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2nd Edition

SUPPORTIVE CARE

▶ *Easing the journey through treatment*

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SUPPORTIVE CARE



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Cancer treatments and the side effects they may cause

One of the most common concerns with cancer treatment is the potential side effects. Fortunately, the advances made recently in treating many types of cancer also offer better ways of managing the variety of physical and emotional side effects that accompany a diagnosis. Rest assured that more services are now available to provide care for the whole person instead of just the disease.

Most cancer treatments have side effects that vary depending on the specific therapies (see Table 1). How you respond to those side effects, however, will depend on many factors, including your diagnosis, health history, age and other characteristics. To ease your concerns about how you will respond, educate yourself about the types of treatments in your treatment plan. Talk with your health care team in advance to prepare for possible side effects, gauge their severity and recognize what to do if they occur. Ideally, your team may help you prevent side effects from occurring or at least diminish their severity.

In addition, make your treatment team aware of your life goals before starting treatment. And, consider future life goals as well. Don't let cancer rob you of your desires — it doesn't deserve it and neither do you.

Being a proactive patient allows you to be an informed partner in your care, which can lead to an improved quality of life. You will be ready to manage side effects when you do your research, prepare for medical appointments, trust your instincts, take care of yourself, track your side effects, accept support and understand your medications. Ask whether telehealth appointments or an online portal are available, which may be easy ways to report symptoms or complications between follow-up visits.

Do not be afraid to report side effects. Some people worry they will be taken off their drug or the dosage will be reduced. Others hesitate to “bother” their medical team by calling. Your symptoms are important and the sooner you call, text or email the medical team, the sooner you can get your side effects managed.

You are encouraged to keep a summary of your treatment plan with you to share with any health care providers you may encounter who are unfamiliar with your situation, es-

pecially during an emergency. Additional information to have includes your exact diagnosis, the specific treatments you are taking and any known biomarkers, the names and phone numbers of your health care provider and other members of your health care team, the cancer center where you are being treated, and the address to the web portal. You can even include nearby hospitals to go to in an emergency if you're being treated in another state. In an emergency situation, more information is better.

It is important to know you are not alone. People facing cancer have access to services

that are designed to help improve their overall well-being before, during and after treatment. These services are known as palliative care.

Though often confused with hospice care, palliative care has different goals. Hospice care is used for patients with terminal cancer and usually starts toward the end of life. Palliative care is actually quality-of-life preservation or restoration and focuses on symptom management associated with the cancer itself and side effects caused by treatment. Palliative care resources help with side effects, nutrition, fitness, spirituality, finances and more.

EXPLORING CANCER TREATMENTS

To understand the side effects that may occur, it is important to learn about the treatments that may cause them.

Systemic drug therapy may be given intravenously into a vein or a port in your body.

Continued on page 2

TABLE 1
COMMON SIDE EFFECTS BY TREATMENT TYPE

Treatment Type	Side Effect*
Chemotherapy	Anemia, appetite loss, blood disorders, bone loss, cardiotoxicity (heart problems), cognitive dysfunction (memory problems), constipation, diarrhea, fatigue, fertility issues, hair loss, mouth sores, nausea and vomiting, nervous system effects, neutropenia, pain, skin and nail changes, weight changes
Hormone Therapy	Cognitive dysfunction (memory problems); deteriorating bone health; fatigue; gastrointestinal symptoms; higher risk for other health issues including blood clots, cataracts, heart attacks and strokes; hot flashes and night sweats; infertility; mood changes; sexual health concerns; vaginal and menstruation changes (in women)
Immunotherapy	Anemia, bone marrow suppression, breathing problems, constipation, cough, cytokine release syndrome (CRS), diarrhea, eye problems, fatigue, fertility issues, fever, gastrointestinal problems, immune effector cell-associated neurotoxicity syndrome (ICANS), immune-related adverse events (irAEs), infections, infusion reactions, kidney problems, lower blood counts, muscle and joint pain, neuropathy, skin reactions
Radiation Therapy	<i>The location of the tissues that are being radiated greatly influences what side effects may occur with the exception of fatigue, which happens for most people.</i> Bone loss, cardiotoxicity (heart problems), cough, diarrhea, difficulty swallowing, dry mouth, extreme fatigue, fever, hair loss (in the area of the body being treated), headache, incontinence, lymphedema, mouth sores, nausea and vomiting (if abdomen is radiated), rectal bleeding, sexual and fertility problems (if pelvis is radiated), shortness of breath (if chest is radiated), skin sensitivity, tooth decay (if the head or neck is radiated).
Stem cell Transplantation	Anemia, appetite loss, blood clots (thrombocytopenia), diarrhea, fatigue, Graft-versus-Host Disease, hair loss, infections, mouth sores, nausea and vomiting, taste changes, weight loss
Surgery	Body image changes, bruising, constipation, drainage, fertility issues, limited mobility, lymphedema, numbness, pain, slow digestion, swelling
Targeted Therapy	Acne-like rash, blood clots (thrombocytopenia), cardiotoxicity (heart problems), constipation, diarrhea, dry or itchy skin, fatigue, flu-like syndrome, increased risk of infection, mouth sores, nausea and vomiting, neutropenia

*Side effects listed alphabetically. Talk to your health care provider about what to expect with your treatment plan.

It may also be given as an injection (shot), subcutaneously (injection under the skin) or orally as a pill or liquid. The goal is to destroy cancer cells throughout the body and lower the risk of future metastatic cancer.

Chemotherapy uses drugs to kill rapidly multiplying cells throughout the body. It is typically delivered in cycles, with treatment periods followed by rest periods to give your body time to recover. Chemotherapy may be used alone or with other drug therapies.

Immunotherapy stimulates or suppresses your immune system to find and attack cancer. This strategy trains the immune system to respond to cancer, giving it the potential for a response that can extend beyond the end of treatment. Types include adoptive cellular therapy, immune checkpoint inhibitors, immunomodulators, monoclonal antibodies, cytokines, modified bacteria, oncolytic virus immunotherapy, photopheresis, radioimmunotherapy and vaccines.

Targeted therapy kills cancer cells or stops the progression of disease. The drugs travel throughout the body via the bloodstream looking for specific proteins and tissue environments to block cancer cell

signals and restrict the growth and spread of cancer (see below).

Hormone (endocrine) therapy blocks the stimulating effect of hormones. It slows or stops the growth of cancer and is used because hormones that occur naturally in the body promote the growth of some cancers.

Surgery is the primary method for treating a solid tumor. Removing it may offer the best chance of becoming cancer-free or for controlling the disease and preventing it from spreading, especially for people with early-stage disease. Your health care provider may also perform a surgical procedure to determine the stage of the cancer or to relieve or prevent symptoms that may occur later.

Radiation therapy uses high-energy radiation to destroy cancer cells and shrink tumors. It can target specific parts of the body for localized disease or bone pain and be given prior to a stem cell transplant.

External-beam radiation therapy (EBRT) delivers radiation from a machine outside the body. Types of EBRT include three-

dimensional conformal radiation therapy, stereotactic body radiotherapy and intensity-modulated radiation therapy. A newer type of radiation called proton therapy uses charged particles called protons.

Brachytherapy, also called internal radiation therapy, uses a radioactive substance sealed in needles, seeds, wires or catheters placed directly into or near the cancer.

Alpha emitter radiation therapy uses radiopharmaceuticals, which are drugs that give off targeted radiation, to suppress cancer in the bones and reduce pain.

