

Cancer Care Journey

Patient Book

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Accreditation and Accolades

MercyOne Waterloo Cancer Center is accredited by the American College of Surgeons Commission on Cancer. Earning accreditation demonstrates MercyOne's commitment to high-quality patient-centered care and access to a full scope of cancer care services required to diagnose, treat, rehabilitate and support. This commitment to quality care at the local level is based on national standards. By demonstrating adherence to performance measures, our cancer program has been accredited since 1995.

Services offered

- Medical Oncology/Hematology
- Radiation Oncology
- Cancer Rehabilitation and Wellness
- Coordinated Patient and Family Education
- Genetic Testing and Counseling
- Counseling and Spiritual Care
- Social Services Support
- Nutritional Guidance and Education
- Transportation Assistance
- Breast Care Navigation
- Certified Oncology Nurses and Care Team
- Lab Services
- Clinical Trials

Our Promise to You!

A cancer diagnosis comes with uncertainty and fear, so we are here to help you navigate your journey every step of the way. Our care team members work closely with medical professionals in surrounding clinics and hospitals to provide collaborative care so you can receive treatment close to home.

Radiation oncology

MercyOne's radiation oncologists are cancer specialists with expertise in the administration of radiation therapy as it is used in the management of cancer.

If radiation therapy is recommended as part of your cancer treatment plan, you will be scheduled for a consultation with one of our radiation oncologists. During this visit, the radiation oncologist will review your medical history. This will include any cancer related surgeries and any other tests that have been done, such as computed tomography (CT) scans, positron emission tomography (PET) scans, and lab tests. The radiation oncologist will use your medical history and national guidelines to determine if radiation therapy is an appropriate treatment method for your cancer. You will receive education on your treatment options, potential benefits and risks of treatment.

Radiation therapy can be given in a number of different ways, most of which are available at MercyOne Waterloo Cancer Center.

Radiation oncology nurse practitioner

The radiation oncology nurse practitioner at MercyOne Waterloo Cancer Center works closely with the radiation oncologist to provide an in-depth history during your initial radiation oncology consultation. Her role includes answering questions prior to your radiation oncologist visit, providing ongoing education, and coordinating specialized visits such as survivorship care plans for patients who have completed treatment.

Radiation

MercyOne Waterloo Cancer Center is the only cancer treatment center in the area to offer radiation therapy treatment services. Radiation treatments are administered through state-of-the-art equipment. The following treatment options are the most advanced and most precise forms of radiation therapy currently available:

- Image-Guided Radiotherapy (IGRT)
- Electronic Brachytherapy (eBx™)
- Other therapies, including Radiopharmaceutical Therapy

The MercyOne Waterloo Cancer Center houses two modern linear accelerators with multiple, high-energy X-ray and electron radiation beams, and digital image guidance capabilities, including Cone Beam CT. The new generation simulation and treatment planning system incorporates CT with the fusion of other imagery modalities such as PET/CT and MRI to develop precise, individualized patient treatment plans. Using these specialized plans in combination with advanced treatment techniques, the treatments are focused precisely on your tumor site and avoid healthy tissue.

Medical oncology

MercyOne's medical oncologists are highly skilled practitioners who specialize in both hematology and oncology. They remain up to date on new and breakthrough therapies. Typically, a patient's journey starts with an in-depth consultation with a medical oncologist where an individualized treatment plan is developed.

Treatment

Our medical oncologists utilize the National Comprehensive Cancer Network (NCCN) guidelines and your medical history to determine the most appropriate choice of treatment. The NCCN is an alliance of leading cancer centers who develop practice guidelines that are recognized as the standard of care for oncology. The guidelines are the most comprehensive and most frequently updated clinical practice guidelines available in any area of medicine.

MercyOne medical oncologists participate in cancer case conference, which is held weekly, and provides a multidisciplinary approach to discuss potential treatment options.

In addition to standard intravenous chemotherapy, our medical oncologists also utilize hormonal therapy, biotherapy agents, immunotherapy, and oral chemotherapy as treatment options when appropriate.

Medical oncology nurse practitioner

The medical oncology nurse practitioner at the MercyOne Waterloo Cancer Center work closely with the medical oncologists. Their role includes meeting with you before the provider to obtain a detailed history and physical assessment, assist with symptom management, provide education and see patients in follow-up office visits after completion of their treatment.

Chemotherapy

Chemotherapy is a cancer treatment that uses drugs to kill cancer cells. In contrast to surgery and radiation therapy which are local therapies, chemotherapy is systemic – meaning it works throughout cells in the entire body. It works by stopping or slowing the growth of cancer cells that are growing and dividing quickly. Chemotherapy is used to cure the cancer through eradication, lessen the chance that it will return, or to stop/slow its growth. Chemotherapy effects normal cells too, which can lead to various side effects. Chemotherapy treatment is offered for a variety of malignant and hematological cancers.

SUPPORTIVE CARE SERVICES

MercyOne Waterloo Cancer Center is comprised of a multidisciplinary medical team who use the most current and comprehensive methods of treatment available to care for individuals living with cancer. In addition to providing state-of-the-art medical treatment, we have several supportive care services available to you.

Oncology social worker

As a strong advocate for cancer patients, our social worker is committed to help you and your family deal with overwhelming emotions and difficult decisions. An oncology social worker can help you:

- Cope with diagnosis and treatment
- Reduce stress and anxiety
- Find support groups
- Access information regarding transportation, home care, and prescription drug coverage
- Apply for programs offering assistance
- Assistance with financial applications
- Understand social security benefits and insurance coverage
- Learn about the hospice programs available in the community

Dietitian

A registered dietitian is an integral member of your care team. The dietitian is available to work with patients who are losing weight or struggling with side effects of chemotherapy and/or radiation. Nutritional support is an important part of the cancer journey. A MercyOne dietitian is available to answer questions, manage nutritious diet plans, and counsel patients.

Cancer rehabilitation

Cancer affects every aspect of your life – physically, mentally and emotionally. That’s why we offer a cancer rehabilitation and wellness program customized for each patient based on their individual needs. You may encounter challenges that may require physical, occupational, speech and psychological therapies.

Some challenges may include:

- Chronic and acute pain
- Impaired mobility
- Deconditioning
- Decreased ability to perform activities of daily living
- Lymphedema
- Energy management and conservation techniques
- Safety and cognitive concerns
- Nutritional advice
- Bladder and bowel dysfunction
- Dysphagia
- Psychosocial difficulties
- Vocational training needs
- Post amputation care
- Prosthetics and orthotics fitting

We offer outpatient services for treatment and preventative care options for patients diagnosed with lymphedema, edema, or venous insufficiency. Lymphedema involves the swelling of a body part (arms, legs, trunk, or face) due to trauma of the lymphatic system. The trauma can include cancer (with lymph node removal), radiation, or any kind of surgery or condition in which the lymphatic vessels and/or lymph nodes have been compromised.

The length of treatment for each patient is dependent on the severity of the lymphedema/edema. Follow-up treatment and assessment is incorporated into the care plan as needed. Throughout the treatment process, patients and their family members, friends, and caregivers will learn to take an active, committed role in managing lymphedema on a long-term basis.

Cancer rehabilitation services require a providers referral and are covered by all major insurances and Medicare.

Cancer exercise program

SURVIVE AND THRIVE

Live your life, not your cancer! Survive and Thrive Cancer Exercise Program's goal is to improve quality of life during and after cancer treatment through individualized exercise programming.

Benefits of exercise during and after cancer treatment include:

- Decreased reoccurrence of cancer
- Improved mobility
- Improved balance
- Increased strength and endurance
- Reduced fatigue
- Decreased nausea
- Improved self-esteem and self confidence
- Lowered risk of heart disease and diabetes
- Reduced depression
- Increased circulation for healing
- Decreased pain
- Supported community network

All cancer exercise services performed at the MercyOne Wellness Center are free of charge up to six months after a cancer diagnosis and do not require a physician referral. The Survive and Thrive Exercise Program is facilitated by a certified cancer exercise specialist who can help individuals through the physical challenges of cancer treatment and recovery. The program is suited for recently diagnosed patients to help increase fitness, battle fatigue, and decrease side effects related to treatment as well as survivors living with cancer as a chronic disease that want help to manage symptoms; and individuals who are cured or in remission who need to boost their immune system and regain strength.

Palliative care

Maintaining or obtaining your best quality of life is always our goal and palliative care providers are available to help you achieve this goal. These providers are specially trained to help you manage any side effects affecting your quality of life. Your radiation or medical oncologist may refer you to palliative care to help improve your quality of life. Many often think that palliative care is only for patients at the end of life, but that is a common misconception. Palliative care can be used in all disease stages to help you have the best quality of life possible. Please speak with your oncologist to learn more about palliative care programs that are available in your community.

Clinical trials

At MercyOne, we recognize the importance of ongoing research in the fight against cancer. We proudly participate in a wide variety of national and regional research studies in order to offer you the benefits of the most up-to-date treatments. The decision to participate in a clinical trial is always up to you. You can be assured that we will provide high-quality treatment and exceptional, personalized care whether a clinical trial is chosen or not. Cooperative treatment and support services are also available for patients enrolled in studies at other tertiary centers.

Cancer risk assessment and genetic testing

Your MercyOne provider may recommend testing given the variety of genes linked to hereditary cancers.

A multigene cancer panel may be the easiest way to identify a potential genetic risk. Approximately five to ten percent of cancers have been linked to an inherited gene.

The cost of testing is typically covered by health insurance if certain criteria are met. MercyOne's genetic counselor helps coordinate payment and insurance coverage for testing.

WHO SHOULD CONSIDER A GENETIC RISK ASSESSMENT?

Personal or family history of:

- Breast cancer diagnosed before age 50
- Ovarian cancer at any age
- Two breast cancers in the same person or same side of the family
- Male breast cancer at any age
- Triple negative breast cancer at any age
- Ashkenazi Jewish ancestry and a personal or family history of and hereditary breast and ovarian cancer (HBOC) associated cancer
- Three or more HBOC-associated cancers at any age (breast, ovarian, prostate, pancreatic)
- A previously identified HBOC syndrome mutation in your family
- Metastatic prostate cancer
- Metastatic breast cancer (HER2-negative)
- Pancreatic cancer
- Colorectal and endometrial cancers at any age with a certain mutation (MMR)
- Colorectal cancer before age 50
- Endometrial cancer before age 50
- Two or more cancers associated with Lynch Syndrome - endometrial, ovary, stomach, small intestine, hepatobiliary tract, upper urinary tract, brain and skin

If you choose to proceed with genetic counseling, an appropriate referral is made to MercyOne's certified genetic counselor. You will receive a packet with information regarding genetic counseling and testing options.

Learning your risk before a cancer has the chance to develop allows for preventative action to be taken. This may include increased screening which can help detect cancer in it's early stages - making it easier to treat.

Wigs and head coverings

Chemotherapy and certain targeted radiation therapy side effects can include hair loss for many cancer patients. For a list of local hair salons that provide wigs and services please ask your MercyOne care team.

Look Good...Feel Better

Look Good...Feel Better is a national program that is free to cancer patients. It is designed to help women cope with skin, hair, and nail changes caused by cancer therapies. A certified cosmetologist conducts the sessions. The Look Good...Feel Better program is offered to MercyOne patients four times a year at the MercyOne Waterloo Cancer Center.

Breast care navigator

MercyOne Breast Center has a breast care navigator who works with you and your family to help guide you through this journey. MercyOne's breast care navigator will attend your first provider visit and will assist with coordinating further testing and/or appointments related to your treatment. The breast care navigator will work closely with you and your care team to help answer questions you might have about your treatment plan. Often your navigator will connect you with other services to assist in resolving your barriers.

Some of the services the navigator can assist you with include:

- Provides support by coordinating appointments
- Allows you access to services offered throughout the health system
- Provides educational resources for breast health, breast cancer and breast care
- Connects you and your family to local resources and support services
- Promotes communication between you and your health care providers
- Enhances quality of life

Transportation assistance: Care-A-Van

For those who need assistance getting to and from their cancer treatment, MercyOne offers a free transportation service to most of our patients. We want to help make your appointment convenient when driving yourself, or finding a ride is not possible. This service also helps relieve transportation expenses.

This service is available to any patient living in the metro area needing transportation to and from the MercyOne Waterloo Cancer Center.

Support groups

Support groups are available for those who want to share their cancer journey while meeting others who may be in different stages of their cancer journeys. For more information about any of these support groups, please contact MercyOne's social worker at 319-272-2816.

- **Care and Share** is a support group for patients and their families/caregivers dealing with any type of cancer. This group meets the first Tuesday of each month at 1:30 p.m. at the MercyOne Waterloo Cancer Center. The group is led by MercyOne's social worker.
- **Young Cancer Survivors.** Meets the third Tuesday of January, April, June and September. Unitarian Universalist Church, 3912 Cedar Heights Drive, Cedar Falls. Call Gabbi Dewitt at 319-292-2225 to learn more.

Spiritual care

What is it that gives you hope and courage as you deal with your diagnosis and treatment? How can you nurture your spirit along with caring for your body? Spiritual care is a valuable part of the cancer journey. You may already have a strong spiritual support system in family, friends, or religion/faith community.

A MercyOne chaplain is available to help you if you want to address spiritual concerns related to your health and/or develop habits of spiritual self-care. To arrange a meeting with a chaplain, call 319-272-7377.

CANCER CONFERENCE

MercyOne Waterloo Cancer Center provides a weekly cancer case conference for physicians and ancillary care team members. This conference provides a major avenue to develop effective multidisciplinary communication and approaches to cancer care at MercyOne Waterloo Medical Center and MercyOne Waterloo Cancer Center. The cancer case conference honors the best medical traditions for sharing meaningful information to colleagues about challenging cases, and for stimulating discussion on best practice management for an individual's specific care needs.

CANCER SURVIVORSHIP

Cancer survivors have some unique needs as they transition to a "new normal" after diagnosis and treatment. The Commission on Cancer created guidelines encouraging the creation of comprehensive care summaries for this population. These comprehensive care summaries, or survivorship care plans, clearly set out a follow-up plan for further care while giving a summary of all treatment received. They also explain possible short-term and long-term effects from treatment, signs and symptoms of recurrence, risk of secondary malignancy, promotion of wellness, as well as resources throughout the community.

CANCER REGISTRY

The cancer registry is committed to collecting and providing information to enhance and improve cancer patient care at MercyOne Waterloo Cancer Center. The registry maintains a complete database for all cancers diagnosed and/or treated at MercyOne. Data collection is a shared service with the State Health Registry of Iowa (SHRI) and MercyOne Waterloo Medical Center. The SHRI assists with data collection, provides quality management, continuing education, and follow-up care of cancer patients.

CANCER OVERVIEW

A cancer diagnosis comes as a shock to most patients and has the potential to change your life. It is a time of uncertainty for patients and their families. We are committed to helping you through this incredibly difficult chapter in your life. You may be overwhelmed by the amount of information you are receiving, and we hope that this information gives you the so you may have a better understanding about what is happening.

Cancer. It is not just one disease, it is actually the name given to a collection of related diseases. All cancers have one thing in common – cells that are dividing without stopping and spread into surrounding tissues.

Normal cells grow and divide to form new cells as the body needs them and when they grow old or become damaged, they die and new cells take their place. This process is altered when you have cancer, those old or damaged cells survive when they should die. The extra cells often accumulate to form growths called tumors.

Tumors can be benign (not cancer–do not spread or invade other tissues) or malignant (cancerous–can spread or invade other tissues). When cancer spreads it is called metastasis. For example, when lung cancer spreads to the bones, it is still referred to as metastatic lung cancer because that is the site of origin that the cancer spread from. It is important to know where the cancer originated because knowing the type of cancer it is helps determine the treatment.

