Does everyone with cancer have surgery?

No. There are many things that determine if surgery should be done. This includes the stage of your cancer and your overall health. Your doctors will be able to tell you whether or not surgery is an option for you.

Why should I have surgery, if it is recommended to me?

For some people, the goal of surgery is to remove cancer from their body. While no one can guarantee cancer will never come back, surgery may help meet that goal.

In other cases, surgery may be an effective way to relieve cancer symptoms.



Is there a lot of pain with surgery?

After surgery, pain medicines are used to reduce pain. Often, people are able to be out of bed walking the same or the next day. Your doctors and nurses are experts in taking care of pain and helping you to be comfortable.

What if I can't have surgery or the cancer comes back?

Surgery is only one of the treatment options for cancer patients. Chemotherapy and radiation therapy are other options. Many people are eligible for clinical trials as well.

I have many more questions before I will be ready for surgery.

We know, and we are here to help. Your healthcare team will take the time to answer your questions. Before you have surgery, you will meet with a patient education specialist who will make sure you have all the information you need.

Use the blank pages in section 12 of your Guidebook to write down your questions, and bring them with you to your appointments.

Facts about Chemotherapy for Cancer

Chemotherapy is the treatment of cancer with one or more medicines. Unlike surgery or radiation therapy that treats cancer in a specific site, chemotherapy is a **systemic treatment** that travels throughout the body.

Though chemotherapy may be given alone, it is often used along with surgery and/or radiation.

- **Neoadjuvant** chemotherapy (with or without radiation) is sometimes given before surgery or radiation to shrink the tumor. This makes it easier to remove or allows for a less extensive surgery.
- **Adjuvant** chemotherapy is given after surgery to destroy any cancer cells left behind.
- Chemotherapy can be used as a **radiosensitizer** making radiation treatments more effective.
- Chemotherapy can be used (with or without surgery or radiation) if the cancer recurs or spreads to other parts of the body.

Why do I need chemotherapy?

It is given to:

- slow the growth of cancer
- control symptoms caused by cancer
- prevent cancer from coming back
- cure **some** cancers

Your **medical oncologist** is an expert who will plan your treatments. The plan is based on:

- the kind of cancer you have
- where the cancer is
- the side effects the cancer and/or treatments have on your body
- your general health

How will I get my chemotherapy?

It can be given in many ways. Some of the most common ways are:

- as a pill – by mouth
- into a vein or **central catheter** – intravenous (IV)
- as a shot (injection) under the skin (sub Q) or into a muscle (IM)
- into an artery directly to the tumor

What about side effects?

The idea of getting chemotherapy can be a scary thing. You may hear stories about the side effects from well-meaning friends and relatives. Research has allowed us to improve the way we give chemotherapy and manage side effects making it more effective and easier to tolerate.

Many side effects of chemo occur because of the effect the drugs have on the normal fast growing cells in the body. The specific side effects you might expect from your treatment will be discussed with you when the treatment plan is made.

You are the most important member of your health care team. If you have side effects or concerns, be sure to let your doctors and nurses know.



Facts about Radiation Therapy

Radiation therapy is the use of high energy rays to treat cancer in a specific site. Radiation therapy may be used alone. It may also be used with surgery and/or chemotherapy.

How does radiation work?

Radiation kills cancer and normal cells in the area being treated. Treatments are planned to deliver as much radiation as possible to tumor cells. Normal cells near the cancer are able to repair damage caused by radiation. Radiation works to stop tumors from growing. In some parts of the body, after cancer cells die, the dead cells may be absorbed by your body which can result in shrinkage of the tumor. Other areas are not able to absorb those cells, or the process may be quite slow so there may be no shrinkage of the tumor.

Types of radiation therapy

External beam radiation is the general term used to describe the delivery of radiation. There are many ways radiation can be delivered and many techniques that can be used to treat the tumor and reduce damage to normal tissue.

Other types of radiation

- **IMRT** (intensity-modulated radiotherapy **and** **FSRT** (fractionated stereotactic radiotherapy) **and** **VMAT** (volumetric modulated arc therapy) are ways to target cancer while causing less damage to normal tissues.
- **Stereotactic radiosurgery-** is used to treat some tumors, usually in the brain. It is a very precise form of radiation. It can also be called Gamma Knife or Cyber Knife.

- **Tomotherapy** is a type of machine that delivers radiation in a spiral pattern to treat certain cancers. It is a combined treatment machine and CT scanner. The CT confirms the precise size, shape, and location of the tumor before the treatment is given.
- **TrueBeam** is a type of machine that delivers radiation to treat cancers. It is a combined treatment machine and CT scanner. The CT confirms the precise size, shape, and location of the tumor before the treatment is given.
- **Brachytherapy** places a radiation source in or near the tumor. The radiation can be given with seeds, rods or catheters depending on the location of the tumor
- **Stereotactic Body Radiation (SBRT)** uses a mold for positioning and allows radiation to be precisely targeted to tumors.
- **Gated RapidArc-** a technique that monitors the patients breathing and allows for tumors to be treated that may move with breathing.

Will I need these treatments?

jody@bgsinc.com Your doctors will talk with you about your treatment options. If radiation therapy is needed, they will explain the type of treatment that is best for you and discuss any side effects.



Facts about Clinical Trials and Treatment

Clinical trials or research studies, test new treatments, procedures and devices in people. Some trials address quality of life issues. Others are designed to find better ways to give treatments like radiotherapy and chemotherapy. Some test new drugs. In all of these cases, the goal of clinical trials is to improve care.

Clinical trials with medicines might test how well a new drug works or how combinations of older drugs can be better. Radiotherapy trials study new techniques and devices. Clinical trials may also compare a standard therapy with a new one to determine which is best.

If a clinical trial is an option for you, and you want to know more, your doctor and a study coordinator will discuss the details of the trial. Participation in a clinical trial is voluntary. You may choose not to participate. If you decide to take part, you may withdraw at any time. Your decision will not affect the quality of your care.

Clinical trials go through stages, or phases, of testing.

- Phase I trials look at how best to give a new treatment safely.
- Phase II trials test the effectiveness and side effects of new treatments.
- Phase III trials compare the new treatments studied in phase I and phase II with standard therapy.

What are the benefits of a clinical trial?

- You will receive high quality care. Even if you do not receive the new drug or have the new technique, you will receive the best standard treatment.
- By looking at the pros and cons of your treatment options, you are taking an active part in decisions that will affect your life.
- You may be one of the first to benefit from a new treatment or procedure.
- You have the chance to help others and improve care.

What are the risks of clinical trials?