Stem cell transplantation, also known as bone marrow transplantation, is an infusion of healthy blood stem cells into the body. The two main types are autologous (auto) and allogeneic (allo) transplants. An auto transplant uses the patient's own stem cells, which are collected, filtered, processed and frozen. An allo transplant uses stem cells donated by a family member or unrelated donor. It may be used for patients with a high risk of relapse, those who are not responding fully to other treatments or those who have relapsed disease. ■

Understanding how targeted therapy works

Targeted therapy is a personalized systemic drug strategy that uses the results from genomic and biomarker testing to select a drug therapy that targets specific genes, receptors, proteins, mutations, abnormalities or other factors that are involved in the development and support of the tumor. They attack cancer in different ways.

Small molecule drugs are able to get inside a cell and target its internal components. These drugs can target the cancer's gene expression, enzymes that affect the tumor, or certain proteins.

Angiogenesis inhibitors block new blood vessel growth that feeds tumor cells. Tumors need a blood supply to survive and grow. Without it, the tumor cells cannot survive.

Monoclonal antibodies (mAbs) are laboratory-made antibodies designed to target specific tumor antigens, which are substances on tumor cells that cause an immune response. They can flag targeted

cancer cells for destruction, block growth signals and receptors, and deliver other therapeutic agents directly to targeted cancer cells.

Different types of mAbs include the following:

Naked mAbs work by themselves. No drugs or radioactive particles are attached.

Conjugated mAbs have a chemotherapy drug or a radioactive particle attached to them. They deliver treatment to the cancer cells. Types include radiolabeled antibodies, which deliver radioactive particles, and antibody-drug conjugates, which deliver a chemotherapy drug (see Figure 1).

They attach to specific receptors or proteins on the cancer cell, get swallowed by the tumor cell and break down inside the cell, releasing the toxin and causing cell death.

Bispecific mAbs are made up of two different mAbs (see Figure 2). They can be used for engaging and activating immune cells, such as T-cells, to attack a tumor, block dual signaling pathways, block immune checkpoints or form a way to replace a missing functional protein.

FIGURE 1
ANTIBODY DRUG CONJUGATE

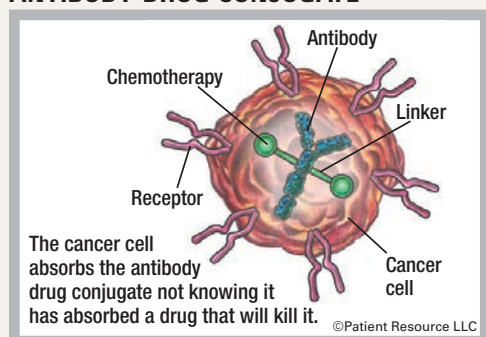
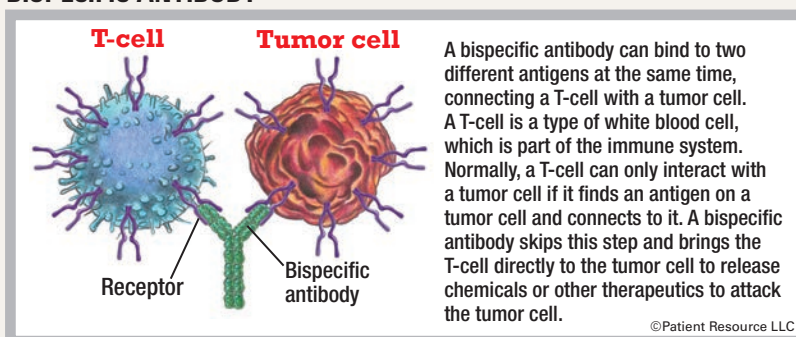


FIGURE 2
BISPECIFIC ANTIBODY



Being an informed patient is a critical safety measure

The advances being made in treating cancer are impressive, enabling medical professionals to continue to manage and cure more types of cancer. However, to do so, they may use powerful drug therapies that are often accompanied by side effects. Some can become serious, with the potential to be life-threatening. Such side effects are sometimes referred to as adverse events. Learn as much as you can about your diagnosis and your treatment plan so you can help reduce the risk — and benefit the most — from these aggressive therapies.

If your treatment plan includes a drug therapy that has the potential for a severe side effect, your health care provider will talk with you about the signs and symptoms to watch for, how to identify them and which require emergency care. Make sure you and a caregiver staying with you know whom to contact and how, especially after hours. Keep the lines of communication open, and do not hesitate to reach out immediately if you experience any symptoms. Prompt treatment

is necessary to keep these conditions from becoming life-threatening.

It is important to know that not all potentially severe side effects are ones you can recognize. Some are identified with lab work and imaging results, so it is crucial to stay on schedule with monitoring at your follow-up appointments.

Medical professionals typically measure the severity of your side effects using a grading scale. How your medical team treats your side effects will depend on how severe they are and which organ or system is affected. Your health care provider may pause your treatment, treat the side effects or refer you to a specialist. With careful management, medical professionals can often resolve reactions while preserving the effectiveness of the medication against cancer cells.

You are encouraged to carry identification that lists your cancer diagnosis, current treatments, oncologist's name and contact information, and cancer center. Keep it in your wallet, purse or phone so you can access it easily in case of emergency.

Following are some of the most common potentially severe side effects of cancer treatments.

» CYTOKINE RELEASE SYNDROME

▲ **Cytokine release syndrome (CRS)** can occur if immune cells affected by treatment rapidly release large amounts of cytokines into the bloodstream. This process can send the immune system into overdrive, leading to CRS.

A cytokine is a type of protein that is made by certain immune and non-immune cells, and it is a part of a healthy immune system. These small proteins help control the growth and activity of your blood cells and immune cells. Some cytokines stimulate the immune system and others slow it down. Cytokines tell your immune system to do its job. But, when too many cytokines are released, it can result in a cytokine storm, which can lead to high fever, inflammation, fatigue and nausea that can be severe or life-threatening and damage multiple organs.

When is CRS likely to occur?

CRS can happen from a few hours to some weeks after treatment with certain forms of immunotherapy, including bispecific T-cell engagers (BiTEs), chimeric antigen receptor (CAR) T-cell therapies or monoclonal antibodies (mAbs). It can also occur as a response to infection.

Some cases are mild but can become serious, causing inflammation throughout the body and problems with many organs. Without swift medical treatment, CRS can be fatal.

How CRS is managed

CRS must be treated by your health care provider. Some people who are treated with immunotherapy are at higher risk for CRS if they also have certain conditions or comorbidities.

Before treatment begins, if possible, inform your medical team if any of the following apply to you and ask whether they increase your risk of CRS:

- Age 65 and over
- Living in a group home or nursing care facility
- Diagnosed with any type of diabetes
- Living with heart disease
- Underlying health conditions that affect the immune system
- Obesity

When should you call your health care provider?

Following are symptoms of CRS that you can recognize and monitor at home; however, when they occur after you have been treated with a therapy that has the potential for CRS, you must consider them very serious and contact your health care provider right away. Common symptoms include:

- Persistent fever of 100.4 °F or more (or as indicated by your healthcare provider)
- Chills
- Nausea

- Fatigue and weakness
- Headache
- Rash
- Muscle aches and pain
- Fast or irregular heartbeat
- Difficulty breathing
- Confusion
- Dizziness
- Seizures

In addition, it is extremely important to stay on a strict schedule with your medical appointments to ensure your health care provider can monitor you for signs that you are unable to see on your own, such as the following:

- Low blood pressure
- High heart rate
- High respiratory rate
- Possible organ damage
- Abnormal liver and kidney test results
- Changes in blood clotting

If you show signs of CRS, your health care provider may give you fever-reducers and/or medications to lower the immune response caused by treatment, adjust or stop your dosage, or give you intravenous fluids, oxygen or medications to manage your blood pressure and heart function. You may have to be admitted to the hospital for treatment and monitoring.