Not all types of cancers are tumors, some can originate in the blood or other tissue.

The National Cancer Institute (NCI) breaks cancer down into the following main categories of cancer:

- **Carcinoma:** begins in the skin or tissues that line or cover internal organs
- **Sarcoma:** begins in bone, cartilage, fat, muscle, blood vessels or other connective or supportive tissue
- **Leukemia:** starts in blood-forming tissue, such as the bone marrow and causes abnormal blood cells to be produced
- **Lymphoma and myeloma:** begin in the cells of the immune system
- **Central nervous system cancers:** begin in the tissues of the brain and spinal cord

What causes cancer

It seems like every other day you can encounter a headline about something that causes cancer. These stories can induce a lot of fear and uncertainty. It is hard to know if the information out there has any truth to it.

Social media posts, blogs and chain emails are often examples of inaccurate data that has been misconstrued. When looking at these articles, it is important to think about the validity of the data.

What do we know about what causes cancer?

We know that determining whether something truly raises cancer risk is not easy. Often the certainty of risk cannot be completely determined and thus agents are sometimes classified as probably carcinogenic (cancer-causing).

There is not a comprehensive list of the agents that can cause cancer, but there are resources that can give you some concrete information.

Reliable resources that have lists available include:

- The International Agency for Research on Cancer (IARC)
- National Toxicology Program (NTP)
- Environmental Protection Agency (EPA)
- CDC's National Institute for Occupational Safety and Health (NIOSH)

Some of the more common cancer causing agents that are proven carcinogenic are:

- tobacco (smoking, second hand smoke and smokeless)
- tanning beds
- radon
- asbestos
- and many others

Diagnosis

Sometimes diagnosing cancer can be relatively easy and other times it can be a very complex process.

Typically, when cancer is suspected, imaging studies are ordered such as CT scans or an MRI. This can show the presence, location and size of an abnormal mass, often it also pinpoints an area where a biopsy can be performed. A biopsy is key in determining the type of cancer it is.

Sometimes further testing will need to be done to determine the extent of your disease such as a bone marrow biopsy or positron emission test (PET). Results from these tests are necessary before any treatment can begin.

Goals of cancer treatment

The extent of disease revealed in the diagnosis phase often determines the goal of cancer treatment. There are three main goals of cancer treatment:

- Cure
- Control
- Palliation

When possible, cancer treatments are used with the intent to cure or curative intent. This would mean that the cancer is destroyed – it goes away and does not come back. Often this would include chemotherapy or chemotherapy combined with other modalities such as surgery or radiation therapy.

When a cure is not possible, the goal is often to get the cancer under control and keep it there. This can help the person with cancer feel better and live longer. The cancer typically does not completely go away but becomes more like a chronic disease such as heart disease or diabetes. Some can live with cancer as a chronic condition for many years and the number of cases such as these are on the rise.

The last goal of treatment is palliation. Improve the symptoms caused by the cancer and increase the quality of life of the patient and help them feel better. People often think that treatment side effects decrease a patient's quality of life. There are many cases where giving treatment can increase quality of life and make someone feel better.

Types of cancer treatment

There are many types of cancer treatment. The types of treatment you receive will depend on the type of cancer you have and how advanced it is. Some people with cancer may have only one modality of treatment but often more than one modality of care is utilized.

The following are examples of the types of treatment utilized and are discussed below: surgery, radiation therapy, chemotherapy, biotherapy and hormone therapy.

Our providers utilize the guiding principles of the National Comprehensive Cancer Network (NCCN) to assist them in making treatment decisions. The NCCN is a not-for-profit alliance of 27 leading cancer centers that work to create clinical guidelines for the care of cancer patients. There are patient resources available on NCCN's website – [NCCN.org](https://www.nccn.org) – to help patients in understanding their diagnosis as well as treatment options available to them.

SURGERY

Many people with cancer are treated with surgery. Surgery typically works best for solid tumors contained in one area. It can be used to remove all or a portion of the primary tumor. Treatment with surgery can sometimes be the only treatment needed, but can also be done before or after another treatment.

Occasionally it is used in a palliative setting to lessen the symptoms the tumor is causing on a patient's quality of life.

RADIATION THERAPY

Radiation therapy is a cancer treatment using high doses of radiation to kill cancer cells and shrink tumors. When given in high doses, radiation kills or slows their growth by damaging their DNA.

The DNA of the cancer cells is damaged causing cell death. It can take days or weeks of radiation to damage the DNA enough for the cancer cells to die. The effects of the radiation continue even after the radiation therapy is completed.

Radiation is a very targeted therapy that treats a specific area and it is more effective for some cancers than others. There are many different types of radiation available. If radiation therapy is indicated, the medical oncologist or other provider will make a referral to the radiation oncologist. MercyOne's radiation oncologist will discuss the different radiation therapy options available to you, most of which are available at the MercyOne Waterloo Cancer Center.

CHEMOTHERAPY

Chemotherapy is a cancer treatment using drugs to kill cancer cells. In contrast to surgery and radiation therapy, which are local therapies, chemotherapy is systemic – meaning it works throughout cells in the entire body. It works by stopping or slowing the growth of cancer cells, cells that are growing and dividing quickly.

Chemotherapy is used to cure the cancer through eradication, lessen the chance that it will return, or stop or slow its growth. Chemotherapy affects normal cells too, which can lead to various side effects.

BIOOTHERAPY

Biological therapy involves the use of living organisms, substances derived from living organisms, or a laboratory-produced version of such substances to treat disease. Some biological therapies for cancer stimulate the body's immune system to act against cancer cells. These types of biological therapy, which are sometimes referred to collectively as "immunotherapy," do not target cancer cells directly. Other biological therapies, such as antibodies, do target cancer cells directly.

Biological therapies that interfere with specific molecules involved in tumor growth and progression are also referred to as targeted therapies. Some types of immunotherapy only target certain cells of the immune system while others affect the immune system in a general way. Some examples of immunotherapy include cytokines, vaccines and some monoclonal antibodies.

This is one of fastest growing areas of cancer care. Even though it is systemic (works throughout the whole body), it often takes a more targeted approach to the individual's cancer. These therapies do not work with every cancer. Special lab tests are often requested by the medical oncologist to determine whether a patient is a candidate for that particular treatment.

These drugs often stimulate an immune response and the side effects are much different from traditional chemotherapy. Biotherapy/immunotherapy agents are more likely to cause a hypersensitivity reaction at the time of infusion, which can often be managed in the infusion room with other medications and prolonging the infusion. Patients often have flu-like symptoms that can include fever, chills, weakness, dizziness, occasional nausea and vomiting, muscle/joint pain, fatigue, headache, fluid retention, diarrhea and others. As with all therapies, side effects can be managed very effectively with collaboration between you and your health care team.

HORMONE THERAPY

Another therapy used to fight cancer is hormone therapy. It often is used in combination with other treatment modalities. It can be used to lessen the chance that cancer will return, stop or slow its growth as well as to ease cancer symptoms.

Hormone therapy is divided into two groups: those that block the body's ability to produce hormones and those that interfere with how hormones behave within the body. Side effects are dependent on the type of hormone involved and how your body responds. It is important to be candid with your providers to help you manage any side effects.

Treatment modality choices are incredibly complex and it is important to be comfortable with your health care provider as well as educate yourself so you know you are getting the best care possible.

COMPLEMENTARY AND ALTERNATIVE THERAPY

Complementary and alternative medicine (CAM) is the general term given to medical products and practices given outside of standard medical care. At times, these two terms are used interchangeably but there is a key difference - complementary medicine is treatment often used alongside standard medical treatments whereas alternative medicine is treatment used INSTEAD of standard treatment.

Some CAM therapies have undergone careful evaluation and have been proven to be safe and effective, while others have been found ineffective and possibly harmful. Just because something is considered natural, does not mean it is necessarily safe. Some supplements can be harmful and are not regulated by the federal government. It is important to discuss CAM therapies with your provider to help you determine if they are right for you.

Some examples of effective complementary therapies are deep breathing, Yoga, meditation, massage, progressive relaxation and guided imagery. For more information visit the National Center for Complementary and Integrative Health's website at NCCIH.NIH.gov.

SIDE EFFECTS

The following section is information on some of the most common side effects encountered by patients undergoing both chemotherapy and immunotherapy as well as some suggested tips to help you manage these side effects. It is not meant to take the place of medical advice and if you have any questions or concerns about your medication or side effects please contact our office. At the end of this section there will be a list of resources used to compile this information.

A guide to blood counts

Cancer therapy not only destroys cancerous cells, but may affect healthy cells in your body. Blood cells are commonly affected during cancer therapy, and this can lead to problems depending on the function of that blood cell.

White blood cells (WBC): These cells are produced in the bone marrow and are a part of the body's immune system, helping to fight infection. A normal WBC count is 4,000 – 10,500 in adults, which may be shown as 4.0 – 10.5 on your labs.

Neutrophil: A type of WBC. It is the most important WBC in fighting infection, so you are at higher risk of infection when this number is below 1,000 sometimes also referred to as less than 1. A normal count (sometimes called an ANC) 2,180–7,800 or 2.18–7.80. A count below 1,000 (or 1) is called neutropenia. When this count is low, wash your hands frequently, avoid large crowds of people or those who are sick and check your temperature at least twice a day. Notify your health care team if you have a temperature greater than 100.5 degree Fahrenheit, a sore throat, a cold or a sore/wound that does not heal.

Hemoglobin: The part of a red blood cell that is responsible for carrying oxygen to the tissues. Normal levels for an adult female are 11.6–15 and 13.2–16.6 for an adult male. A low hemoglobin can make you feel tired. If you notice any difficulty breathing or pain in your chest, you should notify your health care team. If your count becomes too low or you experience breathing difficulties or chest pressure, you may receive a blood transfusion.

Platelet: A blood cell that is involved in blood clotting. When this count is below 50,000, you are at higher risk of bleeding. The risk of bleeding increases as the count becomes lower. A normal count is 150,000– 370,000 in an adult.

When your platelet count is low:

- You should not use a razor (electric razor is ok)
- Do not participate in any contact sports
- Do not take aspirin or ibuprofen products (these can also increase the risk of bleeding)

Let your doctor or nurse know if you have any bleeding, including nosebleeds or bleeding gums. If your count becomes too low or you have bleeding, you may receive a platelet transfusion.

Low red blood cell count (anemia)

Anemia is a decrease in the number of red blood cells (RBCs). Since most cancer therapies destroy cells that grow at a fast rate, and red blood cells have relatively rapid growth rates, they are often affected. An important part of the RBC is hemoglobin, the protein that carries oxygen throughout your body. Therefore, when your hemoglobin is low, oxygen levels are decreased, and your body must work harder in order to compensate. The result is that your body becomes tired. Normal hemoglobin levels for women are usually in the range of 11.6-15 gm/dL; for men, the normal level is from 13.2-16.6 gm/dL. While receiving cancer therapy, your hemoglobin level may drop to lower than these normal levels, so your hemoglobin level will be checked periodically throughout the course of treatments. Any time that your hemoglobin level drops below 10.0 gm/dL you are considered to be anemic.

The signs and symptoms of anemia include:

- Weakness or fatigue
- Dizziness
- Headache
- Shortness of breath or difficulty breathing
- Palpitations or rapid heart beat
- Pale skin
- Feeling cold, particularly in the hands and feet

What can I do to prevent anemia?

Since red blood cells are destroyed as a side effect of cancer therapy, there is nothing specifically you can do to prevent anemia from occurring. Anemia may cause you to feel weak and tired.

Here are some ways that may help you feel better:

- Save your energy.
- Get plenty of sleep.
- Avoid prolonged or strenuous activity.
- Pace yourself; take rest periods during activities that make you feel tired. Take short naps when needed.
- Prioritize your activities so you will have enough energy for important activities or the activities you enjoy most.
- Ask friends and family to help you prepare meals or do chores when you're tired.
- Avoid injury.
- Change positions slowly, especially when going from lying to standing to prevent dizziness.
- When getting out of bed, sit on the side of the bed for a few minutes before standing.
- Eat foods high in iron, including green leafy vegetables, liver and cooked red meats.
- Drink plenty of fluids.
- Avoid caffeine and big meals late in the day if you're having trouble sleeping at night.
- Take iron supplements only if you have been told to by your provider.

When should I call my doctor?

Call your provider immediately if you have any one or more of the following:

- Dizziness
- Shortness of breath or difficulty breathing
- Excessive weakness or fatigue
- Palpitations or chest pain

How is anemia treated?

Depending on the cause and severity of the anemia, there are several ways anemia can be treated. Your doctor may instruct you to take over-the-counter iron pills on a daily basis or may order blood transfusions. In rare cases your doctor may also choose to order injections of a “growth factor” which can be used to stimulate the growth of red blood cells in certain patients.

By increasing your body's production of red blood cells, this growth factor may decrease your risk of becoming anemic, and may also decrease the number of blood transfusions that may be required during your treatment. Growth factors are administered by injection. You may receive the injections from the oncology nurse. Once your red blood cell count has returned to a normal level, the injections will be stopped.

If necessary, your oncologist may decide to delay further treatments until your red blood cell count has returned to normal levels.

Low platelet count (thrombocytopenia)

Thrombocytopenia is a low level of platelets. Radiation therapy, certain chemotherapy medications and some cancers themselves can damage platelets and lead to thrombocytopenia. Patients receiving a combination of radiation therapy and chemotherapy are at greater risk for thrombocytopenia.

Platelets play an important role in blood clotting, so thrombocytopenia puts you at higher risk of bleeding. Therefore, while you are receiving therapy, use caution to avoid any activities that could result in bleeding. Even the most minor of injuries, such as a small cut or bump, can result in excessive bleeding when your platelets are low.

A normal platelet counts ranges from 150,000 - 440,000 per mm³ of blood. While receiving chemotherapy or radiation therapy, your platelet count may drop. Your platelet count will be checked throughout the course of your treatments. Any time your platelet count drops below 50,000 per mm³ you are at increased risk for bleeding. If your platelet count drops below 10,000 per mm³, you may require a transfusion of platelets.

What can I do to prevent bleeding?

Since platelets are at times destroyed as a side effect of radiation therapy and chemotherapy, there is nothing specifically you can do to prevent thrombocytopenia from occurring. There are several things you can do to reduce your risk of injury when your platelets are low. Taking prompt action at the first signs of a low platelet count is essential as it may help to prevent a bleeding episode.

The signs and symptoms of a low platelet count include:

- Excessive bruising of your skin.
- Tiny, pinpoint red spots on your skin called petechiae.
- Bleeding gums.
- Nosebleeds that will not stop.
- Excessive bleeding from a small cut, or bleeding that won't stop even after pressure has been applied.
- Dark colored urine or blood in your urine.
- Blood from your rectum, blood in your stool or black colored stool.
- Menstrual bleeding that is heavier than usual, lasts longer than usual or occurs between periods.

What can I do to reduce bleeding if I develop thrombocytopenia?

- Keep your mouth clean and moist.
- Brush your teeth gently with a soft bristle toothbrush. If you cannot use a toothbrush, use a sponge toothette to clean your teeth and gums.
- Rinse your mouth after each meal with a baking soda solution (2 tsp. baking soda to 8 oz. water).
- Do not use dental floss.
- Avoid any commercial mouthwashes that contain alcohol. Alcohol can dry out your mouth, which may lead to bleeding.
- Use lip balms to keep your lips moist and to prevent cracking. Avoid using oil based balms like Vaseline or petroleum jelly.
- Take sips of water or juice frequently if your tongue or mouth feel dry.
- Modify feminine hygiene practices.
- Use sanitary napkins rather than tampons during menstruation.
- Avoid vaginal douching.