- **New treatments may not always better, or as good as standard care.**
- As with standard care, even if a new treatment helps some people, it might not help you.
- There might be unexpected side effects.

Health insurance may not cover some of the costs of a clinical trial. The study coordinator will be able to tell you what charges are paid for by the study and what can be billed to your insurance.

Resources

- If you would like more information please visit:
 - www.uwhealth.org/cancertrials
 - www.clinicaltrials.gov

Tests and Procedures

Tests and procedures are performed before, during, and after cancer treatment. This section provides you with a place to file handouts about how to prepare for a test or procedure. You may also wish to use this section to keep track of test results. However you wish to use it is up to you.

Surgery

Radiotherapy

Chemotherapy



Carbone Cancer Center

UNIVERSITY OF WISCONSIN
SCHOOL OF MEDICINE AND PUBLIC HEALTH

Research. Treatment. Education. *Hope.*

University of Wisconsin Carbone Cancer Center (UWCCC) Nutrition Appointments

Inpatient nutrition therapy: If you are in the hospital and would like to speak to a registered dietitian before you go home, let your medical team know and they can order a nutrition consult for you.

Outpatient nutrition therapy: To make a clinic appointment with a registered dietitian call **(608) 265-1700**

How to Manage Symptoms from Cancer Treatments

Symptoms from cancer treatments may make it hard to eat. These tips will help you manage your symptoms and maintain a healthy diet.

Sore Mouth or Throat

- Choose bland, soft, moist foods at room temperature.
- Citrus fruits/juices, tomato products, spicy/salty foods, and rough/dry foods may cause pain.
- Ask your health care team about mouthwash and medicine they can prescribe that ease pain.

Dry Mouth

- Take sips of fluid throughout the day.
- Moisten foods with broth, soup, sauce, gravy, butter or margarine.
- Suck on ice chips, frozen pieces of fruit, Italian ice, and popsicles.
- Gum or sucking on candy (no sugar) may help.
- Try dry mouth products by Biotene®, OraMoist®, Orajel®, MedActive®, Act®, and MighTeaFlow®.

Altered Taste

- Try tart flavors like lemonade or citrus fruits. You can also try pickled foods like pickles, coleslaw, and olives.
- Add extra flavor to foods. Try spices or herbs, mustard, ketchup, lemon/lime juice, sauces or dressings.
- If red meat tastes strange, try other proteins like chicken, turkey, fish, eggs, dairy products, beans, or tofu.
- Marinate or cook meats in sweet juices, acidic dressings or marinades.

Nausea

- Have crackers, toast, or dry cereal in the morning to help settle your stomach.
- Instead of large meals, eat small portions 1-3 hours apart.
- Avoid foods that are fatty, greasy or spicy.
- Select bland, mild foods.

Diarrhea

- Take frequent sips of clear fluids.
- Choose bland, mild foods.
- Avoid foods that are fatty, greasy.
- Avoid caffeine and alcohol.
- If you think you are intolerant to dairy, avoid or limit dairy products like milk and ice cream. Try Lactaid® milk, soymilk, almond milk, yogurt, and mozzarella cheese sticks.

Foods Lists

The foods below make good snacks or can be combined to make small meals.

Bland Foods

Grains

Bread/toast, bagels (plain), English muffin, cornbread, pancakes, waffles, pasta, couscous, rice cakes (plain), tortillas, rice, crackers, cereals (Rice Krispies®, corn flakes, Crispex®, Cheerios), pretzels, cream of rice®, Cream of Wheat®, grits, oatmeal

Proteins

Fish (no breading), beef (lean cuts), chicken or turkey (without skin, roasted, baked, grilled, well-cooked), eggs (scrambled, soft or hard boiled, poached), tofu (cooked), lunch meats (ham/turkey/chicken), soups (broth based), peanut butter (creamy)

Vegetables

Well cooked vegetables like carrots, green beans, squash, zucchini, sweet potatoes, potatoes (baked, boiled, or mashed without skin)

Fruits

Bananas, watermelon, honeydew, cantaloupe, canned or fresh peaches/pears, apples (peeled) applesauce, mandarin oranges

Dairy

Milk (skim or 1%, almond/soy/rice milk), yogurt, cottage cheese (2% or less), mozzarella and cheddar cheese

Desserts

Plain cookies or cakes (angel food cake, sponge cake, vanilla wafers), flavored gelatin, popsicle, sherbet, sorbet, frozen yogurt, low fat ice cream, low fat pudding

Drinks

Clear sodas (choose caffeine-free if able), sport drinks, decaf teas, apple juice, cranberry juice, rice milk, almond milk, soy milk, Lactaid® milk, ginger ale, ginger or chamomile tea, fruit punch

Moist/Soft Foods**Grains**

French Toast with syrup, cooked cereals, cold cereals in milk, pasta or rice in sauce

Proteins

Ground meats, poultry, fish (no breading), canned tuna, egg salad, quiche, omelet, soft boiled egg, poached egg, scrambled eggs, tofu, macaroni and cheese, cheese cubes, grated cheese, cheese sauce, creamy peanut butter, hummus, soups (creamy, broth, pureed soups)

Fruits or Vegetables

Soft cooked or pureed fruits, soft cooked veggies, cream or pureed soups, mashed potatoes, applesauce, ripe bananas, watermelon, grapes, frozen fruits

Dairy

Milkshakes, cottage cheese, yogurt/Greek yogurt, frozen yogurt, cheese (sticks or slices), chocolate milk, powdered milk, smoothies, hot cocoa made with milk

Desserts

Flavored gelatin, sherbet, fruit ices, ice pops, pudding, pudding pop, ice cream, cheesecake, mousse

Who to Call

If you have more questions, please contact UW Health at one of the phone number listed below. You can also visit our website at www.uwhealth.org/nutrition.

Nutrition clinics for UW Hospital and Clinics (UWHC) and American Family Children's Hospital (AFCH) can be reached at: **(608) 890-5500**.

Nutrition clinics for UW Medical Foundation (UWMF) can be reached at: **(608) 287-2770**.

Your health care team may have given you this information as part of your care. If so, please use it and call if you have any questions. If this information was not given to you as part of your care, please check with your doctor. This is not medical advice. This is not to be used for diagnosis or treatment of any medical condition. Because each person's health needs are different, you should talk with your doctor or others on your health care team when using this information. If you have an emergency, please call 911. Copyright © 7/2020 University of Wisconsin Hospitals and Clinics Authority. All rights reserved. Produced by the Department of Nursing HF#226.



Food Safety for the Immunocompromised Patient

When your immune system is weak you are at greater risk of getting sick from foods with bacteria, viruses, and mold. This food safety guide will help you avoid foodborne illnesses.