» IMMUNE-RELATED ADVERSE EVENTS

▲ **Immunotherapy drugs work** by altering the way the immune system operates, and it is possible that they may cause the immune system to attack normal, healthy parts of the body, resulting in side effects. The most serious of these side effects are called immune-related adverse events. Some are low-grade reactions, and some can progress to become life-threatening. Knowing the symptoms will help you and your caregivers observe and report any potential problems to your health care provider.

When do these events occur?

Skin reactions tend to appear most quickly, at about 3 weeks after treatment begins; colitis usually begins after 1 to 3 doses of the medication, or about 6 weeks into treatment; hepatitis begins after 3 to 4 doses, or 8 to 12 weeks into treatment; and endocrine reactions tend to start 12 to 24 weeks into treatment. Ask your health care provider what you should expect and when so you are prepared in case a reaction occurs.

Table 1 details possible adverse events and symptoms.

Another type of irAE, immune effector cell-associated neurotoxicity syndrome (ICANS), may also occur. ICANS is a clinical and neuropsychiatric syndrome that can occur in the days to weeks following treatment with certain types of immunotherapy, especially immune effector cell (IEC) and T-cell engaging therapies. ICANS affects a person's nervous system. It is the second most common side effect of CAR T-cell therapy, often

following cytokine release syndrome. Symptoms include confusion, behavioral changes, inability to speak or understand speech, attention, thinking and memory problems, muscle weakness, muscle jerks and twitching, headache and seizures.

When should you call your health care provider?

Before treatment, discuss the signs to watch for and what to do if they occur. Keep your follow-up appointments because some of the signs are only discovered as a result of lab work and imaging tests. Report any symptoms immediately, and stay alert for symptoms for up to two years following treatment.

Once treatment is underway, be prepared for side effects before they occur. If you develop any of the signs of an immune-related response, contact your health care provider right away. Do not delay. Some of these are mild but can become severe or even life-threatening without swift medical attention.

Keep information about your diagnosis and your treatment, including the name of the drug, your oncologist and your cancer center, with you at all times. This is critical should you have an emergency or experience a side effect and you are not able to contact or seek care from a health care provider who is familiar with your treatment. Always tell the health care team there that you are on immunotherapy.

▲ TABLE 1
IMMUNE-RELATED ADVERSE EVENTS (irAES)

Body System	irAE	Symptoms & Signs*
Cardiovascular	Myocarditis	Changes in EKG reading, chest pain, impaired heart pumping function, leg swelling, rapid heartbeat, shortness of breath
Endocrine	Endocrinopathies	Alteration in mood, changes in menstrual cycle, diabetes, extreme fatigue, hyperthyroidism, hypothyroidism, persistent or unusual headaches, visual changes
Gastrointestinal	Colitis	Abdominal pain or cramping, bowel perforation, diarrhea with or without bleeding
Liver	Hepatitis	Abdominal pain, fatigue, fever, nausea, poor appetite, yellow skin or eyes (jaundice)
Nervous system	Neuropathies	A burning sensation or loss of feeling in the hands or feet, numbness, pain, sensory deprivation, sensory overload, tingling
Neurologic	Encephalitis	Changes in mood or behavior, confusion, extreme sensitivity to light, hallucinations, neck stiffness, seizures
Pulmonary/lung	Pneumonitis	Chest pain, fever, shortness of breath, unexplained cough
Renal/kidneys	Nephritis	Appetite loss, blood in urine, decreased urination, swollen ankles
Skin	Dermatitis	Blisters, itching, painful sores, rash, skin changes

*Side effects listed alphabetically. Talk to your health care provider about what to expect with your treatment plan.

» INFECTIONS

▲ **Infections occur when** harmful organisms (germs), such as bacteria, fungi and/or viruses, invade your body and multiply, resulting in disease, illness or damage to your organs and tissues.

Normally, your immune system destroys these harmful organisms before they can cause damage. However, because disease and its treatments weaken the immune system, it often cannot destroy the organisms fast enough, increasing the risk for infection.

Common disease-related causes of infection include:

- Cancers that directly affect the bone marrow, including leukemia and lymphoma

- Cancers that spread to the bone, disrupting the production of white blood cells
- Chemotherapy medications that lower the production of white blood cells
- Treatment side effects, such as stress, poor diet, sleeplessness and others, that weaken the overall function of the immune system
- Among people being treated with drug therapies, alone or in combination with other treatments, neutropenia is a common condition and can make the body more susceptible to infection (see *Neutropenia*, page 17, for ways you can help prevent infection).

When should you call your health care provider?

Report any of these symptoms immediately:

- Fever (oral temperature higher than 100.4 °F), chills and sweating
- Flu-like symptoms (body aches, general fatigue) with or without fever
- Cough, shortness of breath, painful breathing
- Sore throat or sores in your mouth
- Redness, pain or swelling on your skin
- Pus or drainage from any open cut or sore
- Diarrhea (loose or liquid stools)
- Pain or burning with urination
- Vaginal drainage or itching

» TUMOR LYSIS SYNDROME

▲ **Tumor lysis syndrome** (TLS) is a life-threatening condition that can occur after treatment of a fast-growing cancer, especially certain blood cancers such as leukemia and lymphoma. TLS is usually linked with chemotherapy, but other types of cancer treatment may also lead to this syndrome.

As tumor cells die, they break apart and release their contents, including potassium, phosphate and tumor DNA, into the blood. This causes a change in electrolytes and certain chemicals in the blood, which may cause damage to the nervous system, kidneys, heart, liver and other organs or increase the level of potassium in the blood.

If you have one of the following diagnoses most commonly linked with TLS, ask your health care provider whether the therapies in your treatment plan have TLS as a potential side effect:

- Acute lymphocytic leukemia
- Acute myeloid leukemia
- Burkitt lymphoma
- Chronic lymphocytic leukemia
- Large-cell lymphoma (type of non-Hodgkin lymphoma)
- Small cell lung cancer

Some of the factors that can increase your risk of TLS during cancer treatment are identified from test results, making it important to make and keep your follow-up appointments for lab work and imaging scans:

- High white blood cell level
- High blood uric acid level
- Kidney problems
- Dehydration
- Late-stage cancer
- Large tumor size

If it is determined that you have a high risk of TLS, you may stay in the hospital during treatment so your medical team can monitor you closely with lab tests and blood work and deliver intravenous fluids and medications to help prevent TLS.

Whether you are deemed high or low risk, you are encouraged to keep information about your diagnosis and your treatment, including the name of the drug, your health care provider and your cancer center, with you at all times. This is critical in the event you experience TLS and you have to contact a health care professional who is unfamiliar with your treatment.

When does TLS usually occur?

The symptoms of TLS typically begin 12 to 72 hours following treatment. On rare occasions, it may occur before starting any cancer treatment or after a biopsy of a tumor.

When should you call your health care provider?

Because of the life-threatening potential of TLS, it is critical to contact your health care provider right away if you experience any of the following signs or symptoms:

- Vomiting
- Diarrhea
- Muscle cramps or twitches
- Peripheral neuropathy (numbness or tingling in your hands and feet; see *Peripheral Neuropathy*, page 18)
- Decreased urination

These symptoms should be considered an emergency because TLS can potentially cause damage to the kidneys, heart, liver or other organs. The result can be loss of muscle control, seizures, kidney, liver or heart failure, or even death.