Take these other general precautions:

- Do not cough forcefully or harshly. If you have a persistent cough, notify your doctor or nurse who may recommend a cough syrup.
- Do not blow your nose too hard.
- Avoid straining too much with bowel movements. If you have a problem with constipation, take a stool softener or laxative to make it easier.
- Do not use rectal thermometers, suppositories or enemas.
- Use an electric razor for shaving.
- Do not have any dental work or cleaning before talking to your oncologist.
- Do not take any medications that affect blood clotting.
- Do not take aspirin or any product that contains aspirin. Check the labels of all drugs you are taking for salicylic acid, the chemical name for aspirin. If you are not sure about a drug or cannot tell by reading the label, check with your oncologist, nurse or a pharmacist.

- Do not take aspirin (salicylic acid) or any product that contains aspirin, non-steroidal, anti-inflammatory medications (NSAIDs) such as Motrin/Advil (ibuprofen), Aleve (naproxen), Celebrex (celecoxib) etc. as these can all increase the risk of bleeding.
- Adjust your lifestyle to minimize the risk of bleeding.
- Avoid strenuous activity and lifting heavy objects.
- Avoid sports and activities that could result in falling and/or injury including but not necessarily limited to bicycling, rollerblading, skating and skiing.
- Drink 8 to 10, 8 oz glasses of non-alcoholic fluid a day to keep your mouth moist, avoid constipation and keep the intestinal lining in good condition.
- Always wear shoes or slippers to protect your feet.
- Do not wear tight-fitting clothing.
- Consult with your doctor or nurse on the safety of sexual activity as it relates to your low platelet count. Talk with your health care providers if you have specific sexual practices you are concerned about. They may say you should not have intercourse, as vaginal or anal penetration (including toys/props) or oral sex can pose a risk of bleeding. Use a water-based lubricant and avoid vigorous thrusting during sexual intercourse. If intercourse is permitted by your health care provider, remember that two forms of birth control are required to prevent pregnancy.

What if I start to bleed?

Even if you have taken special precautions to decrease the chance of injury and bleeding, it is still possible bleeding will occur. If bleeding occurs, apply firm pressure for five minutes to the area. If bleeding does not stop after five minutes, continue to apply pressure until it has stopped completely.

If you have a nosebleed, apply pressure with your fingers below the bridge of your nose until the bleeding stops. Keep your head raised.

When should I call my doctor?

Call your doctor immediately if you have any one or more of the following:

- Bleeding that does not stop after you have applied pressure for 10 to 15 minutes.
- Blood in your urine or your urine appears dark in color.
- Blood from your rectum, blood in your stool or your stool is black.
- A change in your vision.
- A persistent headache, blurred vision or a change in your level of consciousness such as a decreased attention span, excessive sleeping, confusion, and/or difficulty being awakened.

If you have a major injury or start spontaneously bleeding, go immediately to the nearest hospital emergency department. Make sure you inform the doctor that you are receiving cancer therapy and that your platelet count may be low.

How is thrombocytopenia treated?

If your platelet count drops to a low enough level that your oncologist is concerned about significant risk of bleeding, they may order transfusions of platelets. These transfusions are most often done in an outpatient treatment center. Unless other problems exist, patients rarely are admitted to the hospital just to receive platelet transfusions.

If necessary, your oncologist may decide to delay further treatments until your platelet count has returned to normal levels.

NEUTROPENIA/LOW WHITE BLOOD CELL COUNT

What are white blood cells?

White blood cells (WBC) are one part of the immune system in our bodies. The job of this system is to fight infection and protect our bodies from harmful bacteria, viruses and other foreign invaders. There are five types of white blood cells. Each has its own job in the immune system:

- neutrophils (40-80 of the WBCs)
- lymphocytes (20-52%)
- monocytes (40-10%)
- basophils (0.0-2.0%)
- eosinophils (0.0-8.0%)

A WBC count with differential is the blood test that tells the numbers of these cells in the blood.

What are neutrophils and neutropenia?

Neutrophils make up the largest number of WBCs and are made in the bone marrow. They are the “first responders” and quickly go to the site of infection, taking in and killing foreign particles. They can be found in the pus of a wound and play a role in acute inflammation (redness, warmth, swelling and pain). A normal neutrophil count (also called absolute neutrophil count or ANC) is between 2,180 and 7,800. A low neutrophil count is known as neutropenia.

Neutropenia can be caused by a health issue you are born with, or can be a side effect of a medication or radiation therapy. Chemotherapy medications are the most common cause of neutropenia, but other medications can also cause neutropenia.

Mature neutrophils are sometimes called “segs”, named for their segmented nucleus.

Immature neutrophils are called “bands” because their nucleus appears banded. These two counts together make up the absolute neutrophil count, or ANC.

Cancer therapies, such as chemotherapy, biotherapy and radiation therapy can cause neutropenia. This is because these therapies cannot tell the difference between cancer cells and healthy cells. Most chemotherapies work by killing rapidly dividing cells. Cancer cells divide rapidly, but so do blood/bone marrow cells, hair follicles and the cells that line the gastrointestinal tract (mouth, throat, stomach and bowel). Damage to these normal cells lead to the side effects we see with chemotherapy (low blood counts, hair loss, mouth sores and diarrhea). Radiation damages blood cells by affecting the marrow production in the bones in the area of treatment.

Why is neutropenia important?

A low neutrophil count raises the risk of getting an infection. This is because neutrophils are not available. There are levels of neutropenia, but the lower the ANC, the higher the risk of getting an infection.

Grades of neutropenia:

- An ANC between 1000 and 1500 is considered mild neutropenia (causing minimal risk of infection)
- An ANC between 500 and 1000 is considered moderate neutropenia (causing moderate risk of infection)
- An ANC less than 500 is considered severe neutropenia (causing a severe risk of infection)

What is a nadir?

Nadir is a term used by the health care team to describe the point after treatment when your blood counts are at their lowest. This can include white blood cells, red blood cells and/or platelets, depending on the type of treatment you received and your body's response to the treatment. This decrease in blood counts is also called myelosuppression.

With chemotherapy, this often occurs 7-10 days after treatment. Your blood counts will then slowly climb back before the next treatment. If your blood counts have not gotten back to an acceptable level, your health care team will hold off on giving you more therapy. Giving you more therapy with blood counts that are too low could make it very hard for your body to recover.

Why is it important to prevent neutropenia?

Your health care team has determined the chemotherapy and/or radiation dose and schedule to produce the best opportunity for success in your case. Neutropenia can lead to delays in treatment and dose reductions, which can make your chemotherapy less effective. Studies show that for certain types of cancer, chemotherapy produces the best long-term results when patients receive the full dose on time, every time. With good recovery of your white blood cell count, you may have a better chance of sticking to your treatment schedule. Moreover, most health care providers agree that doing so is the first step to success.

How can I help prevent infection?

- Hand washing, hand washing, hand washing! This includes the patient and those around the patient.
- Avoid large crowds where you may come in contact with germs, such as shopping malls, church or public transportation. If need be, go at off peak hours to avoid the crowds.
- Avoid anyone who is sick (even colds), including other people in your household that are sick.
- Avoid children or adults who have recently received vaccines.
- Do not handle animal waste (including cat litter, birdcage waste, fish tank water, chicken coops, etc.)
- If you have a central catheter (PICC, Port, Hickman), use caution to keep it clean and dry. Check the area for redness or tenderness (soreness) daily.
- Follow an oral hygiene regimen (rinsing after meals to clear out bacteria).
- Wear sunscreen (SPF 30 or higher) to prevent sunburn.
- Use only electric razors to avoid cuts, that can become infected.
- Use caution to avoid any cuts or injuries.
- Avoid contact sports, wear gloves for household chores.
- Do not use rectal suppositories.
- Do not have dental work without first talking with your health care team.
- Do not get any vaccines without first talking with your health care team.
- Women should not use tampons while neutropenic as these can pose a risk of infection and toxic shock syndrome. Use sanitary napkins instead.
- Neutropenic patients should not have intercourse, any type of vaginal or anal penetration (including toys/props) or oral sex as these can pose an infection risk. Talk with your health care providers if you have specific sexual practices that you are concerned about.

You may receive a growth factor to stimulate neutrophil production. This is human-made version of a natural hormone that causes the body to produce more neutrophils. It is given by an injection just under the skin.

Even the best hand washers can end up with an infection. An infection in a neutropenic patient is an emergency! If you notice any signs or symptoms of infection, you should call your provider right away - even if it is the middle of the night.

You will likely need to have blood work drawn and other testing to look for any source of infection. It is important to receive antibiotics in a timely fashion since your body is immunocompromised and unable to fight some infections on its own. Signs and symptoms of infection to look for:

- Feeling feverish. If your temperature is 100.5 or higher, call your provider right away.
- Do not take acetaminophen (Tylenol®) or aspirin to reduce the fever without talking to your provider first.
- Shaking chills.
- Cough, sore throat, nasal congestion or shortness of breath.
- Burning with urination or new lower back pain.
- Blood in urine.
- Diarrhea (worsening) or change in the odor of your stool.
- Rash, redness or swelling of the skin.
- Redness, soreness around central line catheter, feeding tube or a wound.
- Soreness or swelling in your mouth or throat, ulcers or white patches in your mouth or a change in the color of your gums.

PRACTICE FOOD SAFETY

While your immune system is not functioning properly, you could have a more difficult time fighting a food-borne illness. There are some steps you can take to make food safety a priority.

- Wash all fresh fruits and vegetables well before consuming.
- Avoid raw or rare-cooked meat and fish. Meat should be cooked to established safe internal temperatures.
- Use only pasteurized eggs, milk, yogurt, cheese, other dairy products, fruit juices and honey.
- Avoid soft mold-ripened and blue-veined cheese including: Brie, Camembert, Roquefort, Stilton, Gorgonzola and Bleu.
- Hot dogs, lunchmeats and deli meats should be reheated to steaming hot or 165 F.
- Abide by sell by or use by dates.
- Avoid buffets, salad bars and self-serve bulk containers.

Follow these four basic steps to food safety:

- Clean - Wash your hands well before preparing any food and keep your work area clean.
- Separate - Do not cross-contaminate. Keep raw meat and poultry apart from cooked foods.
- Cook - Use a food thermometer to be sure meat and poultry are safely cooked.
- Chill - Refrigerate or freeze food promptly.

Patients undergoing bone marrow or stem cell transplant typically have stricter dietary restrictions. Remember, this diet is only temporary while your blood counts are low.

Common side effects of the gastrointestinal tract

MUCOSITIS (MOUTH SORES) AND ORAL CARE TIP SHEET

Mucositis may also be called mouth sores, oral mucositis, or esophagitis. It can range in severity from a red, sore mouth and/or gums to very painful open sores, causing a patient to be unable to eat. Patients receiving radiation therapy to the head and neck area or those receiving certain types of chemotherapy are at risk to develop mucositis.

Other causes of mucositis include infection, dehydration, poor mouth care, oxygen therapy, excessive use of alcohol and/or tobacco, and lack of protein in the diet.

Oral mucositis leads to several problems including pain, nutritional problems related to the inability to eat, and increased risk of infection due to open sores in the oral and throat mucosa (lining). It has a significant effect on the patient's quality of life and can be dose limiting (requiring a reduction in subsequent chemotherapy doses).

Signs and symptoms of mucositis include:

- Red, shiny or swollen mouth and gums.
- Blood in the mouth.
- Sores in the mouth or on the gums or tongue.
- Soreness or pain in the mouth or throat.
- Difficulty swallowing or talking.
- Feeling of dryness, mild burning, or pain when eating food.
- Soft, white-ish patches or pus in the mouth or on the tongue.
- Increased mucus or thicker saliva in the mouth.

Talk to your health care team about your risk for developing mucositis. Patients at risk for mucositis should perform oral/ mouth care to help prevent mucositis and special care to help the mouth and throat heal if it does develop.

Suggestions for an oral care plan:

- Check the entire mouth twice a day using a small flashlight and tongue depressor. If you wear dentures, remove them and look under the plates. Report any changes to your oncologist or nurse.
- Rinse your mouth (swish, lightly gargle and spit) before and after meals and at bedtime with either
 - Salt water (1 tsp of table salt to 1 quart (32 oz.) of water)
 - Salt and soda rinse (1 tsp of salt and 1 tsp of baking soda in 1 quart (32 ounces) of warm water)
- Use a soft-bristle toothbrush after meals and at bedtime. Soaking in hot water can make the brush bristles softer. If the brush causes pain, toothettes (sponge material) may be used, but these are not as effective as a soft or super soft brush.
- Use non-abrasive toothpaste (or mix 1 tsp baking soda in 2 cups water). Avoid toothpastes with whiteners or other additives.
- Keep lips moist with moisturizers (like ChapStick or Blistex). Avoid using Vaseline or petroleum jelly (the oil base can promote infection).
- Avoid products that irritate the mouth and gums:
 - Avoid commercial mouthwashes and those with alcohol.
 - Limit use of dental floss, DO NOT use floss with platelets below 40,000.
 - Do not use lemon or glycerin swabs or toothbrushes without soft bristles.
- Make dietary changes to decrease pain and discomfort, and promote healing of mouth sores.
- Increase your fluid intake. Try to drink 3 quarts of fluid per day, unless your doctor or nurse tells you not to do so.

- Include foods high in protein such as dried beans, poultry, eggs, peanut butter, meat, fish, and dairy products, such as milk, cheese and yogurt (Greek yogurt is higher in protein than others). Nutritional supplement shakes like Ensure®, Boost® can also provide calories and protein.
- Avoid hot, spicy, greasy or fried foods.
- Avoid alcohol.
- Avoid citrus fruits and juices such as oranges, lemons, limes and tomatoes as these may be too acidic. Try apricots, pears or peaches instead.
- Avoid hard or coarse foods such as crusty breads, crackers, raw vegetables, potato chips, tortilla chips and pretzels.
- Avoid carbonated beverages.
- Try soft foods like puddings, jello, soups, etc.
- Cold treats like popsicles and water ice can be soothing to mouth sores.
- Eat whenever you are hungry, even if it is not a mealtime.
- Eat smaller, more frequent meals throughout the day, rather than three large meals. Create a nice environment when eating to stimulate your appetite.
- Do not smoke cigarettes, cigars or pipes. Do not use smokeless tobacco (chewing tobacco, snuff).

If you wear dentures:

- Clean dentures daily.
- Remove at night and whenever possible to expose gums to air.
- Loose fitting dentures can irritate the mouth and gums and should not be worn.
- Do not wear dentures if mouth sores are severe.

When should I call my doctor?

Mouth sores should not be ignored since they can cause a decrease in your food and fluid intake, can be a source of infection, and can cause pain and discomfort. Call your doctor immediately if you have any one or more of the following:

- Redness or shininess in the mouth that lasts for more than 48 hours.
- When you first notice any type of cut or sore in the mouth.
- Bleeding gums.
- Difficulty or pain with eating or swallowing.
- Oral temperature above 100.5 degree Fahrenheit, chills or sweats.
- Weight loss of five pounds or more since the mouth sores began.

How are mouth sores treated?

Mouth sores generally must heal on their own. Continuing to perform good mouth care can help speed the healing process along. If mouth pain is interfering with eating and swallowing, your oncologist may prescribe a mouth rinse, which temporarily numbs the mouth or an oral pain medication. In addition, if weight loss from poor intake of food and fluids is a concern, you may be referred to a dietitian. If necessary, your oncologist may decide to delay further treatments until the mouth sores have healed.