Below is a guide as to how long you may need to follow these guidelines:

- **Allogeneic stem cell transplant:** follow this guide during pre-transplant chemotherapy (chemo) and until you are no longer taking drugs that suppress your immune system.
- **Autologous stem cell transplant:** follow this guide during pre-transplant chemo and for the first 3 months after transplant.
- If you are immunocompromised but did not have a stem cell transplant, follow this guide until you are no longer immunocompromised.

Types of Food	High Risk Foods to Avoid
Meats, Poultry and Seafood	<ul style="list-style-type: none">• Raw, dehydrated, or undercooked meat, poultry, fish or shellfish• Smoked fish kept in the fridge
Milk	<ul style="list-style-type: none">• Unpasteurized (raw) milk• Kefir and yogurt are safe to eat, even with live cultures
Eggs	<ul style="list-style-type: none">• Foods with raw or undercooked eggs like homemade Caesar salad dressing, homemade raw cookie dough, and homemade eggnog
Fruits/Vegetables	<ul style="list-style-type: none">• Unwashed fruits and vegetables• Fresh produce that cannot be cleaned well like strawberries, blueberries, grapes, blackberries and raspberries• Non-pasteurized fruit and vegetable juice• Raw sprouts (alfalfa, bean or other sprouts)• Fresh mushrooms• Packaged, frozen fruits and vegetables are safe to eat
Cheese	<ul style="list-style-type: none">• Soft cheeses made from unpasteurized (raw) milk like brie, camembert, blue-veined, and queso fresco• These cheeses are safe to eat if cooked
Hot Dogs and Deli Meats	<ul style="list-style-type: none">• Hot dogs, deli meats, and luncheon meats that have not been reheated to steaming hot or 165°F
Other	<ul style="list-style-type: none">• Unpasteurized pâtés or meat spreads• Raw honey
Drinks/Water	<ul style="list-style-type: none">• Sun tea• Kombucha• Well water• Water from lakes, rivers, streams, or springs• All bottled water is safe to drink

General Food Safety Guidelines

- Wash hands, utensils and work surfaces often.
- Separate raw meats, poultry, seafood and eggs from other foods in your shopping cart, grocery bag, and fridge.
- Thaw meat, fish, and poultry in the fridge or microwave – not on the counter.
- Cook foods to the right temperature. Refer to the table below.
- Chill raw meat/poultry and cooked leftovers within 2 hours. Your fridge should be kept at 40°F or below.
- Avoid foods from delis, buffets, salad bars, and bulk food bins. Avoid free food samples in stores.
- Do not buy opened or damaged products, expired foods, or cans that are rusted, bulging or dented.
- Select fruits and vegetables that look and smell fresh and do not have bruises, damaged skins, or mold.
- Wash all raw fruits and vegetables before peeling or cutting. To clean, run under cool water or soak in a basin of water for 1-2 minutes and drain. Do not use soaps, bleach or detergents on produce.

Water Safety

- Avoid well water. No matter how often well water is tested, you can't be sure it will stay safe.
- Tap water is water from your faucet. If the water source is a city water supply or a municipal well it is clean and safe in most cases. If you have questions about the safety of your water, check with your local health department and water utility.
- Bottled water is best. Choose water that has one of these statements on the label: reverse osmosis, distillation/distilled or filtered through an absolute 1 micron or smaller filter.

USDA Recommended Safe Minimum Internal Temperatures				
Beef, Pork, Veal, Lamb, Steaks, Roasts, Chops	Fish	Ground Beef, Veal, Lamb	Egg Dishes	Whole, Pieces, and Ground Turkey, Chicken, Duck
145°F with a 3 minute rest time	145°F	160°F	160°F	165°F

Teach Back

What is the most important thing you learned from this handout?

What changes will you make in your diet/lifestyle, based on what you learned today?

If you have more questions please contact UW Health at one of the phone number listed below. You can also visit our website at www.uwhealth.org/nutrition.

Nutrition clinics for UW Hospital and Clinics (UWHC) and American Family Children's Hospital (AFCH) can be reached at: **(608) 890-5500**. Nutrition clinics for UW Medical Foundation (UWMF) can be reached at: **(608) 287-2770**.

If you are a patient receiving care at UnityPoint – Meriter, Swedish American or a health system outside of UW Health, please use the phone numbers provided in your discharge instructions for any questions or concerns.

The Spanish version of this *Health Facts for You* is #476s.

Your health care team may have given you this information as part of your care. If so, please use it and call if you have any questions. If this information was not given to you as part of your care, please check with your doctor. This is not medical advice. This is not to be used for diagnosis or treatment of any medical condition. Because each person's health needs are different, you should talk with your doctor or others on your health care team when using this information. If you have an emergency, please call 911. Copyright © 11/2019 University of Wisconsin Hospitals and Clinics Authority. All rights reserved. Produced by the Department of Nursing. HF#476



Food Safety Information



Basics for Handling Food Safely

Safe steps in food handling, cooking, and storage are essential to prevent foodborne illness. You can't see, smell, or taste harmful bacteria that may cause illness. In every step of food preparation, follow the four steps of the Food Safe Families campaign to keep food safe:

- Clean - Wash hands and surfaces often.
- Separate - Don't cross-contaminate.
- Cook - Cook to the right temperature.
- Chill - Refrigerate promptly.

Shopping

- Purchase refrigerated or frozen items after selecting your non-perishables.
- Never choose meat or poultry in packaging that is torn or leaking.
- Do not buy food past "Sell-By," "Use-By," or other expiration dates.

Storage

- Always refrigerate perishable food within 2 hours--1 hour when the temperature is above 90 °F (32.2 °C).
- Check the temperature of your refrigerator and freezer with an appliance thermometer. The refrigerator should be at 40 °F (4.4 °C) or below and the freezer at 0 °F (-17.7 °C) or below.
- Cook or freeze fresh poultry, fish, ground meats, and variety meats within 2 days; other beef, veal, lamb, or pork, within 3 to 5 days.
- Perishable food such as meat and poultry should be wrapped securely to maintain quality and to prevent meat juices from getting onto other food.
- To maintain quality when freezing meat and poultry in its original package, wrap the package again with foil or plastic wrap that is recommended for the freezer.
- Canned foods are safe indefinitely as long as they are not exposed to freezing temperatures, or temperatures above 90 °F. (32.2 °C) If the cans look ok, they are safe to use. Discard cans that are dented, rusted, or swollen. High-acid canned food (tomatoes, fruits) will keep their best quality for 12 to 18 months; low-acid canned food (meats, vegetables) for 2 to 5 years.