» INFUSION-RELATED REACTIONS

▲ **An infusion-related reaction** can occur when your body has a strong, adverse immune response to a treatment that is administered intravenously (IV) into a vein, subcutaneously (under the skin) or by injection. Chemotherapy, targeted therapy and immunotherapy can cause this reaction.

Reactions are generally mild, such as itching, rash or fever. More serious symptoms, such as shaking, chills, low blood pressure, dizziness, breathing difficulties or irregular heartbeat, can be serious or even life-threatening without medical intervention.

When do these reactions occur?

Infusion-related reactions most frequently occur soon after exposure to the drug, sometimes even as you are receiving the infusion. Your nurse will be watching for signs of a reaction while you are there. However, they can occur days or weeks later, which makes it important to be vigilant about watching for the symptoms.

How you can help manage an infusion-related reaction

These reactions are often difficult or impossible to avoid, so being able to recognize the following symptoms and report them immediately is important:

- Itching
- Rash or hives
- Swelling of the tongue, lips or eyelids
- Redness on the face and neck area, also called flushing
- Fever or chills
- Cough
- Nausea
- Muscle or joint pain
- Swelling (most common in the hands, legs, ankles and feet, but can occur in any part of your body)
- Shortness of breath

When should you call your health care provider?

Any type of medication can cause a reaction, but certain drugs tend to have a higher

reaction potential than others. Before treatment begins, ask whether the drugs in your treatment plan put you at risk for a reaction, what to do if one occurs and which reactions require immediate medical attention.

In addition, a personal history of reactions to medications, foods or something in the environment can put you at higher risk for a severe reaction to your cancer treatment. If you have had a severe reaction in the past or you think you may be at risk because of allergies, tell your health care provider before treatment begins.

Contact your health care provider as soon as you experience symptoms of an infusion-related reaction.

As a safety precaution, carry information about your diagnosis and the medications included in your treatment plan with you at all times. Also include the contact information for your health care provider and your cancer center. This is critical should you have an emergency or experience a side effect and you are not able to contact or seek care from a provider who is familiar with your treatment. ■

➔ **Kristine Breski's life has taken quite a few unexpected turns. After receiving two cancer diagnoses by the time she turned 30, she has gracefully pivoted to using her own experiences to help others find hope and strength when facing cancer.**

Challenges inspire survivor to help others

After seeing many specialists over a span of 3 years seeking a solution for leg pain, a kind orthopedic surgeon told me he suspected I had cancer. I'd had degenerative disc disease since I was 16, so other doctors had felt it was tied to that. When I heard the word cancer, I fell back on the examination table in disbelief. It felt surreal — like I was in a movie that needed a happy ending.

The orthopedic surgeon referred me to a well-known cancer center. After two bone marrow biopsies in my left tibia, I learned I had primary large B-cell non-Hodgkin lymphoma. It had begun in the bone marrow and metastasized. This diagnosis usually affects males between 40 and 60. I was a 26-year-old female, so my medical team called me a unicorn.

The doctor encouraged me to begin a strong chemotherapy regimen immediately. It would very likely make me infertile, but he was concerned that we didn't have time to harvest my eggs. I made the difficult decision to move forward with the chemo, and my care team discussed other common side effects I could expect and when they might happen. They were encouraging, and I could tell they were trying to help me stay optimistic.

About two weeks after my first round of chemotherapy, my hair began to fall out in clumps. I wanted to turn something negative into something positive, so I went online and found Wigs for Kids, an organization that provides free wigs to kids facing hair loss. My husband Tim shaved my head, then shaved his, and I donated my hair.

I preferred hats to wigs and thanks to the generosity of my friends and family, I had a bunch to choose from. I wore them all the time. They became my comfort blanket. Even now, when I'm feeling uncomfortable for any reason, putting on a hat makes me feel better.



Nausea, a strong metallic taste in my mouth and mouth sores caused me to lose my appetite and about 13 pounds. I turned to my care team and my nurse navigator, Barb, who gave me a lot of advice. I would message her on the medical portal at all hours. Sometimes she responded late at night; otherwise it was first thing in the morning. She also worked with my insurance company and provided documentation for my employer when it was needed. She is a saint.

My care team suggested using plastic silverware instead of metal, and that helped. They also recommended magic mouthwash. It numbed my mouth and, because it was the prescription kind that could be swallowed, it also numbed my esophagus. Just a heads up, it feels really odd the first time you use it, almost like you can't swallow. But you can, and it provides fantastic relief.

Getting dehydrated was a risk, and they encouraged me to get down any liquids I could. For a while, I lived on a steady diet of Jello and ice cream, and to be honest, I was okay with that. I also found a lot of comfort in my dad's homemade chicken and rice soup.

I don't know how Barb and the care team have enough hours in the day to do everything they do. Tim and I did sweet things like bring in specialty chocolates from our hometown just to remind them how much we appreciate them, something I don't think they hear often enough.

At times I struggled, and Tim encouraged me to keep going. We had only been married three and a half years. Our life together was just beginning. And my brother, who is 11 years younger than me, wouldn't understand if I gave up. I was determined to keep on fighting.

Support is available

CAREGIVERS & SUPPORT

- Cactus Cancer Society** www.cactuscancer.org
- CanCare** www.cancare.org, 713-461-0028
- CANCER101** www.cancer101.org, 646-638-2202
- CancerCare** www.cancercare.org, 800-813-4673
- Cancer Connection** www.cancer-connection.org, 413-586-1642
- Cancer Hope Network** www.cancerhopenetwork.org, 877-467-3638
- Cancer Really Sucks!** www.cancerreallysucks.org, 319-393-9681
- Cancer Support Community** www.cancersupportcommunity.org, 888-793-9355
- Cancer Survivors Network** csn.cancer.org, 800-227-2345
- Caregiver Action Network** www.caregiveraction.org, 855-227-3640
- CaringBridge** www.caringbridge.org, 651-789-2300
- Cleaning for a Reason** www.cleaningforareason.org
- Connect Thru Cancer** www.connectthrucancer.org, 610-436-5555
- Family Caregiver Alliance** www.caregiver.org, 800-445-8106
- Friend for Life Cancer Support Network** www.friend4life.org, 866-374-3634
- The Gathering Place** www.touchedbycancer.org, 216-595-9546
- Guide Posts of Strength, Inc.** www.cancergps.org, 336-883-4483
- Imerman Angels** www.imermanangels.org, 866-463-7626
- Living Hope Cancer Foundation** www.getupandlive.org
- Lotsa Helping Hands** www.lotsahelpinghands.com
- MyLifeLine** www.mylifeline.org, 888-793-9355
- National LGBT Cancer Project** www.lgbtcancer.org, 917-301-1913
- Patient Empowerment Network** www.powerfulpatients.org, 833-213-6657
- SHARE Caregiver Circle** www.sharecancersupport.org/caregivers-support, 844-275-7427
- Well Spouse Association** www.wellspouse.org, 732-577-8899
- Wigs & Wishes** www.wigsandwishes.org, 856-582-6600

FERTILITY & CANCER

- Alliance for Fertility Preservation** www.allianceforfertilitypreservation.org
- American Society for Reproductive Medicine** www.reproductivefacts.org, 202-863-4985
- Livestrong Fertility** www.livestrong.org/what-we-do/program/fertility, 855-844-7777
- RESOLVE The National Infertility Association** www.resolve.org, 703-556-7172
- SaveMyFertility** www.savemyfertility.org, 517-884-8848