Nausea and vomiting

Nausea is a sick or queasy feeling in your stomach. Vomiting or throwing up often goes along with nausea. Several things can cause nausea. While nausea with cancer therapy was common years ago, there are now many medications available to manage this side effect. If you experience nausea and/or vomiting, talk to your oncology team about medications to manage this side effect. Here are some tips and strategies to help prevent and/or manage nausea and vomiting:

What causes nausea and vomiting?

- Radiation therapy to certain areas of the body, including the brain, abdomen and head and neck can cause nausea.
- Some chemotherapy and biotherapy agents.
- Anxiety, particularly about upcoming treatments or because of negative prior experiences with cancer therapy.
- Constipation and diarrhea can also cause you to feel nauseous.

What can I do to prevent and better manage nausea?

- Drink 6–8 glasses of decaffeinated fluid per day, such as broth, Gatorade®, Jello® (gelatin dessert), fruit juices, water ices, popsicles, soda and ginger ale.
- Eat dry, bland foods, such as crackers, toast, cereals, pretzels and ginger cookies.
- Eat cold foods such as cereals, salads, cold cuts and desserts. The smell of hot foods can make nausea worse.
- Eat six small meals throughout the day, instead of three large meals.
- Chew food well.
- Try peppermint or ginger tea, flat soda or ginger ale.
- Try to have others prepare your meals.
- Rinse your mouth out frequently and before eating to avoid an unpleasant sour taste.
- Suck on mints, hard candy or ginger candy.
- Loosen clothes, get fresh air and sit upright for 1–2 hours after eating.
- Eat in cool rooms with fresh air.
- Breathe through your mouth slowly during times of severe nausea until the feeling passes.
- Take part in activities such as TV, radio, games, music to take your mind off the feeling of nausea.
- Use relaxation techniques and guided visual imagery.
- Discuss hypnosis and acupuncture with your doctor or nurse.

What things should I avoid?

- Fatty, fried, greasy or spicy foods.
- Citrus fruits, juices and tomatoes.
- Unpleasant odors, sights and sounds that may aggravate nausea.
- Combining hot and cold foods at the same meal.
- Your favorite foods during bouts of nausea and vomiting, so you will not associate them with feelings of nausea later on.
- Drinking liquids during meals, which can fill you up and not allow you to get in needed calories.
- Excessive activity and sudden movements.

How are nausea and vomiting treated?

Treatment of nausea and vomiting will depend on its cause. Your doctor may recommend:

- Anti-nausea medications to be taken before and after a treatment.
- If nausea occurs in the days/weeks following treatment, it may be helpful to take an anti-nausea medication about 30 minutes before meals.
- Anti-anxiety medications can be taken to prevent or treat nausea and vomiting.
- If you become dehydrated from nausea and vomiting, your doctor may give you fluid by IV (intravenous).

When should I call my care team?

Call your care team if you have:

- Bloody or coffee-ground appearing vomit.
- Black stools.
- Temperature over 100.5-degree Fahrenheit.
- Vomited two or more times in a day.
- Abdominal pain, cramping or swelling.
- Difficulty eating.
- Difficulty with drinking 6-8 glasses of fluid a day.
- Light-headedness, dizziness or weakness.
- Dark urine.
- No relief after taking anti-nausea medications prescribed by your provider.

Diarrhea

Diarrhea is the passage of loose or watery stools three or more times a day that may or may not cause pain or discomfort in the abdomen and/or rectum. Because diarrhea can cause many problems, including dehydration, loss of important nutrients, weight loss, and fatigue, it should never be ignored, or left untreated. If you need eating tips, please ask staff at the cancer center to assist you.

What causes diarrhea?

- Diseases of the bowel
- Some chemotherapy agents, as well as radiation therapy and surgery involving the bowel
- Certain medications
- Bowel infections
- Anxiety
- Certain foods and nutritional supplement drinks

What can I do to prevent or lessen diarrhea?

- Eat bland and easy to digest foods such as chicken, fish, eggs, puddings, mashed potatoes, noodles, rice, yogurt, cottage cheese, cream of wheat, farina, smooth peanut butter, white bread, bananas, applesauce, canned fruit and well cooked vegetables.
- Avoid dried fruits, cruciferous vegetables (broccoli, cauliflower, cabbage, peas), raw vegetables, whole grains, beans and legumes.

- Consume soluble fiber, a type of fiber found in some foods that absorbs fluid and can help relieve diarrhea. Foods high in soluble fiber include:
 - **Fruits:** Applesauce, bananas (ripe), canned fruit, orange and grapefruit
 - **Vegetables:** Boiled potatoes
 - **Breads and pastas:** White rice and products made with white flour
 - **Cereals:** Oatmeal, cream of rice, cream of wheat and farina
- Eat small amounts of food 5-6 times throughout the day, instead of three large meals.
- Drink 6-8 glasses of decaffeinated fluid per day. Besides water, consider fluids that replace minerals and electrolytes lost through diarrhea such as sport drinks (Gatorade®) or soup broth.
- Clear liquids may be easier to tolerate. Try clear fruit juices like apple or cranberry, ginger ale and jello.
- Avoid caffeine (cola, coffee, tea), alcohol, milk or milk products, chocolate, dried fruits, beans or popcorn as well as fatty, fried, greasy or spicy foods.
- Avoid very hot and cold beverages.

Care of the rectal area

- Clean the external rectal area well after each bowel movement. Use warm water and soap, and pat dry with a soft towel. This will help to prevent anal burning.
- Inspect the rectal area daily for red, scaly or broken skin. Report this to your doctor or nurse.
- Soak in a warm bath or use a sitz bath, which delivers a continuous, gentle flow of warm water over the rectal area while sitting on the toilet. Sitz baths can be purchased at your local drug store.
- Water-repellent creams, available over the counter at your pharmacy, such as A and D ointments are very effective to protect the skin. Ask your doctor about a numbing ointment if the area becomes very sore.

Can I take over-the-counter medications?

You should not take any over-the-counter medications while receiving chemotherapy without discussing them with your doctor or nurse first. This includes all over-the-counter anti-diarrheal medications, such as Immodium AD or Pepto-Bismol. This is because diarrhea can be caused by an infection or due to a medication you are receiving. Your health care team will want to determine this before you take any medication to stop the diarrhea and may give you instructions for taking the medications that are different from those on the package.

When should I call my provider?

Diarrhea should not be ignored, since it can result in dehydration and can be uncomfortable. Call your provider immediately if you have any one or more of the following:

- Six or more loose bowel movements per day for more than two days in a row.
- Blood in or around the anal area, in the stool, on the toilet paper or in the toilet bowl.
- No urine for 24 hours.
- Inability to drink liquids for more than 24 hours.
- Fever over 100.5 degree Fahrenheit.
- Weight loss of five pounds or more since the diarrhea started.
- Swollen and/or painful abdomen.

Constipation

What is constipation?

Constipation is a decrease in the number of daily bowel movements and/or the difficult passage of hard stool. It may cause discomfort or bleeding from the rectum.

Constipation may be caused by decreased fluid and/or food intake, decreased activity, some medications, cancer treatments (chemotherapy), and/or cancers of the digestive system.

The signs and symptoms of constipation include:

- Small, hard bowel movements.
- No regular bowel movement in three days.
- Leaking small amounts of soft or liquid stool from the rectum.
- Frequent and/or persistent stomach aches or cramps.
- Passing large amounts of gas or frequent belching.
- Blown-up or enlarged belly.
- Nausea and/or vomiting.

When should I call the doctor or nurse?

It is important to call at the first signs of any problem so the constipation can be managed more easily with the least amount of interventions and so complications do not occur.

Call your doctor if you have any of the following:

- No bowel movement in three days.
- Blood in the stool or on toilet tissue.
- Rectal pain.
- No bowel movement within one day of taking a laxative prescribed by the doctor.
- Nausea/vomiting.
- Abdominal pain, cramping or swelling.

What can I do?

- The cause of constipation in patients undergoing cancer treatment can often be related to medications, dehydration or the tumor itself. Talk with your care team about the cause, as this can affect how it is best managed.
- Increasing fiber (including Metamucil) in the diet is often not effective if your constipation is caused by pain medication. In those cases, you should take a laxative after speaking to your health care provider about which one is right for you.
- Drink 6-8 glasses of fluid per day. Try warm or hot fluids, especially in the morning.
- Increase your physical activity as much as possible. Even short walks will help decrease constipation.
- Attempt a bowel movement at a regular time each day, preferably after breakfast.
- Prune, apple, peach and pear nectars/juices may be helpful as they have a laxative effective, but the effectiveness varies person to person, and they may cause diarrhea.

How is constipation treated?

Treatment of constipation will depend on its cause. Your doctor or nurse may recommend a bowel regimen using stool softeners and/or laxatives. Stool softeners (such as docusate sodium or Colace) work by bringing water into the stool, making it softer and easier to pass. A stimulant or laxative (such as Bisacodyl, Dulcolax, or Senakot) works by stimulating peristalsis, moving the stool through the bowel. For occasional or difficult to manage constipation, your doctor or nurse may recommend Miralax (Polyethyleneglycol 3350). Miralax is a different type of laxative called an osmotic laxative. It works by causing water to be retained in the stool, softening the stool so it is easier to pass. These medications can be taken together. There are even some preparations combining stool softeners and laxatives in one pill, such as Senakot-S.

If you have persistent problems with constipation, consider taking softeners and/or a stimulant every day, per the package dosing instructions. Do not use enemas unless instructed by your doctor or nurse. If you do not have a bowel movement in three or more days, talk with your doctor or nurse about a stronger regimen. If you have any questions about constipation or need additional information, ask your doctor or nurse.

Loss of appetite

Loss of appetite is when you do not feel hungry, or you have no desire or interest in eating. If this happens to you during cancer treatment, there are things you can do to improve your appetite. It is important, especially during treatment, to keep yourself well nourished, maintain your weight as much as possible, and to keep hydrated.

Certain symptoms can contribute to loss of appetite, and you should contact your provider if you have any of these symptoms or if your appetite does not improve:

- Constipation
- Pain
- Nausea
- Depression and anxiety

The following tips may be helpful during cancer treatment to maintain weight/nourishment, deal with loss of appetite and keep hydrated:

- Eat high calorie foods and beverages.
- Choose foods that will provide the most calories per serving.
- Avoid diet and low fat foods.
- Drink high calorie beverages such as juices, fruit nectars, milk, cocoa, malted milk, shakes, smoothies, Ovaltine®, Carnation Instant Breakfast®, and commercial nutritional beverages such as Ensure and Boost.
- Eat small, frequent meals.
- Eat small meals throughout the day rather than three large meals. Try to eat 5-6 mini meals.
- Schedule your meals and snacks. Eat a few mouthfuls, even if you are not hungry.
- Serve small portions and use smaller dishes.

Snacks

- Eat high calorie snacks such as peanut butter, cheese, ice cream, puddings, nuts, trail mix, breakfast bars, cereal, yogurt, cottage cheese, deviled and hard-boiled eggs.
- Make a smoothie with fruit and ice cream or yogurt (Greek yogurt is even higher in protein than regular yogurt).
- Make a shake using ice cream and/or milk Ovaltine, Carnation Instant Breakfast, and commercial nutritional beverages such as Ensure and Boost.

- Keep snacks readily available to nibble on.
- Carry snacks with you when going to appointments or doing errands.

Try something different

- Try different foods and drinks. Foods you dislike one day may be appealing on another day.
- Do not be discouraged if foods you always loved do not appeal to you right now. This is not uncommon during treatment. You may find new foods interesting and again, just keep trying as things can change from day to day.
- Go to a buffet and sample different foods.

Eat when you have the most hunger

You may find it easier to make breakfast or lunch your “main” meal of the day. Focus on the meals when your appetite is best and you are able to eat the most. Often, when going through treatment, your appetite declines during the day.

Soft foods and liquids

Soft and smooth foods are easier to eat and digest when you don’t feel well. Try to choose soft foods that are also high in calories such as: casseroles, stews, macaroni and cheese, hearty and creamy soups, eggs, pancakes, waffles, French toast, mashed potatoes, pasta dishes, puddings and ice cream.

Eat high calorie foods first

- At meals, eat the foods with the most calories first. Start with the protein foods (meat, chicken, and fish). Then eat the starches (potatoes, pasta). Then eat the vegetables last.
- Limit your fluid intake during meals to sips, as liquids will fill you up.
- Drink your fluids between meals.
- Also, eat hearty or creamy soups since broth-based soups do not have as many calories.

Count calories

Write down everything you eat for a day and add up the calories. This will help you to see how much you are eating. It will also help you identify foods that give you the most calories per serving. The calorie content of foods can be found on food labels. You can also find the calorie content of foods on the internet, you can buy a calorie-counting book at most bookstores or find online trackers.

Other suggestions to help your appetite

- Try to do some physical activity before meals. Stretch or take a stroll.
- Go to a restaurant for a change of scenery.
- Have meals with family and friends.

Taste changes during cancer treatment

People going through cancer treatments, such as chemotherapy and radiation therapy, frequently report changes in taste. These changes can include food and drinks tasting bitter or like metal, an aversion to certain foods, or a change in the taste of your favorite foods.

Radiation therapy to the head and neck area can damage your taste buds and sense of smell or cause xerostomia (dry mouth caused by a decrease in or loss of saliva), which can exacerbate taste changes and interest in eating. Dental problems can also add to taste changes, so a visit to the dentist may be in order. Be sure to check with your oncology team to identify the best time during therapy to see a dentist. Mucositis (mouth sores) can also cause changes in taste.

Taste changes can impact your enjoyment of eating or drinking. In turn, you may not eat or drink enough for proper nutrition. Although the problem with taste changes typically resolves over time after therapy ends, it can persist for a year or longer. There are some things you can do to help manage taste changes and, in the process, decrease or prevent weight loss.

- Rinse your mouth before meals with salt water, sparkling water, ginger ale or brush your teeth.
- Avoid cigarette or cigar smoking, as this can make taste changes worse.
- Try making the flavors of your food more powerful with the addition of spices, herbs, marinades, lemon juice, sauces or pickled foods.
- Choose foods with strong flavors, lemon, for instance lemon meringue, a lemon marinade, etc.
- Avoid any acidic additives if you have mouth sores. While it seems logical that spicy foods should be avoided with mouth sores; research has found that capsaicin (which is derived from chili peppers) can be used to treat pain from mouth sores, so it may be helpful for some.
- Try to overpower a metallic taste with lemon drops, sugar free hard candy, mints or gum. For those dealing with dry mouth, these can also help stimulate saliva.
- If a metallic taste is your concern, use plastic utensils and drink beverages from bottles, not cans.
- Beef is particularly prone to tasting metallic, so you may want to replace it with other forms of protein like chicken, eggs or dairy products.
- Consult with the cancer center dietitian for help with food selections. Taste changes can make you lose interest in eating. Some activities that can increase your desire or ability to eat enough for proper nutrition include:
 - Eat small, frequent meals throughout the day. Have snacks on hand for when you feel hungry.
 - Make meal time a social and enjoyable experience. Invite your visitors to come at mealtime and eat with you.
 - Eat foods that you enjoy. Milkshakes, puddings, sauces and gravies can provide extra calories or lubrication to assist eating.
 - Attractive presentation of foods can increase your appetite. Try meals that include bright colored foods at a set table to appeal to your other senses.

Hair loss (alopecia) from chemotherapy

Why does chemotherapy cause hair loss?

Chemotherapy attacks cells in our body that are rapidly growing, such as cancer cells. Some normal cells that also grow rapidly, like hair cells, are also affected which causes loss of hair.

Does all chemotherapy cause hair loss?