Preparation

- Always wash hands before and after handling food.
- Don't cross-contaminate. Keep raw meat, poultry, fish, and their juices away from other food. After cutting raw meats, wash hands, cutting board, knife, and counter tops with hot, soapy water.
- Marinate meat and poultry in a covered dish in the refrigerator.
- Sanitize cutting boards by using a solution of 1 teaspoon chlorine bleach in 1 quart of water.

Thawing

- **Refrigerator:** The refrigerator allows slow, safe thawing. Make sure thawing meat and poultry juices do not drip onto other food.
- **Cold Water:** For faster thawing, place food in a leak-proof plastic bag. Submerge in cold tap water. Change the water every 30 minutes. Cook immediately after thawing.
- **Microwave:** Cook meat and poultry immediately after microwave thawing.

Cooking

- Cook all raw beef, pork, lamb and veal steaks, chops, and roasts to a minimum internal temperature of 145 °F (62.8 °C) as measured with a food thermometer before removing meat from the heat source. For safety and quality, allow meat to rest for at least three minutes before carving or consuming. For reasons of personal preference, consumers may choose to cook meat to higher temperatures.
- **Ground meat:** Cook all raw ground beef, pork, lamb, and veal to an internal temperature of 160 °F (71.1 °C) as measured with a food thermometer.
- **Poultry:** Cook all poultry to an internal temperature of 165 °F (73.9 °C) as measured with a food thermometer.

Serving

- Hot food should be held at 140 °F (60 °C) or warmer.
- Cold food should be held at 40 °F (4.4 °C) or colder.
- When serving food at a buffet, keep food hot with chafing dishes, slow cookers, and warming trays. Keep food cold by nesting dishes in bowls of ice or use small serving trays and replace them often.
- Perishable food should not be left out more than 2 hours at room temperature--1 hour when the temperature is above 90 °F (32.2 °C).

Leftovers

- Discard any food left out at room temperature for more than 2 hours--1 hour if the temperature was above 90 °F (32.2 °C).
- Place food into shallow containers and immediately put in the refrigerator or freezer for rapid cooling.
- Use cooked leftovers within 4 days.
- Reheat leftovers to 165 °F (73.9 °C).

Refreezing

Meat and poultry defrosted in the refrigerator may be refrozen before or after cooking. If thawed by other methods, cook before refreezing.

COLD STORAGE CHART

These short, but safe, time limits will help keep refrigerated food from spoiling or becoming dangerous to eat. Because freezing keeps food safe indefinitely, recommended storage times are for quality only.

Product	Refrigerator 40 °F (4.4 °C)	Freezer 0 °F (-17.7 °C)
EGGS		
Fresh, in shell	3 to 5 weeks	Do not freeze
Raw yolks & whites	2 to 4 days	1 year
Hard cooked	1 week	Does not freeze well
LIQUID PASTEURIZED EGGS, EGG SUBSTITUTES		
opened	3 days	Does not freeze well
unopened	10 days	1 year
Mayonnaise Commercial, refrigerate after opening	2 months	Do not freeze
FROZEN DINNERS & ENTREES		
Keep frozen until ready to heat	—	3 to 4 months
DELI & VACUUM-PACKED PRODUCTS		
Store-prepared (or homemade) egg, chicken, ham, tuna, & macaroni salads	3 to 5 days	Does not freeze well
HOT DOGS & LUNCHEON MEATS		
Hot dogs		
opened package	1 week	1 to 2 months
unopened package	2 weeks	1 to 2 months

Product	Refrigerator 40 °F (4.4 °C)	Freezer 0 °F (-17.7 °C)
Luncheon meat		
opened package	3 to 5 days	1 to 2 months
unopened package	2 weeks	1 to 2 months
BACON & SAUSAGE		
Bacon	7 days	1 month
Sausage, raw — from chicken, turkey, pork, beef	1 to 2 days	1 to 2 months
Smoked breakfast links, patties	7 days	1 to 2 months
Hard sausage — pepperoni, jerky sticks	2 to 3 weeks	1 to 2 months
SUMMER SAUSAGE labeled "Keep Refrigerated"		
Opened	3 weeks	1 to 2 months
Unopened	3 months	1 to 2 months
HAM, CORNED BEEF		
Corned beef, in pouch with pickling juices	5 to 7 days	Drained, 1 month
Ham, canned labeled "Keep Refrigerated"		
Opened	3 to 5 days	1 to 2 months
Unopened	6 to 9 months	Do not freeze

Basics for Safe Food Handling

Product	Refrigerator 40 °F (4.4 °C)	Freezer 0 °F (-17.7 °C)
HAM, FULLY COOKED		
Vacuum sealed at plant, undated, unopened	2 weeks	1 to 2 months
vacuum sealed at plant, dated, unopened	“Use-By” date on package	
Whole Half Slices	7 days 3 to 5 days 3 to 4 days	
HAMBURGER, GROUND & STEW MEAT		
Hamburger & stew meat	1 to 2 days	3 to 4 months
Ground turkey, veal, pork, lamb, & mixtures of them		
FRESH BEEF, VEAL, LAMB, PORK		
Steaks	3 to 5 days	6 to 12 months
Chops	3 to 5 days	4 to 6 months
Roasts	3 to 5 days	4 to 12 months
Variety meats — tongue, liver, heart, kidneys, chitterlings	1 to 2 days	3 to 4 months
Pre-stuffed, uncooked pork chops, lamb chops, or chicken breasts stuffed with dressing	1 day	Does not freeze well
SOUPS & STEWS		
Vegetable or meat added Cooked meat & meat casseroles	3 to 4 days	2 to 3 months

Product	Refrigerator 40 °F (4.4 °C)	Freezer 0 °F (-17.7 °C)
COOKED MEAT LEFTOVERS		
Gravy & meat broth	3 to 4 days	2 to 3 months
	3 to 4 days	
FRESH POULTRY		
Chicken or turkey, whole	1 to 2 days	1 year
Chicken or turkey, pieces	1 to 2 days	9 months
Giblets	1 to 2 days	3 to 4 months
COOKED POULTRY LEFTOVERS		
Fried chicken	3 to 4 days	4 months
Cooked poultry casseroles	3 to 4 days	4 to 6 months
Pieces, plain	3 to 4 days	4 months
Pieces covered with broth, gravy	3 to 4 days	6 months
Chicken nuggets, patties	3 to 4 days	1 to 3 months
OTHER COOKED LEFTOVERS		
Pizza, cooked	3 to 4 days	1 to 2 months
Stuffing, cooked	3 to 4 days	1 month

Food Safety Questions?