LYMPHEDEMA

- Lymphatic Education & Research Network** www.lymphaticnetwork.org
- Lymphedema Treatment Act** www.lymphedematreatmentact.org
- National Lymphedema Network** www.lymphnet.org, 800-541-3259

NUTRITION

- American Cancer Society** www.cancer.org, 800-227-2345
- CancerCare** www.cancercare.org, 800-813-4673
- Cancer Support Community** www.cancersupportcommunity.org, 888-793-9355
- LLS | PearlPoint Nutrition Services** www.pearlpoint.org, 877-467-1936

PAIN MANAGEMENT

- American Chronic Pain Association** www.theacpa.org, 913-991-4740
- American Society of Anesthesiologists** www.asahq.org, 847-825-5586
- Cancer Pain Research Consortium** www.cancerpainresearch.com, 707-260-0849
- U.S. Pain Foundation** www.uspainfoundation.org, 800-910-2462



Scan for more Resources

PatientResource.com/Patient_Support_Groups

Tim is quite possibly the best human being on the planet. He was my main source of support. He was there for me in ways that I never anticipated another person could be. I truly believe that God made him for me. We joke that he has become the new standard of “man” in our family. All guys we meet now are unknowingly being judged ... But, is he a “Tim?”

After all the treatments, I still had severe leg pain, and a PET scan revealed cancer cells in my left tibia. Twenty rounds of radiation therapy later, the pain was still intense. They found that the plugs from the two bone marrow biopsies had melted, making holes in the bone. A carbon fiber rod and cadaver bone were inserted. We found that whenever the weather turned cold, my pain intensified, so we quit our jobs and moved to a warmer climate.

About a year after the move, I was diagnosed with a second cancer that was completely unrelated to my first. There is a one in a million chance of being diagnosed with synovial sarcoma, a rare soft tissue sarcoma, and I had it in my left hand. A wonderful sarcoma specialist performed two surgeries before declaring me no evidence of disease. It happened so fast that I almost didn't believe it.

This experience took a toll on my emotional well-being, but I didn't want my family and friends to see that. Instead I put up a strong front, which hid the fact that I was experiencing depression. I met with an oncology therapist a few times, but it wasn't until we moved that I found one I really connected with. She is phenomenal, and I feel like myself again. Medication, adult coloring books, exercise, power cleaning and reading help me relax.

I've always been a reader, but with everything going on, I didn't have the time or energy to do it. When my mother-in-law gave me Robin Roberts' book about her cancer journey, *Everybody's Got Something*, I made it a nightly ritual to read a little before bed. Her story really changed my mindset. It wasn't that I was having a pity party, but I did wonder what I'd done in my life to deserve this. Her book reminded me that you could be the best person in the world and still have something like this happen. I stopped thinking, “Why me?” and switched to “Why not me?” That planted the seed for wanting to give back.

I started by participating on two Light the Night teams to raise funds for the local chapter of the Leukemia & Lymphoma Society. When LLS asked me to share my story, I was terrified but I did it. It turned on a switch inside of me, and now I'm passionate about raising cancer awareness. I am an Honored Hero for the LLS Visionary program. As one of the “faces of the disease,” I have made the first of many videos that provides inspiration and support to staff members, event participants and volunteers who support the mission of LLS.

I speak from experience when I say that I don't think enough time is spent on preparing young adults for life after cancer. I've had people ask me, “So you're good now, right?” There is much more to survivorship than that, like dealing with infertility, long-term effects and what is next for someone who can't work at such a young age. As an advocate, I address topics like these and provide encouragement to people with cancer through other nonprofit organizations, including Friend for Life Cancer Support Network. I am a patient consultant on a Cancer Panel for the Department of Defense - Congressionally Directed Medical Research Programs. I've also presented to new residents at a medical school about how to communicate and work best with people who have cancer from the patient perspective.

It turns out my body is a bit of a unicorn in side effects, too, meaning I've experienced different effects than most people. I was diagnosed with Complex Regional Pain Syndrome, a neurological pain disorder, and Inappropriate Sinus Tachycardia, a heart condition. Both require daily medication.

Did I ever get my happy ending? I believe I have because I have a wonderful husband and family and life, and I get a lot of joy out of helping others.

At the end of the day, regardless of your diagnosis or treatment, remember that it is okay to feel down and scared. But, whatever you do, don't get stuck thinking about what could go wrong or the unknowns. Look for small blessings along the way. Life is unpredictable. No one, whether you have cancer or not, is guaranteed tomorrow. Live your life in the now, and don't let your fears for tomorrow limit you. ■

Communicating with your medical team is key to managing treatment

Although most cancer treatments have side effects, it may comfort you to know that advances in research have made it possible to minimize and even prevent some of them. The key is communication. As you talk about your treatment options with your health care provider, discuss the potential side effects of each option so you consider them based on your expectations for your quality of life. Ask how to recognize symptoms and when to expect them. Make sure you know what to do if a side effect occurs and when to seek medical attention.

Continue to update your health care team between your follow-up appointments about your symptoms, including when they occur, how they make you feel and whether anything relieves them. You can download a free tracker at PatientResource.com/Tracker to help you remember the details. Addressing side effects early is important because when you feel better, you will be more likely to stay on your treatment plan.

This section contains some of the most common side effects of cancer treatment.

» COGNITIVE DYSFUNCTION

▲ **During treatment**, many people report thinking and memory problems, as if they are in a “mental fog.” They have trouble remembering information such as names, dates and telephone numbers. Many say they have memory lapses in the middle of tasks or conversations and have difficulty paying attention. These symptoms all represent cognitive dysfunction, which is commonly known as “chemo brain.” Originally thought to accompany chemotherapy only, research has shown that cognitive dysfunction is related to many types of cancer treatment, affecting attention, concentration, short-term memory, language skills, organizational ability and math skills. These problems are not typically serious but can certainly be frustrating and affect your quality of life.

What causes cognitive dysfunction?

The cause of cognitive dysfunction, commonly referred to as chemo brain, may be caused by the cancer itself or by its treatment, such as chemotherapy, radiation therapy, hormone therapy and surgery. Combination therapies further increase the risk. It may also be caused by conditions related to cancer treatment, such as anemia, fatigue, infection, pain, hormone changes, sleep problems, nutrition problems, stress, anxiety and depression.

When does cognitive dysfunction typically occur?

Cognitive dysfunction often begins slowly. It can occur during treatment as well as months or years after the end of treatment. It is generally short-term, but how long it lasts varies from person to person.

How you can manage cognitive dysfunction

Research is underway to determine how to best manage cognitive dysfunction. Some people find the following helpful:

- Track your symptoms so you and your health care team can see any patterns. Note when they occur, how soon after treatment they start and whether anything makes them better. Download a free symptom tracker at PatientResource.com/Tracker.
- Use a calendar or daily planner. Write down all appointments, activities, medication schedules, important dates (birthdays and anniversaries), “to do” lists, phone numbers and addresses, etc.
- Keep important items, such as your keys, wallet, purse and phone, in a basket in the same place so they are always where they should be.
- Exercise your brain. Read a book or magazine every day, do crossword puzzles or word or number games, do jigsaw puzzles, play card games, play a musical instrument or learn a new language.
- Get physical exercise. Walk, swim, ride a bike, do aerobics, practice yoga or garden.
- Avoid alcohol and other substances that can disrupt your cognitive function.
- Follow a nutritious diet.
- Stay rested. Fatigue can worsen cognitive dysfunction.
- Don't try to multi-task. Focus on one thing at a time.
- Ask for support. Tell friends and family that you're having cognitive problems.
- Ask people to repeat information or to

write down new information (phone numbers, dates, etc.). Take a caregiver or friend with you to medical appointments to help you keep track of what is said during the visit and share their opinion of your cognitive issues.