Many chemotherapy drugs have no effect on your hair. Others cause mild hair thinning or complete hair loss. Your doctor or nurse can tell you if hair loss is expected with your treatment. Scalp hair is the most frequently affected, but loss of eyelashes, eyebrows, facial hair, pubic hair and body hair can also occur. The degree of hair loss will depend on several factors, including the chemotherapy drug(s) and dose received, how it is given and other treatments.

When will the hair loss occur?

Hair loss usually begins two weeks after your first treatment. Some people notice achiness or tingling of the scalp as the hair loss begins. If complete hair loss is expected, the hair may come out in large amounts and is usually complete within 3-7 days.

Is the hair loss permanent?

Hair loss caused by chemotherapy is usually temporary. Your hair will start to regrow after your treatment is completed. Some people experience a small amount of regrowth during treatment. Most people experience significant hair regrowth 3-5 months after treatment is completed. It is not uncommon for hair to grow back curlier and a slightly different color. In rare cases, persons who have received Taxotere as part of their treatment have had instances of no return of hair growth.

How should I care for my hair while receiving chemotherapy?

Even if your chemotherapy treatment is not expected to cause significant hair changes, some precautions are still recommended. If hair thinning is expected, these precautions may decrease damage to your hair:

- Use a soft bristle brush.
- Use a gentle, pH-balanced shampoo.
- Avoid using hair dryers, hot rollers or curling/flat irons too often.
- Avoid bleaching or coloring your hair.
- Avoid permanent waves.
- Avoid braiding or placing hair in a pony tail.
- Sleep on a satin pillowcase to decrease friction.
- Wear a hat when in the sun.
- If your hair is long, cutting it shorter may help decrease the impact of your hair loss when it occurs.
- Some people find it easier to deal with hair loss by shaving their heads before hair loss occurs.
- Be sure to protect your head with a hat to prevent sun exposure on sunny days- and not just in the summer months! This is especially important for men who are less likely to wear a wig or turban/scarf.

Why am I so upset about my hair loss?

It is normal to be upset about hair loss from cancer treatment. It may affect how you feel about yourself. It is also a visible reminder of your cancer. Share your feelings with your doctor, nurse, family and friends. There are many educational and supportive programs available.

Nail and skin care

During cancer therapy, you may notice changes in your skin and/or nails. These changes vary based on the type and dose of therapy you are receiving. Some common changes with radiation therapy include redness, peeling, thin or fragile skin and/or increased sensitivity to sunlight. If you are receiving chemotherapy, you may notice changes in skin tone or pigmentation, very dry skin, rashes, redness, peeling, and/or increased sensitivity to sunlight. If you develop any of these problems, be sure to show them to your oncology health care team, as they can be signs of reactions to some medications or can require adjustments to the doses of chemotherapy or radiation. Your fingernails, and possibly toenails, may become discolored, weak, break or lift off, or develop ridges (which will grow out over time). For most people, the nail changes are temporary and will grow back to normal after some time. It may take about six months after treatment is stopped for nails to return to prior condition.

General tips for caring for your skin:

- Wash with warm water and a mild, unscented soap.
- You can use your normal deodorant. If a product appears to cause irritation, stop using it and try another brand. You may benefit from a “non-allergenic” product.
- Use an electric razor for shaving to avoid cuts.
- Avoid tight clothing or irritating fabrics, such as wool, that may rub your skin.
- Protect your skin from sunlight. Use SPF 30 or higher, even on overcast days. Wear a hat and long-sleeved clothing to cover exposed skin and/or carry an umbrella when out during peak sun hours. Ask a MercyOne colleague about our hat program that provides you a SPF rated hat.
- Protect your skin from extreme cold or heat.

Dry skin is a common side effect.

Tips for dealing with dry skin include:

- Use an emollient, which are creams that soften skin and moisturize. Creams tend to be more effective than lotions. Some examples are Eucerin, Aquaphor, Nivea and Cetaphil.
- Avoid perfumed or scented lotions, as these can be irritating.
- Apply your moisturizer or cream after your shower or bath when skin is still damp.
- Do not forget to moisturize your lips! Try an eye or face cream to moisten the sensitive skin on your face.
- Drink 8-10 glasses of non-alcoholic fluid a day.

Nails can be affected by cancer therapy too.

Here are some tips for dealing with nail changes:

- Avoid cutting cuticles; this can be a source of infection. Use a cuticle cream instead. If you need to cut your cuticle, be sure to clean the clipper before using it.
- Artificial fingernails can harbor bacteria and lead to infections, so you should not use them.
- Nails absorb water and expand, then contract as they dry out. The more they expand and contract, the weaker they become, so wear gloves to protect your nails when doing housework or gardening.
- Keep your hands moisturized and your nails cut short.
- You may want to use nail polish to give your nails extra strength and cover imperfections.
- Soaking your nails in or massaging the nail with oil, such as vegetable or olive, helps replace moisture lost from water exposure. Tea tree oil rubbed into nails has been effective in decreasing nail loss, especially when taxanes are used in treatment and is a proven natural antiseptic. These natural oils lack the alcohol containing fragrance often found in commercial nail products.
- If your nails break or lift off, try to keep them clean and protected. Covering the nail with a band-aid can protect it from trauma. Clean with soap and warm water and apply an antibiotic ointment twice a day.
- If the nail or nail bed appears infected (redness, swelling, warm to the touch), inform your health care team.

Hand-foot syndrome

What is Hand-Foot Syndrome (HFS)?

HFS is a skin reaction that appears on the palms of the hands and/or the soles of the feet as a result of certain chemotherapy agents. It may also be referred to as acral erythema, palmar plantar erythema (PPE), or Burgdorf reaction. Chemotherapy drugs known to cause HFS include: capecitabine (Xeloda), fluorouracil (5-FU), liposomal doxorubicin (Doxil), doxorubicin (Adriamycin), cytarabine (Ara-c), sunitinib (Sutent) and sorafenib (Nexavar).

HFS can start as a feeling of tingling or numbness in the palms and/or soles, which progresses to swelling, redness, peeling skin, and tenderness or pain. If there is no change in the treatment, the hands and/or feet can blister (which can then become infected), becoming very painful and interfering with daily activities. It is very important to notify your doctor at the first sign of HFS. Most patients that develop HFS do so within the first few weeks of therapy, but it can also happen after being on the medication for many months.

What causes HFS?

No one knows for sure, but there are a few theories. The most widely accepted theory is that the small blood vessels in the palms and soles break due to use, pressure or increased temperature, causing an inflammatory reaction and possibly releasing the drug into the area. Many of the suggested prevention strategies or treatments for HFS are based on this theory.

How can I prevent HFS?

Unfortunately, there is nothing guaranteed to prevent HFS. The key is to catch it early and adjust the chemotherapy dose to prevent it from getting worse or happening again. It is important to understand that several studies have shown that reducing the dose of chemotherapy to relieve HFS does not reduce the effectiveness of the treatment. Some tips to help prevent HFS include:

- Avoid tight fitting clothing (socks, stockings) or tight shoes. Wear loose, comfortable shoes when going out and slippers around the house. Do not go barefoot.
- Avoid activities that rub the skin or put pressure on the palms or soles for one week after treatment (or as often as possible if you are on a daily medication). Any activity that puts pressure on the palms or soles should be avoided, but some examples include: washing vigorously, running, jumping, aerobics, long periods of walking, working with garden or repair tools (i.e. shovel, screwdriver, hammer) or chopping food.
- Apply a moisturizer to your hands and feet liberally and often, but gently to avoid rubbing the skin too harshly. Try applying a generous amount of moisturizer at bedtime and wear a loose pair of cotton gloves or socks to bed to promote absorption of the lotion. Some recommended moisturizers are Bag Balm, Udderly Smooth Cream, Eucerin, and Aveeno. Avoid any lotions or creams that contain perfumes, alcohol or glycerin.
- Avoid hot water such as a hot tub, steam room, hot bath or shower, or when washing dishes. Use warm water to shower or bathe and keep showers/baths short. Use tepid water when washing dishes. Do not use rubber gloves to wash dishes as they can cause further irritation by holding heat against your palms.
- Avoid sun exposure, as your skin is very sensitive to the sun while on treatment. Remember, you get sun exposure just sitting in a sunny window! Wear SPF 30 or higher daily or wear long sleeved shirts and pants.
- Applying ice packs to the palms of the hands and soles of the feet during the infusion of some chemotherapy medications may be helpful in preventing HFS. Ask your provider if this is appropriate for your treatment.

If I develop HFS, what can be done?

The first and most important step is to notify your doctor right away if you notice any numbness, tingling, redness, peeling, swelling or pain. Your doctor may stop the chemotherapy for a short period to allow the skin to heal, but in many cases, reducing the dose is enough to allow the skin to heal. Dose reduction or a break from therapy is the only thing proven to heal HFS, but some other strategies can help you deal with the discomfort or help HFS to heal faster.

- Soaking the hands and/or feet in cold water or applying ice packs can relieve pain and tenderness. Use a bag of frozen peas or corn, as these can conform to your hand or foot. Do not keep the cold on for more than 15-20 minutes at a time, but you can alternate the ice on and off.
- Continue to use lotions or moisturizers often, applied gently.
- Elevating the hands or feet may help decrease swelling.
- Some providers use vitamin B6 (50 to 150 milligrams per day) to help speed healing. Talk to your care team before taking any vitamins.
- An over-the-counter pain reliever, such as acetaminophen, may help with the discomfort. A topical pain reliever, in a cream or patch form, may also be used. Talk to your provider before taking any medications.
- If you develop blisters, do not break them, as they can become infected.
- If you develop a fever (temperature above 100.5), call your care team right away.

Most importantly: Notify your care team as soon as you notice any symptoms of HFS! Do not wait and see if the symptoms will improve on their own.

Side effects of the nervous system

PERIPHERAL NEUROPATHY (NERVE DAMAGE)

What is peripheral neuropathy?

Neuropathy is irritation or damage to the nerves. Nerves are long, wire-like fibers that transmit information from one area of our body to another. They carry sensations (feeling) of temperature, pressure and pain to the brain and control the movement of your arms and legs. Peripheral neuropathy is a condition in which a nerve or group of nerves have difficulty “communicating” with each other.

What causes peripheral neuropathy and how long will it last?

Certain chemotherapy drugs can cause neuropathy, especially at higher doses or after multiple doses. Chemotherapy medications that can cause neuropathy include: vincristine, vinblastine, vinorelbine, Taxol, Taxotere, oxaliplatin, bortezomib and cisplatin.

Peripheral neuropathy can occur acutely – meaning during or shortly after receiving a treatment and last a few days, or it can be chronic, that is, long-lasting and persisting between treatments. You may experience tingling, a feeling of pins and needles, or numbness in your fingers or toes, especially in response to cold. The sensation of tingling can be triggered by eating, drinking or touching something cold, or even breathing in cold air. This is colder sensitivity with Oxaliplatin use.

Symptoms often resolve within a few days of treatment, but sometimes symptoms persist.

In some, the peripheral neuropathy can become severe leading to constant numbness in the hands or feet, especially for those who have had multiple doses of chemotherapy known to cause neuropathy. It can cause difficulty doing fine motor tasks with your hands like buttoning a shirt, picking up small objects, or cause problems with balance or walking. For people whose symptoms continue after treatment is complete, these often improve or resolve within 6-12 months. Some people do experience these symptoms for a longer period of time and for some, they become permanent.

Occasionally during radiation therapy or surgery, injuries or scarring can occur, putting pressure on nerves and causing neuropathy. In addition, finally, tumors can put pressure on nerves or release substances that affect nerves.

What are the common symptoms of peripheral neuropathy?

When neuropathy occurs, one or several of your peripheral nerves have difficulty sensing information. This may lead to symptoms such as weakness, pain, imbalance, or numbness. These symptoms may limit your ability to safely perform daily activities such as walking or dressing.

Call your care team if you have any of the following symptoms of neuropathy:

- Arms or legs feel heavy, numb or tingling, or feel like “pins and needles.”
- Tripping, falling or pain when walking.
- Difficulty lifting up foot or toes.
- Difficulty picking up or holding objects or manipulating them in your hand.
- Difficulty using buttons.
- Cold feeling in arms or legs.
- Increased sensitivity to hot and cold.

What can I do?

- Stay safe! Since peripheral neuropathy may affect your mobility and ability to sense temperatures, it is important to take some simple precautions to ensure your safety.
- Contact your care team immediately if you have any of the above symptoms. Treating nerve damage early, potentially lowering the dose, or taking a break from the chemotherapy causing the problem may prevent the symptoms from getting worse.

- Wear gloves and warm socks, especially in winter.
- Always wear shoes both indoors and outside.
- If you have neuropathy in your hands, use knives, scissors, box cutters, and other sharp objects with care.
- Protect your hands by wearing gloves when you clean, work outdoors, or do any repairs.
- Make sure your house is well lit.
- Keep a night light on in your room and along the path to the bathroom.
- Cover steps and bathtub/shower with a non-skid surface.
- Clear stairs and hall of objects.
- Mark the edge of the step with a bright color to help determine where the step ends.
- Use handrails.
- Tape down the edges of all throw rugs to avoid tripping.
- Test the temperature of the water with an area of your body that is not affected by neuropathy before any bathing and dish washing.
- Always check your feet and shoes at the beginning and end of each day. You may not feel small pebbles or poorly fitted shoes that can irritate your foot and cause an open sore. Look for any redness or blisters that you may not feel developing.
- If you experience pain, your provider may recommend medications that are used to treat pain caused by nerve damage, such as gabapentin or vitamin B6. These medications may have side effects and should be closely monitored by a physician.
- Physical therapy can enhance your balance, strength and safety. Braces may be needed to help with extreme muscle weakness and instability.
- Occupational therapy can enhance fine motor coordination, such as writing, and therapists can help adapt your home to account for the changes in your situation.

It is important that you speak with your care team if you feel that you are experiencing peripheral neuropathy so that you can create a plan regarding how to manage it.

Pain

What is pain?

- Pain is whatever the person says it is and exists whenever the person says it does. It is an unpleasant sensation that can be described as causing a vague discomfort or significant distress. It can be stabbing, aching, pinching, throbbing or shooting in nature.
- Acute pain is temporary and lasts for a relatively short time. It is usually confined to one area and is easy to describe.
- Chronic pain lasts for long periods of time. It is not always confined to one area and can be difficult to describe. Often patients with chronic pain don't look like they are in pain.
- Pain can decrease your activity and appetite, cause difficulty sleeping and make you feel anxious or depressed.

What causes pain?

Pain is caused by damage to the body's tissues. Some common causes include:

- Cancer itself putting pressure on or damaging organs, nerves or bones.
- Some cancer treatments like surgery, radiation, chemotherapy and growth factors.

- Other diseases (e.g., arthritis).
- Infections.
- Blocked blood vessels.

When should I call my provider?

If you have:

- Any new pain, especially if it is persistent or severe.
- An increase in the amount or frequency of pain that you experience.
- Pain that does not improve after taking pain medication or returns before the next scheduled dose.
- Difficulty with side effects from pain medications (e.g., sleepiness, nausea, constipation).
- Pain that is accompanied by numbness, tingling or weakness of arm or leg, difficulty walking, urinating or having a bowel movement.

What is a pain scale?

A pain scale is a way of describing how bad the pain is so that the pain can be treated correctly. There are a variety of scales, but the numeric scale from 0-10 is most commonly used. On the 0 to 10 scale, 0 means no pain and 10 means the pain is as bad as it can get. Another scale commonly used for children and for those who have difficulty using the numeric scale is the faces pain scale. Different faces are presented to the patient and the patient pick the face that best represents how they are feeling and best describes their pain.

How is pain treated?

Medications are usually used to treat cancer-related pain. Do not take any medications, even over the counter medications, unless instructed by your provider as some can have side effects that are a concern for oncology patients.