Call the USDA Meat & Poultry Hotline

If you have a question about meat, poultry, or egg products, call the USDA Meat and Poultry Hotline toll free at **1-888-MPHotline (1-888-674-6854)**. The hotline is open year-round.



Monday through Friday from 10 a.m. to 4 p.m. ET (English or Spanish). Recorded food safety messages are available 24 hours a day. Check out the FSIS Web site at

www.fsis.usda.gov.

Send E-mail questions to MPHotline.fsis@usda.gov.

AskKaren.gov

FSIS' automated response system can provide food safety information 24/7 and a live chat during Hotline hours.



Mobile phone users
m.askkaren.gov
Preguntele a Karen.gov



Facts about Physical Activity for Cancer Patients

For most people with cancer, regular activity is helpful. It can make you feel better both physically and emotionally.

What are some of the benefits of an active lifestyle?

- Improved quality of life
- Increased sense of control and well being
- Decreased fatigue
- Increased energy and endurance
- Increased ability to perform normal activities of daily living
- Less dependence on others
- Increased muscle strength and flexibility
- Reduced risk of blood clots
- Increased ability for social contacts and recreation

Other long-term benefits

- Reduced risk of heart disease
- Prevention of osteoporosis

What type of physical activities or exercises can I do?

The amount of activity varies from person-to-person and may change during and after your cancer treatments. In general, you should start slowly and progress slowly.

Cancer treatment can affect endurance and muscle function, and increase your need for hydration and rest. Athletes and others who already exercise may find that they need to

modify their exercise program during their treatment for cancer.

Consult your doctor before you begin any exercise program to make sure your plan is appropriate and safe for you. Your doctor may suggest Physical Therapy to plan a specific exercise program.

How do my blood counts effect my activity level?

Patients with **low platelet counts** (20,000 per cubic mm or less) should avoid heavy resistance work and activities that traumatize the joints. Low intensity exercise (range of motion, light strengthening with low weights (less than 5 pounds), and walking) can be tolerated, if cleared by your doctor.

Patients with **low red blood cell (RBC)** counts can have increased fatigue. Resting heart rate may be higher, and you may need to adjust the level of intensity of your exercise program accordingly. Please discuss appropriate exercise intensity with your physician. Wearing a heartrate monitor may be helpful. Your doctor may recommend that you meet with a physical therapist to develop an appropriate exercise program.



Carbone Cancer Center

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SCHOOL OF MEDICINE AND PUBLIC HEALTH

Research. Treatment. Education. *Hope.*

Managing Symptoms and Self Care

We are interested in helping you manage symptoms and side effects that may occur as a result of cancer or cancer treatment. This section of your Guidebook includes information on managing some common symptoms you may have. If you are having a symptom or side effect not mentioned here, please ask your doctor or nurse for ideas on how to manage it.

In addition to physical symptoms, you may feel stressed, anxious, or depressed. You may have changes in relationships or your job situation. We have cancer psychologists, social workers, spiritual care providers, and support groups to help you manage these concerns. To learn more about these services, refer to the sections titled *Managing Symptoms and Self-care; Sexuality* and *Support Resources*.

Managing your symptoms is an important part of your care. We encourage you to try techniques that have worked for you in the past. Also, we encourage you to tell us about your symptoms, side effects, and other concerns so we can help you through them.

Your Oncology Care Team

Cancer-Related Fatigue

What is cancer-related fatigue?

Cancer-related fatigue is a common feeling for cancer patients. It is not the same as the fatigue caused by the demands of daily living. It can keep you from enjoying life and your daily routine. Patients have described it as:

- Feeling tired
- Feeling tired
- Feeling exhausted
- Feeling worn out
- Heaviness in their body
- Feeling slow
- Having trouble concentrating
- Feeling irritable
- Feeling moody
- Feeling sad

What causes cancer-related fatigue?

The exact cause is unknown. Some of things that might lead to feeling fatigued are:

- The cancer itself
- Medicines, such as chemotherapy
- Radiation
- Low blood counts
- Poor nutrition
- Sleep problems
- Depression, fear, worry or anxiety
- Lack of activity

How can I manage my cancer-related fatigue?

Talk to your provider about your fatigue. They can help you find ways to make you feel better.

Eat and drink. Eating and drinking enough will also help you feel less fatigued. We know that your disease and treatment may make it hard to eat and drink enough. Try eating many small meals and taking sips of fluids throughout the day rather than eating

a few larger meals each day. Ask your provider if you can talk to a dietician. They can suggest ways to help you get enough to eat and drink enough.

Be active. We know that exercise can help you feel less tired and improve your sleep. It can also improve your mood. Try going for a short walk. Plan to be active when you have the most energy.

Don't do too much. You may not have enough energy to do everything you want to do in a day. While you have energy, do the things you want to do and ask someone to help you with the others (such as, cleaning, grocery shopping, cooking meals). Know your limits and don't be too hard on yourself.

Rest and relax. Save energy and only do the things that need to do. If you feel tired and want to take a nap, you should limit your nap to 10-15 minutes. Longer naps can make it hard to sleep at night. Relaxation methods may allow your body to rest while helping to decrease your stress. Try meditation, prayer, guided imagery or visualization to relax.

Sleep at night. Some people have trouble sleeping. Have good sleep habits. Go to bed at the same time each night, limit caffeine, be active during the day, use your bed only for sleeping and limit naps.

Find support. Cognitive therapy, relaxation, counseling, support groups, social groups, keeping a journal, hypnosis, and biofeedback may help you manage your fatigue. Talk with your provider if you want to learn more.

Take medicines. Medicines may help ease fatigue. This may not be an option for all. Your provider will let you know if there is a medicine that may help you.

References

1. National Comprehensive Cancer Network (2020). *Patient and Caregiver Resources: Fatigue*. Retrieved from https://www.nccn.org/patients/resources/life_with_cancer/managing_symptoms/fatigue.aspx
2. National Cancer Institute (2018). *Support for People with Cancer: Chemotherapy and You*.

Your health care team may have given you this information as part of your care. If so, please use it and call if you have any questions. If this information was not given to you as part of your care, please check with your doctor. This is not medical advice. This is not to be used for diagnosis or treatment of any medical condition. Because each person's health needs are different, you should talk with your doctor or others on your health care team when using this information. If you have an emergency, please call 911. Copyright © 6/2020 University of Wisconsin Hospitals and Clinics Authority. All rights reserved. Produced by the Department of Nursing HF#4384.

Pain Management

There are many causes and kinds of pain. Pain can be caused by injury, illness, sickness, disease, or surgery. You and your health care team work together to treat your pain. Ask questions to find out how to relieve your pain. This Health Fact has some common questions and answers.

What questions should I ask my health care team?