When to call your health care provider

Before treatment begins, if possible, ask about the possibility you may experience cognitive dysfunction. If you are at risk, consider your age, predisposition for cognitive decline or any other condition that may worsen if you begin a therapy that has cognitive dysfunction as a side effect.

Contact your health care team when you first notice symptoms. Your health care provider may order blood tests and neuropsychological testing to see whether they are caused by a condition something other than your treatment, such as anemia, a chemical imbalance in your blood, dementia or Alzheimer's disease.

If no underlying cause is found, your health care provider will suggest ways to cope and improve your mental processing. Additional treatment options are available for cognitive dysfunction that gets worse or continues for many months after treatment.

If you notice your symptoms suddenly get worse or you have new ones, contact your health care team right away. They can evaluate whether they are signs of metastasis or another medical issue. If you have any other neurological symptoms such as headaches, new balance problems or weakness/numbness in a body part, an MRI of the brain may be recommended.

» ANEMIA

▲ **Anemia is an abnormally** low number of red blood cells in your bloodstream. The low number of these cells means there is not enough hemoglobin (an iron protein), the part of the red blood cell that carries oxygen from your lungs to the rest of your body. When anemia is moderate to severe, the body tissues do not get enough oxygen.

Anemia often causes fatigue and weakness. Other signs may include:

- Fast heartbeat
- Shortness of breath
- Dizziness
- Feeling chilled
- Chest pain
- Swelling in the hands and/or feet
- Pale skin

These symptoms usually occur gradually and get worse as the hemoglobin level decreases.

What causes anemia?

Anemia occurs when the bone marrow or kidneys are damaged from cancer or its treatment, which reduces red blood cell production. Treatments that can increase the risk for anemia include chemotherapy, immunotherapy and radiation therapy.

Platinum-based chemotherapy drugs may damage the bone marrow or tissues in the kidneys that help produce erythropoietin, which is naturally produced in the kidneys

and stimulates bone marrow to make red blood cells. Risk of anemia also increases when chemotherapy is combined with radiation therapy, particularly when radiation is directed at certain bones rich in bone marrow (such as the pelvis, legs, chest or abdomen).

Certain types of cancer can also cause low numbers of red blood cells, which damage bone marrow.

Other causes include nausea, vomiting and loss of appetite, which may deplete the nutrients your body needs to produce red blood cells, such as iron, vitamin B12 and folic acid. Too much blood loss from surgery or a tumor causing internal bleeding can also result in anemia.

When does anemia typically occur?

Anemia related to drug therapy can occur any time during treatment. It is usually corrected within one to two weeks after treatment ends.

Your health care provider will measure your hemoglobin level during your treatment, and if the level is too low, treatment may be delayed until it increases. Anemia may be managed in several ways, depending on the cause. The goal is to increase the hemoglobin level, and this will alleviate symptoms. Medication, increasing the iron and folic acid in your body with supplements or food, or a blood transfusion may be recommended. Exercise, such as walking, has been shown to increase the hemoglobin level in your blood.

How you can manage anemia

Your health care provider may recommend supplements and vitamins you can take to increase your iron levels, including iron, folic acid or vitamin B12. An over-the-counter iron supplement may help, but you should not take a supplement without consulting your health care provider. Eating foods high in iron, which include green, leafy vegetables; dried fruit; seafood, chicken and beef; eggs; and nuts may also help. Foods high in folic acid include asparagus, broccoli, spinach, lima beans and enriched breads and cereals.

If you are experiencing fatigue caused by anemia, consider the following.

- Conserve your energy. Choose to do the most important tasks each day. If people offer to help, let them.
- Strive for a consistent sleep schedule. Taking short naps may help, but too much sleep may make you feel weak.
- Exercise. A daily short walk or brief exercise may be helpful.
- Eat nutritiously. Consult a registered dietitian for assistance.

When to call your health care provider

Ask about the risk of anemia with your treatment plan. Call your health care provider if you feel extremely tired and weak; feel dizzy or short of breath or have difficulty breathing; and/or experience a rapid heartbeat, heart palpitations or chest pain.

» THROMBOCYTOPENIA

▲ **Various treatments** can interfere with the body's ability to make platelets. The result is thrombocytopenia, and it can lead to bleeding and clotting problems.

When does thrombocytopenia typically occur?

Thrombocytopenia typically occurs within about a week following the beginning of treatment. It often corrects itself, which means platelets return to an appropriate level, after the conclusion of treatment.

How you can help manage thrombocytopenia

Help lower your risk of thrombocytopenia by doing the following:

- Be gentle when you blow your nose, and

use a room humidifier to prevent nosebleeds.

- Choose an electric shaver instead of a razor to avoid cuts.
- Be especially careful when handling sharp objects, such as scissors or knives, to avoid cutting yourself.
- Avoiding flossing, using an extra-soft toothbrush, and eating soft foods to protect your mouth and gums.
- Wearing loose-fitting clothing to avoid skin irritation.
- Avoiding high-contact activities to protect against bruising.
- Avoiding alcohol and aspirin (which can slow the production of platelets and thin your blood) without your health care provider's permission.

When to call your health care provider

Call your health care provider if you experience any of the following:

- Unexplained bruising
- Bleeding that doesn't stop by itself
- Tiny red spots on your skin
- Nosebleeds, bleeding from your gums and/or blood in your urine or stool
- Vomiting blood or something that looks like coffee grounds
- In women, heavier menstrual periods or bleeding when it is not your period
- Severe headaches and/or vision changes

If you have a serious injury or unexpected bleeding, go to the nearest emergency room and tell them you are receiving cancer treatment and may have a low platelet count.

» BONE LOSS

▲ **Cancer and its treatments** can cause bone loss and damage, resulting in bone pain and fractures. Bone destruction can also be caused by cancer that has spread, which can weaken bone and cause pain. Inactivity, or a lack of physical activity, can also contribute to bone loss. Your health care provider may order a bone density scan, also known as a dual-energy X-ray absorptiometry (DEXA scan), before treatment begins to get a baseline measurement of your bone mass that can be compared with measurements taken later.

What causes bone loss?

Certain drug therapies may cause thinning of the bones. In addition, chemotherapy can reduce calcium levels in the body, which can lead to bone loss. Steroids can interfere with the body's ability to absorb calcium, which could result in bone loss. Some hormone therapies, such as aromatase inhibitors, can cause it for women depending on their menopausal status. Men being treated with hormone therapies are also at risk.

Radiation therapy results in bone loss

only to the part of the body that was treated, but it may not occur for several years. In younger patients, radiation therapy can cause growth-hormone deficiency and delayed bone growth, which can increase the risk of fractures later in life.

When does bone loss typically occur?

Cancer treatment often increases the risk of osteopenia (mild bone degeneration) or osteoporosis (severe bone loss); however, the rate of bone loss depends on your unique characteristics, including age, bone health before diagnosis, family history of osteoporosis, menopausal status and treatment.

Radiation therapy typically does not immediately affect bone health. Deterioration can take several years, making it important to continue to keep follow-up appointments.

How you can manage bone loss

Maintain a consistent follow-up schedule for tests that can detect bone problems, and choose healthy habits such as the following:

- Take medications, vitamins or supple-

ments as prescribed by your health care provider.

- Eat foods that are rich in vitamin D3 to help your body absorb calcium.
- Maintain a healthy body weight. Being underweight increases bone loss risk.
- Walk, jog or perform other weight-bearing exercises to help stimulate cells that help grow bones and build muscle.
- Do not smoke or use tobacco products.
- Limit your alcohol consumption.
- Take safety precautions to prevent falls.