Remember: Do not take any medications, even over the counter medications, without first checking with your provider. Take medications only as prescribed.

How often should I take my pain medications?

- Take the medication as prescribed by your provider. Most pain medications start to work in 30 to 60 minutes. Other medications, such as the anticonvulsants and antidepressants that are used to treat some types of pain, take a few days to start working.
- It is also important to take the medication as soon as you start to feel the pain. If you wait until the pain is severe, it will take more medication and a longer period to control the pain.
- If you require multiple doses a day of narcotic pain medication, your doctor may prescribe a long acting pain medication.
- You should keep a record of how often you take your pain medication and how much relief you feel. Share this record with your care team so that they may evaluate the effectiveness of your pain management.

Will I become addicted to my narcotic pain medications?

- No. Addiction happens with use and abuse of the drug for nonmedical purposes. You are taking it as prescribed by your provider.
- Anyone taking narcotic pain medications on a regular basis may experience physical withdrawal symptoms if the medication is stopped suddenly. Withdrawal can be avoided by gradually decreasing the amount of pain medication as directed by your provider.

Can I drive while taking pain medications?

Some pain medications can cause drowsiness. Your doctor or nurse may not recommend driving while you are taking pain medications. Please be sure to check with them before you do drive. Avoid or limit the use of alcohol and other sedating medications as these can increase sleepiness especially when combined with pain medications.

Are there any other ways to treat pain?

- If the pain is being caused by a cancerous tumor your provider may recommend treatments such as surgery, chemotherapy or radiation therapy to remove the tumor or decrease its size.
- A nerve block is a method of injecting a medication into or around a nerve that is causing pain.

Additional ways to decrease pain include:

- Heat and cold applications
- Massage
- Acupuncture and acupressure
- Relaxation techniques
- Guided imagery
- Biofeedback
- Hypnosis
- Counseling
- Diversionary activities (watching TV, listening to music)

BREAKTHROUGH PAIN

Breakthrough pain refers to a sudden flare of pain that breaks through the long-acting medication prescribed to treat chronic pain. These flares may be caused by disease, treatment or other unrelated factors, such as over exerting yourself. People may also experience breakthrough pain flares as they reach the end of their dose of long-acting pain medication, signaling that this long-acting dose may not be truly adequate and should be reevaluated by your health care team.

How is breakthrough pain treated?

With proper evaluation and treatment, breakthrough pain – like most pain – can be successfully managed. It is different from persistent pain and requires a different treatment. Breakthrough pain medication is taken as needed, as soon as symptoms are experienced and is prescribed in addition to long-acting pain medication.

What if breakthrough pain is not treated effectively?

Untreated breakthrough pain can have significant consequences for individuals. Without treatment, breakthrough pain flares can harm a person's sense of well-being, interfere with daily activities and may even interrupt your treatment schedules.

As discussed above, you must call your provider if you experience:

- Any new pain, especially if it is persistent or severe.
- An increase in the amount or frequency of pain that you experience.
- Pain that does not improve after taking pain medication or returns before the next scheduled dose of breakthrough medication.
- Difficulty with side effects from pain medications (e.g., sleepiness, nausea, constipation).
- Pain that is accompanied by numbness, tingling or weakness of arm or leg, difficulty walking, urinating or having a bowel movement.

Pain can be a challenging side effect of cancer and cancer treatments, but it can be treated effectively in many cases. Do not hesitate to communicate with your care team regarding any pain management issues you are experiencing.

General fatigue

What is Cancer-Related Fatigue?

Although health care professionals frequently talk about fatigue, I rarely hear a patient describe this feeling as fatigue. Patients know it as the feeling of exhaustion, being completely worn out, unable to concentrate, feeling heavy, and most of all, feeling more tired than they have ever felt. It is the health care provider who then explains that this is cancer-related fatigue.

Fatigue is one of the most common symptoms experienced by cancer patients. Studies have reported that 26% to 90% of patients experience fatigue at some time during treatment. The reason for this large range is that the definition of fatigue has varied in these studies, as has the extent and type of tumor, and the type of treatment. In addition, fatigue is very subjective. That is, it is a personal experience, and is different for each person who experiences it. The National Comprehensive Cancer Network defines cancer related fatigue (CRF) as “a persistent, subjective sense of tiredness related to cancer or cancer treatment that interferes with usual functioning.” This sense of tiredness is usually not relieved with rest and is not related to an excessive amount of activity. Many patients describe it as feeling bone tired. They feel physically, mentally and emotionally drained.

As you can imagine, this exhaustion has a great impact on a person’s quality of life. Unfortunately, many patients see this as par for the course and do not seek help from their health care providers. On the other hand, many health care providers may do little more than recommend rest, which research has found is not particularly helpful. Fatigue can fluctuate during the cancer diagnosis. In general, patients who are receiving chemotherapy typically have a peak in fatigue 4-5 days after treatment, or at the time when blood counts are low (nadir). For patients receiving radiation, fatigue tends to reach a peak at the end of treatment, improving anywhere from 1-3 months following therapy. These may be the normal periods, but many patients report fatigue persisting for many months or years after therapy, even if the cancer is in remission. Patients having undergone chemotherapy, radiation therapy, and/or bone marrow/stem cell transplants, as well as those with a terminal diagnosis, often suffer the most fatigue.

What Causes Cancer-Related Fatigue?

Researchers have found several abnormalities that are related to CRF, but it is uncertain if these changes actually cause CRF or are just associated with it. There are several medical and psychosocial conditions that can either cause fatigue or increase CRF (see table below). If it is determined that a patient has one or more of these conditions, the condition(s) should be treated first and foremost.

- Medical conditions associated with fatigue
- Psychosocial conditions associated with fatigue
- Anemia
- Lack of social support
- Pain
- Poor coping skills
- Infection
- Anxiety
- Cardiac (heart) or pulmonary (lung) disease
- Depression
- Medication side effects
- Sleep problems or deprivation

- Thyroid conditions
- Nutritional deficiencies
- Renal (kidney) failure

There are several other theories as to why cancer patients suffer from this fatigue. The first involves cytokines, which are proteins released by cells that act as a messenger for the immune system. These proteins regulate many functions of our immune system, including inflammation, immune function and stimulating the production of all blood cells.

Researchers have found that cancer causes an increase in the release of certain cytokines, and levels of these cytokines were found to be higher in people experiencing CRF, suggesting they could be a cause. It is also known that some cancers cause people to have higher resting energy consumption, in other words they burn more calories at rest than someone without the disease, and thus require more energy to carry out daily activities. A decrease in the production of certain hormones has also been found in patients with CRF, which may contribute to the feeling of fatigue. These are all theories, and none has been proven to be the cause. In fact, it is likely there is not one single cause, but rather a combination of factors.

It is understood that a lack of physical activity can aggravate or cause fatigue. This may be because deconditioned muscles require a person to exert more energy and effort to perform a task. For this reason, exercise has been studied as a preventive measure and has been shown to work best when started before fatigue sets in, but exercise also can help to relieve fatigue associated with cancer and treatment.

How can we help relieve or prevent fatigue?

Only two interventions have been proven truly effective in large clinical trials to relieve or prevent fatigue: correction of anemia and exercise.

Anemia

Anemia is defined as a hemoglobin level below the normal range and symptoms include: shortness of breath or difficulty breathing with exertion, and fatigue. Anemia in a cancer patient can have many causes including:

- bleeding
- bone marrow involvement of disease
- chemotherapy
- radiation therapy
- organ dysfunction (heart, lung, liver or kidney disease)
- nutritional deficiencies

Anemia is believed to be one factor contributing to fatigue, and its correction may alleviate fatigue. One way to correct anemia is through the use of blood transfusions.

Correction of anemia is one intervention in the treatment of fatigue, but not every cancer patient with fatigue has anemia.

Exercise

Many studies show that exercise improves fatigue ratings and overall quality of life. People found themselves in a better mood, with more energy, feeling more rested and better able to concentrate. This type of exercise refers to light exercise, such as taking a walk, doing some simple arm exercises to lift cans of soup, marching in place, non-strenuous swimming, or pedaling on a stationary bike. Make sure your health care team knows of your plans and has approved the exercise. Certain exercises may not be recommended, especially for those with bone metastases, low blood counts, or other health conditions.

It is important to do something that you enjoy and start off slow then progress as you can. It is helpful to start an exercise routine shortly after a diagnosis of cancer or early into the course of cancer treatment to prevent or minimize fatigue. It can be much harder to start a program once fatigue has set in, but it is not impossible. It is important to know that even if you are experiencing fatigue, even light exercise can help you feel better. Patients who are already experiencing fatigue can start with a short walk and increase the distance each day or week, as you are able. It may be helpful to ask someone to walk with you as encouragement. A walk to a nice park or garden may help a person relax and take their mind off worries. Remember, the type of exercise is not that important; do whatever form of exercise you enjoy that is approved by your health care team.

ENERGY CONSERVATION

Rest is commonly recommended to deal with CRF, but it often does not help. One way rest can help is through energy conservation and activity planning. This is planning and saving your energy for when you want or need it most. For instance, if your child is playing in a soccer game this afternoon that you really want to go to, take it easy in the morning and conserve energy for the afternoon event. Remember that you may not have the energy to stay for an entire game, so if you want to be there until the end, go a little late.

Another way to conserve energy is to ask for help; do not be afraid to do so. Ask a friend to clean the house for you, prepare a meal for your family, drive the school carpool or just sit and talk. These may seem like simple tasks, but they can be extremely helpful to someone with CRF.

Sleep problems and deprivation can add to or cause fatigue. Keep a normal sleep schedule as much as possible, and talk to your doctor about options if you are unable to sleep at night. Avoid caffeine later in the day so you will be more likely to sleep at night. Avoid naps, or if not possible, limit them to 20-30 minutes and not too late in the day.

COMPLEMENTARY THERAPIES

Mind-body interventions have been studied in the treatment of fatigue. The therapies that have shown promise include acupuncture, healing touch, hypnosis, massage, yoga, guided imagery and relaxation. One downside too many of these therapies is the out of pocket expense for the patient, without a guarantee of it working. Use caution with these modalities and talk with your health care provider before starting them.

Several fatigue management programs have demonstrated the benefits of support groups. Patients who chose to participate in a support group may note an improved mood and coping responses. Stress management was found to be helpful in studies, but interestingly, self-guided stress management was more helpful than a group-led session.

MEDICATIONS

Depression and anxiety are known to contribute to fatigue, so medications to treat these conditions may also help with fatigue. Your provider may suggest medication, but if you think you are suffering from depression or anxiety please bring this up with your provider. It is normal to have a reaction of sadness to a diagnosis of cancer, but this does not always lead to depression.

Chemo-brain

What is chemo-brain?

Many survivors who have previously received or are currently undergoing chemotherapy report experiencing cognitive changes, often referred to as chemo-brain. These changes include difficulty with short term memory, multi-tasking, new learning, reading comprehension, working with numbers and a decrease in concentration. For many years, this was attributed to depression or anxiety over the diagnosis and treatment of cancer.

More recently, researchers have begun to study what survivors have been saying all along, cognitive changes after chemotherapy are real. Although we are not yet able to pinpoint whether only certain chemotherapy drugs are responsible, it seems certain that the effects are cumulative. That is, those who receive more chemotherapy tend to experience greater deficits. Studies have found that cognitive ability may improve over time in some survivors, but deficits are still present in many long-term survivors, even years after treatment.

Rule Out Other Causes

It is important to remember that some very treatable problems can result in cognitive difficulties, such as thyroid dysfunction, depression and anxiety, so it is important rule out other causes first.

TREATMENTS

Medications

Currently, there are no medications used specifically to treat chemo-brain.

Brain rehabilitation

Cognitive rehabilitation programs are structured programs utilizing exercise, tasks that use memory and puzzles to rehabilitate your mind. These programs are typically used for people with brain injuries, but therapists have tailored programs for cancer survivors.

Several companies offer computer programs that aim to improve brain function. Puzzles using numbers, like Sudoku, may help exercise your brain. It is likely that any brain stimulation may be helpful and certainly cannot hurt, whether through a game, taking a course at a local school or joining a book discussion club.

Fatigue can enhance cognitive problems, so avoiding fatigue by getting enough sleep, incorporating exercise into your life and eating a healthy diet.

TIPS FOR MANAGING LIFE WITH CHEMO-BRAIN

There is no quick fix for chemo-brain. It is important to be creative and incorporate things into your daily life that can help combat the symptoms.

- Keep a detailed calendar or planner. Use your smart phone to set alarms to remind you of important appointments.
- The all-to-important sticky note – just be sure to put them in places you will see them!
- In the evening, start a list for tomorrow- what needs to get done and who do I need to call? Create a notebook for this so you can flip ahead and add something to next week's list when it comes to mind.
- Keep a pad in the kitchen for a shopping list. When you see something is running low add it right away.
- Put a basket near the front door for those items you need every day- cell phone, keys, wallet, etc.
- Trouble remembering names? Think of a silly thing to jog that memory- I remember my neighbor Rena's name by thinking Xena Warrior Princess. Sounds silly, but I never forgot her name again!

- Trouble remembering something is cooking? Get into the habit of setting a timer. This is also a great use for your smart phone!
- GPS/navigation systems/navigation apps can be lifesavers for getting places.
- Most importantly, know your limitations. Do not take on tasks that require too much multi-tasking. Ask for help. Try to keep a positive outlook and find some humor in your “chemo-brain moments.”

Bone loss during and after cancer

People who have received or are actively receiving certain cancer therapies are at an increased risk for developing osteoporosis. Osteoporosis and osteopenia (the precursor to osteoporosis) are medical terms for decreases in bone density, or a thinning or weakening of the bones. This increases the risk of fracture of the bones. It most often affects the hips, spine and wrists, and is the cause of two million broken bones a year in the United States. Cancer survivors at risk for osteoporosis should learn more to take steps to prevent it and have appropriate screening.

Our bones provide support and structure for our body, as well as storage for essential nutrients. Your bones are continually being damaged and repaired by a complex system involving osteoclasts, which are cells that break down old bone, and osteoblasts, which are cells that form new bone. The body maintains a delicate balance between the breakdown of old or damaged bone, and the formation of new bone, to maintain bone strength. The hormones estrogen, testosterone and parathyroid hormone play critical roles in regulating bone remodeling. In osteoporosis, more bone is being destroyed than is being formed, leading to weakened bones.

Who is at risk?

- Women who have premature menopause or decreased estrogen production due to cancer therapy (i.e., women taking hormonal therapy, such as aromatase inhibitors or leuprolide; or menopause induced by surgery, chemotherapy or radiation). Of note, tamoxifen increases the risk of osteoporosis in premenopausal women, but can increase bone density in menopausal women, thereby decreasing the chance of osteoporosis.
- Men who have decreased testosterone production. This is a common concern for men treated with androgen deprivation therapy (ADT) or orchiectomy (surgery to remove testicles) for prostate cancer.
- Treatment with some chemotherapy medications, radiation to the brain or weight bearing bones (spine, hips, legs), or allogeneic stem cell or bone marrow transplant.
- Survivors of childhood cancers.
- Long-term use of corticosteroids (dexamethasone and prednisone, greater than 5mg per day for two months or more).
- Patients who have had their stomach surgically removed (gastrectomy).

There are additional risk factors that are not specific to having cancer, including smoking, consuming excessive alcohol, leading an inactive lifestyle, being petite and thin, having a diet low in calcium and vitamin D and missing menstrual periods. Osteoporosis is more common in women (80% women, 20% men), those with a family history, Caucasians and those of Asian or Latino descent, although all races have some risk. You can learn more about other risk factors by visiting the National Osteoporosis Foundation.

How is osteoporosis detected?