- What pain medicine should I take?
- Can you explain the doses and times that the medicine needs to be taken?
- How often should I take the medicine? What should I do if I miss a dose?
- How long will I need to take the pain medicine?
- Can I take the pain medicine with food?
- Can I take the pain medicine with my other medicines?
- Should I avoid drinking alcohol while taking the pain medicine?
- What are the side effects of the pain medicine?
- What should I do if the medicine makes you sick to my stomach?
- What can I do if the pain medicine is not working?
- What else can I do to help treat my pain?

Talking About Pain

Why does my health care team need to ask about my pain?

This is because pain changes over time or your pain medicine may not be working. Your team should ask about your pain often.

What should I tell my health care team about my pain?

Tell them that you have pain, even if they don't ask. Your team may ask you to describe how bad your pain is on a scale of 0 (zero) to 10, with 10 being the worst pain. They may use other pain scales that use words. They may use scales with colors, faces or pictures for children. Tell them where and when it hurts. Tell them if you can't sleep or do things like getting dressed or climbing stairs because of pain. The more they know about your pain the better they can treat it. The words below can be used to describe your pain.

- Aching
- Bloating
- Burning
- Cramping
- Comes and goes
- Constant
- Cutting
- Dull
- Numbing
- Pressing
- Pressure
- Pulling
- Radiating
- Searing
- Sharp
- Shooting
- Soreness
- Stabbing
- Throbbing
- Tightness

What if my pain gets worse?

Tell your health care team. Tell them how bad your pain is or if you're in pain most of the time. Tell them if your pain medicine is not helping.

Should I include pain medicine on my list of medicines or medication card?

Yes! Even pain medicine that you will take for a short time should be listed with all of your other medicines. List all of your pain medicines, those ordered by your team and those you buy over-the-counter on your own.

Managing Your Pain**How can I treat my pain?**

There are many ways to manage your pain. There are medicines and other ways to treat pain without taking medicine. You and your health care team will find a plan that works for you.

What are some common pain medicines?

Some pain medicines are acetaminophen, aspirin, and opioids. Opioids include morphine, oxycodone, and hydromorphone. Many of these medicines come in pills, liquids, suppositories, and skin patches. Some pain may be treated with medicines that are not usually thought of as pain relievers. For example, antidepressants.

What are the side effects of pain medicines?

It depends on the medicine. Side effects can include constipation, nausea, vomiting, itching, and sleepiness.

Constipation can be a major side effect of opioid pain medicines. It can include hard stools or not having a bowel movement more than every 2-3 days. Talk to your health care team about how to prevent or treat constipation. You should have a bowel movement every day or every other day.

What can I do if I have side effects or a bad reaction?

Call your doctor or nurse as soon as you can. Find out what can be done to treat the side effect. Ask if there is another pain medicine that may work better for you.

What if I'm afraid to take a pain medicine?

You may have had a bad side effect or bad reaction to a pain medicine in the past. Or you may be taking a lot of other medicines. Talk to your team about your fears.

Will I become addicted to pain medicine?

This is a common concern of patients. Addiction is unlikely. This is especially true if the patient has never been addicted. Talk to your team about your fears.

Will my pain medicine stop working if I take it for a long time?

This is called "tolerance." It means that after a while your body gets used to the medicine and you need to make a change to get pain relief. The condition causing your pain could also be getting worse or you may have a new type of pain. You may need more medicine or a different kind of medicine to control your pain. Tell your doctor or nurse about your fears.

Can I crush pills if I can't swallow them?

Check with your health care team or pharmacist. Some medicines can be crushed and some cannot. For example, time-release medicines should not be crushed. Ask your doctor or nurse if the medicine comes in a liquid or can be given another way.

Are there other ways to relieve pain?

That will depend on the cause of your pain and how much pain you have. Sometimes pain can be relieved in other ways.

Other treatments for pain are:

- Acupuncture, which uses small needles to block pain
- Taking your mind off the pain with movies, games and conversation
- Electrical nerve stimulation, which uses small jolts of electricity to block pain
- Physical therapy
- Exercise
- Hypnosis
- Massage
- Relaxation
- Heat or cold

Your health care team may have given you this information as part of your care. If so, please use it and call if you have any questions. If this information was not given to you as part of your care, please check with your doctor. This is not medical advice. This is not to be used for diagnosis or treatment of any medical condition. Because each person's health needs are different, you should talk with your doctor or others on your health care team when using this information. If you have an emergency, please call 911. Copyright © 11/2020. University of Wisconsin Hospital and Clinics Authority. All rights reserved. Produced by the Department of Nursing. HF#4922

Anemia

When your red blood cell count is low, you have anemia. Red blood cells are made in the bone marrow. They carry oxygen throughout the body. When there are fewer red blood cells, the body tissues may not get enough oxygen. Anemia can be measured by a blood test.

Normal Values

- **Men**
 - Hematocrit (Hct): 40-52%
 - Hemoglobin (Hgb): 13.6-17.2
- **Women**
 - Hematocrit (Hct): 34-46%
 - Hemoglobin (Hgb): 11.6-15.6

Causes

Common causes include:

- Low iron levels
- Low levels of folate or vitamin B12
- Cancer
- Medicines, such as chemotherapy
- Radiation
- Blood loss
- Chronic kidney disease
- Sickle cell disease
- Thalassemia

Symptoms

- Fatigue
- Shortness of breath
- Trouble breathing when walking, climbing stairs or talking
- Pale skin
- Ringing in the ears
- Light-headedness
- Pounding or fast heart rate
- Chest pain
- Blood in your stool
- Dark brown or red vomit

Treatment

Treatment depends on the cause of your anemia. Your provider may have you take iron supplements, vitamins, hormones or growth factors. Your provider will also decide if you need a blood transfusion.

How to Manage Your Anemia

- Plan frequent, short rest periods
- Change positions slowly:
 - Lying to sitting
 - Sitting to standing
- Stand awhile before walking
- Dress warmly
- Eat a well-balanced diet and drink lots of fluids (8-10 8oz glasses) unless your provider gives you other instructions
- Talk with your providers and nurses about an exercise plan to deal with fatigue
- Ask for Health Fact #4384, Cancer-Related Fatigue

When to Call

Call if you have any of the listed symptoms.

Who to Call

Call: _____

Hours: _____



Sexuality after Cancer Diagnosis

Adapted with permission from “Taking Time,” an NCI publication

Some couples grow stronger when they face cancer together. They look at their lives in a new way. Problems that once seemed big don't feel that way now. Other couples facing cancer have more trouble.

Your Sex Life May Change

Sometimes people with cancer and their partners or spouses have trouble showing their love for each other. For instance, one man said that his wife wouldn't kiss him any more because she was afraid that she would catch cancer. In truth, people cannot give each other cancer.