When to call your health care provider

Report pain as soon as it occurs. You may be at increased risk if you experience signs of bone deterioration, including joint or back pain, arthritis-like symptoms, slouched posture or shorter stature. The vitamin D3 level in your blood will be checked periodically to ensure it is at a level of 30 or above. Sometimes, a PET/CT or MRI may be needed to determine whether cancer has spread to the bone. Call your health care professional right away if you break or fracture a bone.

» HAIR LOSS

▲ **Alopecia, commonly referred** to as hair loss, is the abnormal loss of hair on the head and elsewhere on the body, such as eyelashes, eyebrows, in the armpit and pubic area, and on arms and legs.

What causes hair loss?

Chemotherapy, radiation therapy and some other drug therapies work by killing rapidly dividing cells. Because cells in the hair follicles divide rapidly, they may be damaged by these treatments.

When does hair loss typically occur?

Hair loss from drugs usually begins within 10 to 14 days after the start of treatment and increases within 1 to 2 months. In some instances, hair loss may begin with a sensation of the scalp itching, and within a few hours, hair begins to fall out. Hair on the head often falls out in clumps during shampooing or brushing, or even during sleep.

Hair usually begins to grow back 4 to 6 weeks after the end of treatment with drug therapy. In general, it grows at a rate of about one-quarter inch per month. For radiation

therapy, only the areas where radiation is directed experience hair loss. Hair tends to grow back after several months, but it may be thinner or a different texture.

Not every person will lose their hair, even when taking the same drug or having the same treatment that causes hair loss in someone else. In some instances, hair loss is permanent.

Some drug therapies, such as hormone therapy, immunotherapy and targeted therapy, do not cause hair loss. Instead, hair may thin, become dry or change in texture.

Preventing some hair loss may be possible with a technique called scalp cooling. A helmet-shaped cooling cap is worn before, during and after chemotherapy is given. The cold temperature reduces blood flow to the head, preventing the chemotherapy drugs from destroying the cells in the hair follicles. To learn more about the risks and benefits and insurance coverage, talk with your health care provider before treatment begins.

How you can help manage hair loss

First, decide what will make you most com-

fortable with your appearance.

Consider wearing a wig. To make it eligible for health insurance coverage, request a prescription from your health care provider for a "skull prosthesis for hair loss caused by radiation or chemotherapy treatment." Contact your local American Cancer Society office to learn about free wigs.

Use a scarf, hat, cap or other head covering. Your scalp may be tender from treatment, so protect it against cold and sunlight. Use sunscreen when you are outside.

Be gentle to your hair as it grows back or as it thins. Use a soft-bristle brush and/or a wide-toothed comb. Avoid shampoos with strong chemicals or fragrances and hair dryers, curling irons, straighteners and elastics that pull on or break hair. Do not bleach or color your hair or get a permanent. Sleep on a satin pillow case to decrease friction.

When to call your health care provider

Talk about hair loss before treatment so you are prepared. Ask for referrals to support groups. Learning how other people cope with hair loss can also help.

» DIARRHEA AND CONSTIPATION

▲ **Diarrhea is the passing of** loose or watery stools three or more times a day. It may also be accompanied by cramps in the abdomen and pain or discomfort in the rectum. When mild, diarrhea is an inconvenience, but left untreated, it can lead to serious problems, such as dehydration, loss of important nutrients, weight loss and fatigue.

Constipation occurs when your stool becomes hard, dry and difficult to pass, and bowel movements occur less frequently than normal. Other symptoms may include painful bowel movements, and feeling bloated, uncomfortable and sluggish.

What causes diarrhea?

Causes may include treatment, the cancer itself, certain foods, and conditions and medications not related to cancer.

Treatments that can cause diarrhea include chemotherapy, immunotherapy, targeted therapy, radiation therapy to the pelvis, surgical removal of a part of the bowel, and Graft-versus-Host Disease, a side effect of bone marrow/stem cell transplantation.

Cancers that affect the pancreas, colorectal cancer and neuroendocrine tumors of the gastrointestinal tract can cause diarrhea.

Other conditions and medications that may lead to diarrhea include:

- Antibiotics
- Infection with *Clostridium difficile*, a bacterium also known as *C. diff*
- Inability to digest certain foods
- Infection with other bacteria
- Irritable or inflammatory bowel disease
- Viral infection

When does diarrhea occur?

Treatment-related diarrhea is usually a short-term side effect that typically occurs within the first few days or weeks after treatment and typically resolves within a few weeks after the end of treatment.

How you can manage diarrhea

Following a bland diet can help prevent or lessen diarrhea. Once diarrhea occurs, switching to only clear liquids may help the lining of your intestines heal. Clear liquids include water, cranberry juice, ginger ale, clear broth, popsicles, decaffeinated tea and gelatin. As diarrhea begins to improve, you can slowly add solid foods to your diet, starting with low-fiber foods (such as white rice or noodles).

When you have diarrhea, your body loses fluid and important minerals. Drink plenty of clear liquids to help replace fluids in your body. Eat foods that are high in potassium, such as spinach and bananas, as this important mineral is often lost during diarrhea.

Over-the-counter medicines are available to control diarrhea, but be sure to consult your medical team before taking them. If diarrhea is severe, a prescription may be necessary.

Severe diarrhea may cause discomfort in the rectal area. To help soothe the area, clean the external rectal area with warm water and soap after bowel movements, soak in a warm bath or use a water-repellent cream.

Suggestions to help prevent and control diarrhea:

- Drink six to eight glasses of fluid per day.
- Avoid beverages with alcohol or caffeine, such as beer, wine, cola, coffee and tea.
- Eat bland, low-fiber foods, such as white rice, boiled chicken, noodles and bananas.
- Eat foods high in protein, calories and potassium that are easy to digest, such as eggs, baked potatoes, cooked cereals, bananas, macaroni and pasta, white toast, applesauce, apricots, crackers, pretzels and smooth peanut butter.
- Eat more frequently but in smaller amounts.
- Avoid foods that are high in fat, including fried or greasy food and cream sauces.
- Avoid food that can irritate the digestive tract, such as milk products, chocolate, dried fruits, beans, popcorn, or spicy, greasy or fried food.

When to call your health care provider

Talking about diarrhea may seem embarrassing, but it is important to control diarrhea to avoid complications. Ask about your risk for it before treatment begins and share what your normal bowel regimen is. For example, if you have a history of irritable bowel syndrome (IBS), your health care provider may start you on an anti-diarrheal medication sooner, rather than waiting for diarrhea to strike.

Consult with your health care provider before taking over-the-counter medications and again if your diarrhea does not improve with them, especially if you have recently

been taking antibiotics. Call if you experience any of the following:

- Six or more loose bowel movements per day for more than two days in a row
- Blood in the stool, around the anal area, on the toilet paper, or in the toilet bowl
- Inability to urinate for at least 12 hours
- Signs of a fever
- Loss of five pounds or more after the diarrhea starts
- A swollen and/or painful abdomen
- Dizziness or light-headedness when moving to a standing position

What causes constipation?

Cancer drugs can affect your bowel cycle because they disrupt nerve signals to your abdomen. Pain-relieving medications can also reduce your bowel activity. Constipation may also be caused by lifestyle changes, especially if you are less active during treatment. A change in your diet can also affect your bowels, especially if you are drinking fewer fluids and eating less fiber. Many other imbalances within your body during treatment can affect your ability to pass stools.