Screening for osteoporosis is done with a bone mineral density (BMD) test. A DEXA scan is the most used test. The National Osteoporosis Foundation recommends that women should have the test at age 65 and men at age 70, when no risk factors are present. They recommend screening for younger individuals with risk factors. The test is also used to monitor the bone health of people with osteopenia or osteoporosis.

Experts recommend screening for all patients with cancer who are at increased risk because of their age or the treatments they received. Cancer survivors should discuss their specific risk and need for screening with their health care team. Risk can be evaluated using the FRAX® tool, which was developed by the World Health Organization to evaluate the risk of fracture in people.

What can I do to protect my bone health?

While you may not be able to change your family and health history, there are some steps you can take to protect your bones. Remember to always check with your provider before starting any new medications, including vitamins and other supplements.

- Get 1000-1200mg of calcium a day – ideally in your diet (see more below).
- Take 800-1000 IU of vitamin D3 daily.
- Do not smoke or drink excessive alcohol (no more than 2 drinks per day).
- Watch your caffeine intake- studies have shown large amounts of caffeine increase the risk of fractures. Drink milk instead!
- Get your weight-bearing exercise and strength and resistance training! This strengthens bones and muscles.
- Have appropriate bone health screening.

Dietary tips

CALCIUM

Our bodies cannot produce calcium, so we must be sure to get enough in our diet to support healthy bones. You should aim to get 1000-1200mg of calcium per day. It is best to get calcium in a balanced diet, including 4-8 servings of calcium rich foods a day.

Dairy foods, such as milk, yogurt and cheese, are highest in calcium. Canned fish (sardines and salmon with bones), dark, green vegetables, such as broccoli, kale and collard greens contain calcium as well. Some foods are fortified with calcium, but read the labels to get an idea just how much they contain. Calcium fortified orange juice is one good source.

Spinach and rhubarb contain calcium, but also contains large amounts of oxalate and phytate, which prevent the body from absorbing their calcium. However, they do not interfere with the absorption of calcium from other foods. Other good sources of calcium include almonds, sunflower seeds, apricots and figs. A dietitian can provide more guidance in choosing calcium rich foods.

If you cannot take in the recommended amount of calcium in foods, your provider may recommend calcium supplements.

VITAMIN D

Vitamin D is often called the sunshine vitamin because our skin converts ultraviolet rays from the sun into vitamin D. In general, 10-15 minutes of sun exposure on the hands, arms and face creates the needed amount. However, it is difficult to measure how much vitamin D you are getting by this method and the amount can vary by season or location. In addition, avoiding the sun and using sunscreen limit how much UV exposure we get.

Very few foods contain vitamin D naturally; these include certain fish (salmon, tuna, mackerel) and fish liver oils, while egg yolks and beef liver contain small amounts. Many foods are fortified with vitamin D, read the nutrition labels to know how much. Milk is often fortified with vitamin D, but keep in mind that foods made with milk (cheese, ice cream) are not.

Vitamin D is available in two forms, D2 and D3. Supplements typically contain D3. Research has found that both are beneficial for bone health. A cup of fortified milk contains about 100 international units (IU) of vitamin D. A multivitamin contains 400 IU and some calcium supplements also include vitamin D. You should aim for 800-1000 IU per day. Your care provider may check your vitamin D blood levels to see if you should take a supplement.

MEDICAL THERAPY

If your health care team determines that you have osteoporosis or osteopenia, they may recommend medications to prevent it from getting worse. Currently, there are two main types of medications that are utilized to treat bone loss. One of the types is referred to as bisphosphonates, some of the common drug names associated with this class are Fosamax, Reclast, and Zometa. The other class includes the medication referred to as Prolia or Xgeva. It is very important to talk with your provider and dentist before you have any dental work done while on these types of medications. Each of the medications has some risk of side effects and may not be appropriate for every patient. Discuss your medical options for treating osteoporosis with your health care team.

Side effects of biological/immune therapies

The side effects of biological therapies (including immunotherapy) mainly reflect the stimulation of the immune system and can differ by the type of therapy and by how individual patients react to it. Often side effects can be the result of inflammation associated with the affected organ. The most common areas affected are the skin, thyroid gland, lung, colon and liver. Some of the most common biologic/immune therapy side effects are listed below while others have already been discussed in the previous section such as diarrhea. Treatment for these side effects is almost always the same. If the side effects are severe enough treatment will be withheld and your provider will likely prescribe steroid therapy to suppress the immune system.

Skin reactions, including redness, blistering, dryness and rash are a common reaction to immunotherapy/biotherapy. Skin can also be more sensitive to sunlight. These skin reactions are rarely severe but can be quite uncomfortable, the following are some tips to managing these reactions.

- Avoid the sun and use a sunscreen with a SPF of at least 15. If the sunscreen causes a burning sensation, you can try sunscreens that contain zinc oxide or titanium dioxide. Remember to use enough sunscreen. Reapply sunscreen every two hours when outdoors, or more often if sweating or swimming.
- Use a broad-brimmed hat if going outside. In addition, avoid being in direct sunlight between 10 a.m. and 4 p.m.
- Use a mild soap in the shower. Avoid soaps with strong scents. Shower with lukewarm water and avoid long, hot showers. Also, avoid laundry detergent with strong perfumes.
- Apply a cream-based moisturizer to all skin within 5 minutes of showering or bathing. Use hypoallergenic moisturizers that do not have perfumes or preservatives, such as Vanicream, Aveeno, CeraVe, Cetaphil, and Eucerin.
- Avoid anti-acne skin products containing alcohol or retinoids. They can dry out your skin.
- Your doctor may prescribe medicated skin creams to effectively relieve symptoms of rash. If the rash is severe or covers a large area of the body, you may need oral corticosteroids, such as prednisone or dexamethasone.
- Antibiotics, usually taken for 2 to 4 weeks in pill form, are an effective therapy for rashes and nail tenderness.
- Whenever there is discharge of pus, your doctor may want a sample to determine the appropriate antibiotic treatment.

For hand/foot skin reactions:

- Use mild, scent-free moisturizing creams are also options.
- Wear thick, comfortable socks and shoes, or try gel insoles. Also, do your best to protect against injury. Avoid really hot water and increased friction.

For itching in one specific area, called localized itching:

- Apply a cream containing a corticosteroid. For more generalized itching or itching that affects sleep, talk with your doctor about taking an antihistamine pill, such as loratadine (Claritin) or diphenhydramine (Benadryl), as needed.

FLU-LIKE SYNDROME

Often side effects related to immunotherapy/biotherapy are referred to as flu-like.

Symptoms of Flu-Like Syndrome:

- Fever (sudden onset, timing associated with the therapy causing the flu-like syndrome).
- Chills (often come before the fever, usually involve upper body first).
- Muscle/joint aches (generalized aches and pains, accompanied by sensation of weakness, may or may not be relieved by rest).
- Headache (usually across forehead, accompanied by sensitivity to light, may include visual disturbances, such as blurring of vision).
- Poor appetite.
- Nausea, vomiting.
- Diarrhea.
- Nasal stuffiness (runny nose usually clear, watery and persistent).
- Cough (dry, hacking, and persistent, rarely productive).
- Bone pain.
- Fatigue (malaise) (lack of energy or motivation).

FEVER

Things you can do for fever:

- Take a lukewarm (tepid) bath if flu-like syndrome causes a fever. In addition, you can use cold or ice packs on your body for comfort. Some patients find it comforting to have a cool, moist washcloth on their foreheads or on the back of their necks.
- When you have a fever, you lose water and can become dehydrated. Therefore, it is important to drink lots of (non-alcoholic and non-caffeinated) fluid during these times.
- Take medication to control symptoms of fever as recommended.

Drugs that may be prescribed by your doctor for fever:

- Anti-pyretic (anti-fever) medications such as acetaminophen (Tylenol®) are used to treat fever related to flu-like syndrome. This may be prescribed to be taken around the clock, or prior to when expected fever may occur. Do not take more than the recommended amount of acetaminophen in a 24-hour period. No more than 3 grams of acetaminophen should be taken. Higher doses may lead to toxicity to the liver. Check the bottle for the milligram dose (mg) of each pill, 1000mg = 1 gram. If you are taking medications that have acetaminophen as one of the ingredients, this needs to be taken into account of the total dose for the day. For example: Percocet® and Darvocet each contain 325mg of acetaminophen per pill. It is important to review all of the medications you are taking with your health care professional.
- If you have a bleeding disorder, you should avoid non-steroidal anti-inflammatory (NSAID) drugs, as well as aspirin, because these drugs may interfere with blood platelets, and prolong bleeding. Use of such drugs to treat fever symptoms should be discussed first with your health care professional.

CHILLS

Things you can do for chills:

- In contrast, if flu-like syndrome causes the chills, you should put on some warm clothes, blankets or take a warm bath. If you like to use hot packs or heating pads, use caution to avoid burning your skin.

MUSCLE AND/OR JOINT ACHES

Things you can do for muscle and joint aches:

- Some patients find the application of heat or cold to the joints and muscles helps in relieving some of the discomfort.
- Rest when you feel achy and tired, however, there should be a balance between rest and exercise. Some exercise can boost your energy levels. Ask your doctor if exercise is right for you during flu-like syndrome.
- Relaxation techniques.

Drugs that may be recommended by your doctor for muscle and joint aches:

- Analgesics (pain medication) such as acetaminophen. Do not take more than the recommended amount of acetaminophen in a 24-hour period. No more than 3 grams of acetaminophen should be taken. Higher doses may lead to toxicity to the liver. Check the bottle for the milligram dose (mg) of each pill, 1000mg = 1gram. If you are taking medications that have acetaminophen as one of the ingredients, this needs to be taken into account of the total dose for the day. For example: Percocet® and Darvocet® each contain 325mg of acetaminophen per pill. It is important to review all of the medications you are taking with your health care professional.
- If you have a bleeding disorder, you should avoid non-steroidal anti-inflammatory (NSAID) drugs, as well as aspirin, because these drugs may interfere with blood platelets, and prolong bleeding. Use of such drugs to treat headache should be discussed first with your health care professional.

HEADACHE

Things you can do for headache:

- Rest in a quiet, dimly lit room. Perhaps, relaxing music would help soothe your headache.
- Cool cloth on the forehead.
- Headaches that may be due to sinus congestion may be helped by warmth and steam.
- Headaches originating in the back of the head or neck may be related to muscle tension - heat and/or massage may help

POOR APPETITE

Things you can do for poor appetite:

- Try to eat small meals or snacks, every two to three hours, instead of three large meals a day (become a grazer). Do not expect to eat regular size meals when you suffer from flu-like syndrome.
- Foods high in protein or calories are good snacks to have handy. Examples include milk shakes, cheese, fruits, peanut butter, nuts, crackers and juices.
- Eat foods rich in calories and nutrients. Avoid low-calorie foods that fill you up, such as lettuce, broth and diet soda.
- When choosing beverages, select nutrient-dense fluids such as milk, milk shakes, juice and punch-type drinks.
- Avoid heavy meals, greasy/fried foods, and foods that cause gas. Examples of gasproducing foods include beans, cauliflower, broccoli, cabbage and carbonated drinks.
- Prepare food that is colorful and appealing to the eye.

SURROUNDINGS

- Try to eat with friends or family. Make eating a social event. Often, people will eat more when they are socializing.
- Try changing the time, place, and surroundings of meals. Watch your favorite TV program while you eat.
- Use a plate that is larger than needed and put small portions on the plate. That way the amount of food that you

need to eat does not look so overwhelming.

- Avoid smells that are obnoxious or bothersome to you while you are eating.

TASTE CHANGES

- If you are not eating much during flu-like syndrome because you have lost your sense of taste from chemotherapy, you may want to try adding different seasonings to your foods.
- If you have a bad taste in your mouth, try sucking on hard candies/mints or chewing gum. Also, keep your mouth clean by brushing at least two times per day and rinsing your mouth out with water between meals/snacks.

DRY MOUTH

- If you aren't eating much because flu-like symptoms cause your mouth to be dry, try increasing your non-alcoholic fluid intake to at least two liters per day; just make sure it is okay with your doctor to drink this much fluid. Also, limit the amount of food you drink with meals. Liquids make you feel full. Save the liquids for between meals.
- Avoid toothpaste and mouthwashes that contain alcohol as this can cause further drying of your mouth. To stimulate saliva, or to make your mouth moist, try sucking on ice cubes, candies, or gum.

MOUTH SORES

- If you are not eating because your flu-like symptoms include having sores in your mouth, use a soft bristle toothbrush. You can also rinse your mouth with a mixture of 1/2 to 1 teaspoon of baking soda or 1/2 to 1 teaspoon of salt in 8 ounces of water about four or five times a day. Check with your doctor if it is okay to use acetaminophen (Tylenol®) or ibuprofen for the discomfort.

EXERCISE

- After getting approval from your doctor, try to do some daily, mild exercise during flu-like symptoms. Sometimes some daily activity, like 20 minutes of walking or yoga, will help stimulate your appetite, relieve stress, improve your mood and help you sleep better at night.

RUNNY NOSE

Things you can do for runny nose:

- Use a vaporizer or a humidifier to moisten the air. Avoid dry air. This will help liquefy your mucus secretions when you are congested. Although you may have a runny nose due to flu-like syndrome, it is important that these secretions continue to drain, to prevent overgrowth of bacteria in your sinuses from congestion.
- Drink 2 to 3 liters of fluid every 24 hours, unless you were told to restrict your fluid intake, and maintain good nutrition. Keeping well hydrated will prevent congestion, and liquefy your secretions.

COUGH

Things you can do for cough:

- Describe your cough the best you can to your doctor. Think about what kinds of things/activities aggravate or relieve your cough. Think about how long you have had your cough. Do you cough out mucus or blood with it? Do you have a fever? Have you been losing weight suddenly without explanation? Do you get short of breath?
- Quit smoking and avoid environmental/occupational exposure to irritants.
- You may try using a humidifier to keep your throat and nasal passages moist if you have a chronic, persistent dry cough.

WHEN TO CONTACT YOUR DOCTOR OR HEALTH CARE PROVIDER:

Keep in mind flu-like symptoms, especially fevers, may represent a serious infection, therefore, it is important to seek medical attention if:

- You have a fever greater than 100.5 degree Fahrenheit that is new and not associated with the expected fever related to your medication.
- You develop flu-like symptoms that are unusual, unexpected or bothersome.
- Nausea interferes with ability to eat and unrelieved with prescribed medication.
- You are vomiting more than 4-5 times in a 24-hour period or vomiting is not relieved by medication.
- Fatigue limits your ability to care for yourself.
- You experience increasing shortness of breath with minimal exertion.
- Unable to eat or drink for 24 hours or have signs of dehydration: tiredness, thirst, dry mouth, dark and decrease amount of urine, or dizziness.
- Diarrhea (4-6 episodes in a 24-hour period).
- Pain not relieved by comfort measures, prescribed analgesics (pain medications).
- Uncontrollable anxiety or nervousness.
- Ongoing depression.

Always inform your health care provider if you experience any unusual symptoms during flu-like syndrome or you have questions or are having difficulty with side effects.

Sexuality and fertility

SEX/INTIMACY

Likely, this is not the first thought that comes to mind when you are diagnosed with cancer, but as treatment begins new questions emerge. For everyone, body changes during and after cancer treatment can affect sexuality and it is important to address those concerns with your provider. Whether it is pain, loss of desire or displeasure during sex, know that these concerns are not uncommon and your health care team is here to support you.

In general, sexual activity is safe during treatment as interest, energy and comfort levels allow. Chemotherapy can be excreted in vaginal secretions and semen for 48-72 hours after a treatment. You should use a condom for oral sex or intercourse during this period to prevent your partner from being exposed to the chemotherapy. (This includes IV and oral chemotherapy – even those chemotherapy medications that are taken daily). It is also important to prevent pregnancy while undergoing cancer treatment.