People can also have problems with sex because of cancer and its treatment. For instance, you may not like how you look and not want to have sex. If this happens, talk with your spouse or partner.

Your spouse or partner may be afraid to have sex with you. He or she may be afraid of hurting you or having sex when you are not feeling well. Let your partner know if you want to have sex or would rather just hug, kiss, and cuddle.

Sometimes, cancer and its treatment cause other problems with sex.

- Fatigue can make you so tired that you don't want to have sex.
- Surgery can make certain positions painful.
- Some men may have trouble having an erection.
- Some treatments cause women to have vaginal dryness.
- Orgasm is sometimes hard to achieve.

Remember that you are special for who you are, not how you look. Your sense of humor, intellect, sweetness, common sense, special talents, loyalty, and many other qualities make you special. Sex is one of many ways to express love and respect.

Even though it may be awkward, discussing your concerns about your sex life with your health care provider can help. Medicines may help. There may be different ways of providing pleasure to your partner. Some people are helped by talking with other couples about how to stay close while dealing with cancer.



Carbone Cancer Center

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Cancer Support Services

Counseling and Support

Having cancer may be emotionally and spiritually trying. We offer services to help you cope with cancer and cancer treatment.

During your care, you and your family may find one or more of these services helpful. Social workers, cancer psychologists, and spiritual care staff are available for counseling and emotional support. Also, each offers unique services.

Social Workers provide many resources. They can assist you with:

- Advance medical directives
- Community resources
- Financial concerns such as insurance, disability, and medical assistance
- Transportation and lodging
- Short and long-term care placements
- Hospice and Home Health Care

Cancer Psychologists help with coping and stress management skills.

- Treatment for depression and anxiety
- Relaxation and mindfulness training
- Individual, family, and group therapy

The Spiritual Care Services staff recognizes that care of the spirit is an important part of health and wellness.

- Spiritual comfort
- Faith-based support and guidance
- Prayer and worship services
- Communion, anointing, baptism, and confession

Any staff member can help you contact these services.



Palliative Care Service at UWHC Cancer Clinics

Q: What is Palliative Care?

A: Palliative care eases suffering and promotes quality of life for patients and families facing a life-threatening illness or disease.

Q: How can the UW Palliative Care Service help me and my family?

A: The palliative care team works with your doctors and nurses to help meet your special goals of care. This care can help relieve the symptoms of disease or treatment, including pain, nausea, fatigue, shortness of breath, constipation, depression, and anxiety. The team provides emotional and spiritual support, guidance with difficult decisions, and health information.

Q: Who are the UW Palliative Care Team Members?

A: One or more of our team members may help you. Our team members include but are not limited to doctors, advanced practiced providers, nurses, pharmacists, social workers and chaplains. We try our best to help you meet your goals while enjoying your life.

Q: If I use the UW Palliative Care Service, will my regular doctor stop seeing me?

A: No. The Palliative Care Team always works with your current doctors and nurses to make sure your treatment goals are being met.

Q: How is Palliative Care different from Hospice?

A: Palliative care begins early in the course of a disease. Our focus is on the impact of the diagnosis and treatment. The UW Palliative Care Team is available to those who receive cancer care in the clinic or hospital. Hospice provides care to those living with a terminal illness. Hospice care is given in the home, nursing home, or in-patient hospice unit. Our Palliative Care Team works closely with Hospice and provides information and referrals.

Q: How do I get help from the UW Palliative Care Service?

A: If you want to see a palliative care provider in the clinic, call **608-265-1700** and request to schedule an appointment. If you are in the hospital you can request a palliative care consult by letting your provider or nurse know.



Honoring a Patient's Advance Directives at UW Health

What is advance care planning?

We'd like you to think about your healthcare wishes in advance. Advance care planning helps you think about and name what is vital to you. You, your loved ones and your care team will have a better sense of your healthcare wishes. Advance care planning will help you prepare your advance directives.

What are advance directives?

These are legal forms that allow adult patients to state their healthcare wishes. These papers let others know about your wishes. The papers can help guide your medical care in the event you cannot make your own decisions in the future. There are two kinds of these forms – the Power of Attorney for Healthcare (POA) and the living will.

The POA allows you to name the person(s) you want to make healthcare decisions for you. This is helpful in case you are not able to state your wishes, whether short-term or at the end of life.

The living will (statement to doctors) allows you to state your care wishes, if you have a terminal illness or you are in a vegetative state (permanent coma). Though the Living Will is a sound statement of your wishes, it should not be used alone.

If you wish to complete these forms while in the hospital, please ask your nurse or social worker for help.

Can advance directives be changed?

Your healthcare wishes may change with life events. It is important to reflect on what's vital to you and make updates as your life changes. We can help you complete a new form if you want to make changes.

Who makes medical decisions when a patient can no longer do so?

Patients who have a POA for healthcare will have a healthcare agent. Most often, this is a family member or close friend. When doctors rule patients can no longer make their own medical choices, the healthcare agents will be asked to do so.

What if I don't have an advance directive?

In this case, doctors may turn to adult family members to make choices. Being a family member does not make someone a healthcare agent. Your best legal option is to complete an advance directive to name healthcare agents who act as your voice. Sometimes family members don't agree about what should happen. When this occurs, a guardian may need to be chosen by a judge. This takes both time and money.

What are UW Health's policies on end-of-life matters?

UW Health honors patients' advance directives to the extent that's legal.

Adult patients who can make their own decisions have a right to refuse or stop all forms of treatment. This includes treatment that will prolong life, such as dialysis, breathing machines (ventilators), feeding tubes, and CPR.

At UW Health we do all we can to promote health. If your heart stops beating or you stop breathing, we will attempt CPR unless you and your doctor have chosen not to. If you make that choice, your doctor will write a Do Not Resuscitate Order (DNR). If you do not want CPR, please be sure to talk with the doctor caring for you to request that an order be written each time you are in the hospital.

If you have a DNR order and are planning to have surgery, please talk with your doctor about the status of your DNR Order.

Some patients may ask their doctors to write an Out of Hospital DNR Order. Patients who have this type of DNR Order wear a special wristband when they are not in the hospital. The wristband lets emergency staff know of the patient's DNR wishes. State law says these orders are valid only in Wisconsin.

If a patient has an emergency in one of our clinics, the patient will likely be taken to our Emergency Room. Here, patients can receive or refuse treatment to prolong life and will receive comfort. All patients wearing an Out of Hospital DNR wristband will receive comfort measures only during transport.

The Ethics Committee can help patients, families, and members of the health care team talk about ethical issues that may arise. To talk about these issues, contact the Ethics doctor on-call through the paging system.

Questions?

Please talk with your social worker or UW Health Patient Resources at **(608) 821-4819** or **(800) 552-4255**. You can find out more online at uwhealth.org/ACP.

Your health care team may have given you this information as part of your care. If so, please use it and call if you have any questions. If this information was not given to you as part of your care, please check with your doctor. This is not medical advice. This is not to be used for diagnosis or treatment of any medical condition. Because each person's health needs are different, you should talk with your doctor or others on your health care team when using this information. If you have an emergency, please call 911. Copyright © 1/2019. University of Wisconsin Hospitals and Clinics Authority. All rights reserved. Produced by the Department of Nursing. HF#6162



Glossary of Terms – Hematologic Cancers

Adjuvant therapy – treatment given after the primary treatment to increase the chance of cure (for example giving chemotherapy after surgery)

Anemia – a low number of red blood cells that may contribute to fatigue

Antibodies – proteins produced by white blood cells that help recognize and attack foreign particles such as virus' and bacteria

Advance directive – legal form that allows adult patients to write down their health care wishes; A Living Will and a Power of Attorney for Health Care are both examples of advance directives.

Advance Practice Provider (APP) – work as part of your health care team and have advanced training and education in their field. They can include: Nurse Practitioners (NP), Physician Assistants (PA), Clinical Nurse Specialists (CNS) , Certified Nurse Midwives (CNM) and Certified Registered Nurse Anesthetists (CRNA)

Benign – not cancer, not malignant

Biopsy – a sample of tissues, cells or fluids removed from the body for examination under a microscope

Bone marrow biopsy – a test to look at the cells in the bone marrow; a large needle is placed into the bone to obtain the biopsy

Central catheter – a tube placed in a large vein used to draw blood or give intravenous fluids and chemotherapy

Chemotherapy – the treatment of cancer with medications

Clinical trial – tests new treatments, procedures and devices; may also be called a research study or protocol

Consolidation therapy – treatment with chemotherapy after induction therapy; the goal is to kill any remaining cancer cells

CT scan – computed tomography scan, also known as CAT scan; an x-ray that takes detailed pictures of the body

Growth factor – medication given to increase the number of blood cells

Hematology – the study of blood

Hematopoiesis – the process of blood cell maturation in the bone marrow

Intrathecal – the space around the spinal cord that contains cerebral spinal fluid; chemotherapy may be administered using a needle inserted through the back into this space, or fluid may be collected through a needle to look for cancerous cells

Immunotherapy – treatment using medications to help the body's immune system kill cancer cells

Induction therapy – the first treatment with chemotherapy; the goal is to establish a remission (little to no evidence of cancer cells)

Intravenous (IV) catheter – a tube placed into a vein to draw blood, or administer intravenous medications

Leukemia – a cancer of the blood resulting from the over production of abnormal cells in the bone marrow

acute lymphocytic leukemia	}	Fast moving forms of leukemia identified by the specific type of cell that is cancerous.
acute myelogenous leukemia		
chronic lymphocytic leukemia	}	Slow moving forms of leukemia identified by the specific type of cell that is cancerous.
chronic myelogenous leukemia		
hairy cell leukemia		An uncommon type of chronic lymphocytic leukemia; viewed under a microscope, the cancer cells look like they have little hairs sticking out.

Living Will – a written statement of your care wishes if you have a terminal illness. For most people, a Power of Attorney for Health Care is more flexible than a Living Will.

Lymph node – Lymph is a thin fluid found in the body. Lymph nodes are small, bean-shaped structures that filter lymph and store white blood cells that help to fight infections. Lymph nodes can also collect cancer cells that travel through the lymph to other parts of the body.

Lymphoma – cancer of the lymphatic system further separated into two groups: **Hodgkin's lymphoma** (a single disease) and **non-Hodgkin's lymphoma** (a group of related cancers)

Maintenance therapy – treatment with chemotherapy after consolidation therapy; the goal is to prevent cancer cells from growing back

Malignant – containing cancer (cancerous)

Mass – a lump or bump of abnormal cells; may also be called a nodule or tumor

Medical oncologist – a doctor who treats cancer with chemotherapy

Myeloproliferative disorder – a group of disorders distinguished by the over production of blood cells in the bone marrow

Myelodysplastic syndrome – a group of cancers of the blood originating from an immature cell in the bone marrow; usually causes an under-production of one or more types of blood cells

Metastasis – the spread of cancer from its primary site (starting point) to other parts of the body

local metastasis – spread to nearby areas

regional metastasis – spread of cancer to lymph nodes

distant metastasis – spread of cancer to distant organs

Monoclonal antibody – a protein, given as an IV infusion that targets and kills specific cancer cells

Multiple myeloma – a cancer of the plasma cells in the bone marrow; plasma cells make antibodies

Neoadjuvant therapy – chemotherapy and/or radiation treatments given before surgery to shrink the tumor; This makes it easier to remove or allows for a less extensive surgery

Neutropenia – a low number of white blood cells that is associated with an increased risk of infection.

Nodule – a lump of abnormal cells; may be used in place of the words tumor or mass.

Oncology – the treatment of cancer

Opioid analgesics – narcotic pain medicines

Pancytopenia – a low number of all blood cells: red blood cells, white blood cells, and platelets.

PET scan – positive emission tomography scan; a whole body scan that detects the presence of cancer cells and records metabolic activity

Pheresis – a process to remove cells from the blood; also called apheresis

Power of Attorney for Health Care – a written statement that allows you to name a person to make health care decisions for you if you become unable to do so

Primary cancer – the site where the cancer started

Prophylactic therapy – chemotherapy given to kill small amounts of undetected cancer cells; the goal is to prevent cancer from growing

Protocol – the plan for a clinical trial (research study)

Radiation oncologist – a doctor who treats cancer with radiation

Radiosensitizer – chemotherapy used with radiation therapy to make the radiation treatments more effective

Radiation therapy/radiotherapy – the treatment of cancer with high energy rays

Remission – no evidence of cancer

Research study – a clinical trial or protocol that tests new treatments, procedures or devices

Splenectomy – removal of the spleen, an organ that helps filter out and destroy dead and damaged cells

Staging – description of the cancer based on its size, cell type, the aggressiveness of the tumor, and the extent it has spread in the body

Standard of care – the current, best, medically proven treatment

Study coordinator – the person responsible for coordinating tests and treatments, and collecting data if you are on a clinical trial

Thrombocytopenia – a low number of platelets that may cause an increased risk for bleeding

Tumor – an abnormal group of cells which may be benign or malignant