SEXUALITY AFTER CANCER

Sexuality encompasses much more than sex; it includes the physical, psychological, emotional and social aspects of sex. In the real world, this means how you see yourself, how does your partner view you, how do you date after cancer, how do you fulfill your need for sexual relationships after cancer and so much more. How cancer affects your sexuality is different for every person. Some find the support they need through their health care team, their partner, friends or fellow survivors. For those that find things more difficult, a behavioral health provider can help you cope with the physical and emotional trauma cancer brings and determine how to move forward, whether with a partner or looking for one. Look for a therapist with expertise in working with people with cancer and/or sexual and relationship issues.

FERTILITY

Fertility – the ability to reproduce, can be affected by both chemotherapy and radiation therapy. It is important to proceed quickly with fertility preservation before starting treatment if this is something that you want to do. Fertility preservation services are not available at MercyOne Waterloo Cancer Center, so patients are referred to the University of Iowa Hospital and Clinics.

WOMEN FERTILITY AND CANCER TREATMENT

Why does chemotherapy affect fertility?

Chemotherapy works by killing quickly dividing cells. These can be cancer cells or normal cells. Many cells in our bodies are quickly dividing, like those lining the gut, hair follicles and germ cells. When these cells are damaged by chemotherapy, it causes side effects, including diarrhea, mouth sores, hair loss and loss of the ability to have children.

It is often impossible to predict whether a woman will become infertile because of cancer treatment. The risk is related to the medications used, the dose that is given, how long it is given for and the woman's age at the time it was given. Rarely does a person get only one chemotherapy agent. Receiving multiple medications makes predicting fertility an even greater challenge. Higher doses and longer duration of treatment cause the highest risk of infertility. The older a woman is at the time of the treatment, the more likely it is that her periods will stop and/or she will become infertile. As a woman ages, smaller doses of chemotherapy can result in infertility. Speak with your provider if you would like a referral for fertility preservation services.

RADIATION THERAPY AND FERTILITY

Damage to fertility caused by radiation therapy is dependent on the dose received, part of the body treated, and the woman's age at time of treatment. Your radiation oncologist can discuss the fertility risks with you and refer you to fertility preservation services if they are needed.

SURGERY AND FERTILITY

Surgery that removes both ovaries or the uterus, cervix, and/or fallopian tubes will affect fertility in some way. Depending on how advanced the cancer is, some women may be eligible for fertility-preserving surgeries and should discuss these choices with your surgeon or oncologist.

MALE FERTILITY AND CANCER TREATMENTS

Your oncologist will discuss your risk factors and refer you to fertility preservation services if needed.

EMOTIONAL SIDE EFFECTS

Everyone is affected differently by his or her cancer diagnosis and treatment and your ability to cope with your experiences greatly can affect how you get through this journey.

While a lot of focus is put on managing your physical side effects, your emotional wellbeing is just as important.

COPING WITH YOUR EMOTIONS

When facing a cancer diagnosis and treatment you are likely to experience a roller coaster of emotions. There are ups and downs, peaks and valleys, positives and negatives.

Emotions you may experience include:

- Worry
- Sadness
- Anger
- Nervousness
- Disinterest in usual/pleasurable activities
- Uncertainty
- Hope
- Numbness/disconnect
- Relief
- Happiness

These are all normal, expected emotions that cancer patients and their loved ones experience daily. You are not overexaggerating, different or alone in experiencing this vast range of emotions at various points in your cancer journey.

There are many things you can do to help yourself and your family and friends deal with the vast range of emotions you may experience, including:

- Give yourself permission to feel and think the way you do in that moment.

Inventory your support network:

- Who can provide different kinds of support? You may need emotional, practical, spiritual support or support through providing information and knowledge.
- How accessible are persons in your support network?

Communicate with your loved ones about how you are feeling. Though you may be feeling angry and upset, try to avoid an angry or critical tone. Explain your feelings by using this formula:

- "I feel/felt" - a particular feeling or emotion.
- "When" - a specific situation you are communicating about.
- "Because it" - further explanation of the situation/your reaction.
- For example, "I feel scared about my visit to the doctor tomorrow when I will hear my test results because it will guide much of my future plans." Or "I felt loved when you gave me that hug this morning because you showed me how much you care about me."

Use active coping techniques:

- Be comfortable with asking for and refusing help. Be prepared with tasks you need help with so that you can delegate to those who ask to help. It is okay to say you do not want help with something- and you do not need a reason.
- Exercise: engaging your body in physical activity helps to manage stress and anxiety, as well as anger and worry.
- Guided imagery or visualization, meditation and mindfulness focus on compassion, awareness of thoughts, feelings and sensations. These can help clear the mind and encourages less rumination on the past (guilt) or the future (fear/anxiety/worry).

- Thought re-direction/opposite thinking: when a negative thought invades your mind, say aloud, no. When negative thoughts are overwhelming you, think about the opposite that may happen. For example: "This chemo is going to make me nauseous." Think the opposite thought: "I may not have nausea with this cycle of chemo. If I do, I have medication to help me feel better."
- Take a time out, walk away. Sit in a quiet place, gather your thoughts and feelings, breathe, reflect and regain control of your mind.
- Go to a support group or use online and telephone support resources through Cancer Care. You are not alone; going to a group helps to counter isolation you may be feeling.
- Journal or blog to allow yourself to let go of feelings and find meaning in your experience.

Online websites:

- My LifeLine, Caring Bridge and Facebook can help build a supportive community of friends and family, as well as give you a platform to share your thoughts and feelings.

Emotional distress greatly affects your ability to manage your cancer diagnosis, treatment and survivorship. By engaging your mind with functional, positive coping mechanisms and communicating with your support network about what you need, you will be better equipped to manage the roller coaster ride.

Anxiety, worries and fears

Anxiety in cancer is common. It occurs at various points across the cancer journey. Anxiety in cancer patients can be associated with the stress related to the diagnosis, treatment plan, change in roles, fear and uncertainty about the future, fear of death, lifestyle changes, body changes, fear of recurrence, anxiety related to routine cancer screening tests and financial concerns.

Anxiety is the body's natural response to real or perceived threat. Feeling anxious is the body's response to dangerous or stressful situations. Anxiety is a defensive mechanism that manages our fight or flight reaction. Anxiety can help the individual to process threats and cope or avoid real or perceived dangers. Anxiety can also be challenging, manifesting as obsessive thoughts, worry, rumination, avoidance, fear, hypervigilance and panic. Anxiety affects the body systemically. It can cause symptoms, impacting your:

- **Cognition:** Feeling like the walls are closing in or that you are trapped, or that going outside of your home is unsafe; you cannot focus on anything other than what is scaring you.
- **Affect:** Feeling emotions such as worry, nervousness, terror or fear.
- **Behavior:** Avoidant, immobility, inability to speak, crying or screaming.
- **Physical well-being:** Palpitations, fainting, shortness of breath, tremor, muscle tightness, restless, abdominal discomfort, loss of appetite, nausea, vomiting, diarrhea, sweating, shivering, feeling itchy, hot or cold.

Anxiety is a problem when it does not go away, interferes with daily activities or does not respond to behavior modifications techniques.

Management

Anxiety is treated through a combination of behavioral and medical interventions. Understanding your cancer diagnosis, treatment and expected side effects can be helpful in reducing anxiety.

The following tips can also help reduce your anxiety, especially when your anxiety is associated with a fear of the unknown:

- Ask questions about procedures so you know what to expect.
- Ask for written materials about your diagnosis, treatment and potential side effects.
- Connect with others who have experienced a similar diagnosis and learn what helped them through treatment.
- Talk to your support network about your worries, concerns, fears and hopes.

- Be aware of potential anxiety triggers; for example, you may have a fear of needles and the idea of having IV's placed weekly triggers an anxious response.
- Regular physical activity releases natural pheromones that combat anxious feelings.
- Reduce alcohol, caffeine and nicotine intake. Do not rely on substances to help manage your symptoms.
- Use relaxation techniques when facing anxiety-provoking situations. These may include meditation, deep breathing, listening to your favorite music, prayer, etc. Find what works best for you.
- Consider a referral to a cognitive-behavioral therapist who specializes in the treatment of anxiety and adjustment disorders. These therapists focus on reframing thoughts, deep breathing, guided imagery, hypnosis, relaxation and meditation to help manage anxiety.
- Prescription anti-anxiety medications can be very helpful in the management of situational and adjustment related anxiety.

When to contact your care team

If you are having anxiety that is limiting your ability to perform or enjoy normal activities or is interfering with your sleep, concentration or appetite, talk to your care team.

Severe anxiety can result in a panic attack. Symptoms associated with a panic attack mimic symptoms associated with a heart attack including heart palpitations (racing heartbeats that you can feel), shortness of breath and sweating. If you think you are having a panic attack, contact your care team.

Depression

Many cancer patients experience some level of distress associated with their diagnosis and treatment. This distress can affect your functioning (physically, emotionally and psychologically). Most cancer patients will experience worry, sadness, anger and hopelessness at various points in their cancer experiences. However, most cancer patients are resilient and possess strategies for managing these feelings, harnessing social support, accessing assistance and processing emotions. Individuals who experience unbearable and/or sustained distress that does not respond to self-care interventions and influences mood should be evaluated for a major depression.

Depression occurs in 10% to 25% of cancer patients. Cancer patients who are depressed report lower quality of life, difficulties with adherence to treatment plans and increased/longer inpatient hospital stays.

Signs of depression

Some symptoms you may experience with depression include:

- Having a sad mood for most of the day and on most days.
- Loss of pleasure and interest in most activities.
- Changes in eating and sleeping habits.
- Nervousness or sluggishness.
- Feeling tired most of the time.
- Feeling worthless or guilty.
- Inability to concentrate.
- Recurrent thoughts of death or suicide.

These symptoms cause distress or impairment in social (relationships), occupational (work) and/or other important areas of functioning and participation/completion of activities of daily living. These symptoms are not due to medical conditions. This can make the diagnosis of depression in cancer patients more difficult, as fatigue, weight and appetite changes and sleep changes can all be related to the actual cancer (and treatment).

Treating depression

Treatment of depression can be via medications, therapy or a combination of these modalities. Medications can be very successful in reducing depressive symptoms, but do take 2-4 weeks to become effective and can have side effects including decreased sex drive, dry mouth, weight gain, nausea and dizziness. A word of caution: St. John's Wort (*hypericum perforatum*) has been used as an over-the-counter herbal antidepressant, but can interfere with many chemotherapy agents. Be sure to talk with your care team about any medications, including vitamins and herbal therapies.

Your care team can also make referrals and recommendations for therapists (psychologists, counselors, social workers and psychiatrists). This treatment focuses on counseling, support, life skills teaching, relaxation, education and cognitive/behavioral interventions to increase coping and resilience.

Cancer support groups may also help. Support groups have been shown to improve mood, help develop coping skills and improve quality of life. For more information about available local support groups, contact the Cancer Center Social Worker at 319-272-2816. Many organizations, such as Cancer Care, also offer online support groups.

When to contact your care team

If you experience symptoms of depression for two weeks or more, contact your care team. If you are uncertain about your mood, emotions or coping, contact your care team to request further assessment.

If you have thoughts of suicide or harming yourself, contact your care team immediately. If you are a family member or support person of an individual who is experiencing thoughts of suicide, contact your care team or call 911.

Living with metastatic disease

When you first learn you have metastatic disease, many questions and emotions arise. How can I possibly cope? Can my family handle it? Can I work and how can I afford not to? What do I do now? You may feel fearful, shocked, angry, overwhelmed and out of control. Do not hesitate to seek out help and support- social workers, therapists, support groups (in person or online) and behavioral health care. Family, friends and spiritual guides can be great sources of support during cancer treatment.

If you have been through cancer treatment before, keep in mind that you know much more now than you did at the time of your original diagnosis. Use that knowledge to guide your treatment decisions and help you put into place the support you need to get through this battle.

If you are newly diagnosed with cancer that is discovered to be metastatic, call on your best support people to help you research treatment options, weigh the pros and cons and make decisions. Bring your support person(s) to your appointments to take notes and help you recall what was discussed when you get home.

Metastatic cancer means something different to each person that hears those words and what this means for prognosis is no different. Advances in therapies allow some cancers to become a chronic illness, with people surviving for many years on and off therapy. For others, time may be much more limited. Nevertheless, this does not mean you cannot aim for the best possible quality of life while living as fully as possible.

Hope can exist even when what was originally hoped for is not likely to happen. Focus on achievable daily goals, such as attending a child's soccer game or lunch with a friend. This may help you appreciate the little treats in life and keep you focused on the good things. Some survivors like to set a long-term goal or milestone, such as seeing the birth of a grandchild. Save your energy to spend doing things you enjoy. Be realistic in your goals, accept that you will not always be up for the task and may need to adjust your goals for the day based on how you feel. Do not be afraid to ask for help when needed.

Metastatic cancer can be a devastating part of the journey. It may be hard at times to remember that you have a lot to live for, but do not let the cancer keep you down. Do not let it keep you from moving forward, enjoying life and spending time with loved ones. Make the most of what you have and do not dwell on things that happened in the past or what could happen in the future. Live each day as best you can and realize some days will be better than others.

CANCER RELATED WEBSITES

National organizations

- American Cancer Society™ - [cancer.org](https://www.cancer.org)
- American Society of Therapeutic Radiology and Oncology™ - [astro.org](https://www.astro.org)
- American Society of Clinical Oncology® - [asco.org](https://www.asco.org)
- Cancer Care® - [cancercares.org](https://www.cancercares.org)
- National Comprehensive Cancer Network™ - [nccn.org](https://www.nccn.org)
- Radiological Society of North America® - [radiologyinfo.org](https://www.rsna.org)
- Breast Cancer - [breastcancer.org](https://www.breastcancer.org)
- National Lymphedema Network™ - [lymphnet.org](https://www.lymphnet.org)
- Susan G. Komen for the Cure® - [komen.org](https://www.komen.org)
- Y-ME National Breast Cancer Organization - [Y-Me.org](https://www.y-me.org)
- Young Survival Coalition® - [youngsurvival.org](https://www.youngsurvival.org)
- National Cancer Institute® - [cancer.gov](https://www.cancer.gov)
- Beyond Pink Team - [cedarvalleybreastcancer.org](https://www.cedarvalleybreastcancer.org)
- Living Beyond Breast Cancer - [lbbc.org](https://www.lbbc.org)

Survivorship and support groups

- National Coalition for Cancer Survivorship™ - [canceradvocacy.org](https://www.canceradvocacy.org)
- University of Iowa Holden Comprehensive Cancer Center Support Groups - [cancer.uiowa.edu/support-groups](https://www.cancer.uiowa.edu/support-groups)

General cancer information – clinical information

- Chemotherapy basics - [chemocare.com](https://www.chemocare.com)
- OncoLink® - [oncolink.org](https://www.oncolink.org)
- MD Anderson Cancer Center - [mdanderson.org](https://www.mdanderson.org)
- Cleveland Clinic Foundation - [ccf.org](https://www.ccf.org)
- Patient Resource™ - [patientresource.net](https://www.patientresource.net)

Radiation specific information

- Radiation Therapy specific website and videos - [rtanswers.org](https://www.rtanswers.org)

These sites may be helpful. Many are nationally recognized organizations and several are world famous cancer teaching hospitals. BEWARE of what you may find on some sites – remember, anyone can publish anything on the internet without restrictions, proof or evidence. Just because you read it on the internet does not mean it is true. If you have questions on information you find, please talk to your doctor.