When does constipation typically occur?

Constipation can happen at any time during treatment and depends greatly on its origin. If the constipation is related to your drug therapy, it is typically worse during treatment and will lessen in the weeks following your last dose. If it is related to diet or lifestyle, it will likely improve as you change your diet or practices to promote healthier stools.

How you can manage constipation

The best way to manage constipation is to prevent it. Talk to your health care provider about preventive medications, dietary changes or lifestyle changes. In addition, drink more liquids, eat more fiber or take fiber supplements, and be more active.

When to call your health care provider

Let your health care team know if you experience constipation for more than a day. They may want to monitor your symptoms.

Trying to stay hydrated during this time is very important.



Laretta Dortch, Stage IV colon cancer survivor

» FATIGUE

▲ **Cancer-related fatigue** is an ongoing lack of energy and sense of exhaustion. It is a much more intense feeling than the tired feeling felt by healthy people, and it isn't relieved by sleep. It is one of the most common and most challenging side effects for many people.

Although the exact cause isn't known, theories suggest that it could result from healthy cells and tissues becoming inflamed or damaged by cancer and its treatments or that your body is working extra hard to repair that damage. Additionally, it appears that fatigue is often worse in people who have a combination of treatments, have advanced cancer or are elderly.

What causes fatigue?

This common side effect can be caused by many cancer treatments, including chemotherapy, targeted therapy, immunotherapy, radiation therapy, bone marrow/stem cell transplantation and surgery. Conditions such as anemia, pain and mental stress can also cause or worsen fatigue.

When does fatigue typically occur?

Fatigue that is due to cancer and its treatment can last for weeks, months or years and depends on the type of treatment and how much treatment is received.

For people who have surgery for cancer with no other treatment, fatigue is likely to last for a few days to a few weeks after surgery. It is commonly caused by side effects from general anesthesia, as well as your body recovering from having had an operation.

For patients receiving chemotherapy, targeted therapy or immunotherapy in cycles, fatigue often gets worse at first and may get better until the next treatment, when the pattern starts again. Once treatment is complete, the fatigue often lessens within a few months but may last up to a year.

Fatigue as a result of radiation therapy tends to worsen as the treatment goes on. It

usually lessens within a few weeks to a few months after treatment is complete.

You can also expect fatigue from a bone marrow/stem cell transplant, which is typically accompanied by chemotherapy, to last for up to a year.

How you can manage fatigue

These suggestions may help.

- **Exercise.** Although many people think exercise will increase fatigue, the opposite is actually true. Regular exercise, such as walking or riding a bike, is the best way to help manage and reduce your fatigue. Taking short walks and getting light exercise several times a week can actually increase your energy level.
- **Practice good sleep hygiene.** Be consistent. Go to bed and get up at the same time each day, including on the weekends. Keep your bedroom quiet, dark and at a comfortable temperature. Do not look at electronic screens before bed. Avoid large meals, caffeine and alcohol before bedtime. Be physically active during the day because it can help you fall asleep more easily at night.
- **Balance rest and activity.** Do activities that are relaxing for you. Listen to music, read, meditate, practice guided imagery or spend time with people you enjoy.
- **Plan time to rest.** If you are tired, take short naps of less than 1 hour during the day. However, too much sleep during the day can make it difficult to sleep at night.
- **Don't overdo.** Prioritize the activities that are most important to you and do them when you have the most energy. Ask for help with important tasks such as making meals or driving.
- **Address cancer-related pain.** Unrelieved pain may affect your activity level, appetite, ability to sleep and emotional well-being, all of which may add to your fatigue. Don't be afraid to tell your health care provider or nurse that you have pain

or ask for a referral to a pain or palliative care specialist.

- **Seek relief from other symptoms.** Practice strategies to relieve symptoms that may contribute to fatigue, such as nausea, vomiting and depression. If you need additional help, ask your health care provider for ways to manage them.
- **Reduce stress.** Consider meeting with a psychiatrist or therapist to learn how to manage stress. Supportive expressive therapies, such as support groups and journaling, may help.
- **Eat and drink well.** Meet with a registered dietitian to learn about foods and drinks that can increase your energy level, such as foods high in protein and calories. Some people find it easier to eat many small meals throughout the day instead of three big meals. Stay well hydrated. Limit your intake of caffeine and alcohol.
- **Coordinate with your work schedule.** If you plan to work during treatment, talk to your supervisor or your Human Resources department about the potential for fatigue on the job and ways you can manage it, such as taking time off or scheduling important tasks for times when fatigue may be at its lowest.
- **Ask for a referral to a cancer rehabilitation facility.** Before treatment, if possible, ask your medical team whether you have access to a rehab facility that offers proven techniques for reducing fatigue.

When to call your health care provider

Tell your health care team if fatigue is preventing you from being able to carry out your normal activities or if you are very tired even after resting or sleeping. Keep track of your energy levels throughout the day to help them assess your fatigue. Write down how it affects your daily activities and what, if anything, makes the fatigue better or worse.

Download a free side effects tracker at PatientResource.com/Tracker.

Call immediately if you have the sudden onset of any of the following symptoms:

- Confusion
- Dizziness or loss of balance
- Extreme tiredness that forces you to stay in bed for more than 24 hours
- Fatigue that has gotten worse or a sudden decrease in energy level
- Feelings of being out of breath or of a racing heart after mild activity

The fatigue was the worst I ever experienced. I exercised and walked to relieve it. When that became too hard, my doctor encouraged me to swim. I wasn't a swimmer before, and now I swim an hour or more daily. It helps my fatigue tremendously.



Michael Riotta, multiple myeloma survivor

» FERTILITY ISSUES

▲ **Parenthood is something** you may envision for yourself, and cancer and its treatments can sidetrack your path to getting there. Age and overall health also play a role in your fertility. Because fertility issues often arise as soon as treatment begins, it is essential to talk to your oncologist and a fertility specialist before beginning treatment. Options for preserving your fertility become much more limited after treatment starts.

Because the causes of cancer-related fertility issues and ways to manage them differ for women and men, this information is explained by gender.


Females: For a woman to become pregnant naturally after cancer treatment, she must have at least one healthy ovary to produce the egg, one healthy fallopian tube through which the egg travels, a healthy uterus for the baby to grow, and correct levels of certain hormones that help maintain the pregnancy. An absence or imbalance of any these factors can lead to fertility problems after cancer treatment.

Males: Men who are unable to produce or ejaculate healthy sperm are technically considered to be infertile. This can happen for a number of reasons and can often be a result of different types of cancer treatment.

What causes fertility issues?

Many conditions during cancer treatment can affect fertility after treatment ends. Drug therapies, radiation therapy and surgery can cause fertility issues. The endocrine glands and related organs release hormones that control fertility. When cancer or cancer treatments, such as certain drug therapies, surgery or radiation therapy, damage one of these glands or organs, or alter the area of the brain that controls the endocrine system, challenges with fertility can occur.

Females: In some cases, the effects of some therapies may be reversible, with function returning gradually over a few months or even years after treatment has ended. Ovarian shielding (placing external shields over your ovaries during radiation therapy to minimize exposure and damage) and ovarian suppression (taking a medication that causes the ovaries to temporarily shut down during chemotherapy) may be options. In contrast, loss of function is permanent when reproductive organs are surgically removed.



Because radiation could affect my fertility, my doctor asked if I planned to have kids. I didn't have a serious girlfriend at the time, so I asked my mom and sister for advice. I chose to have my sperm cryopreserved and stored. It might be a tough dating conversation one day, but it doesn't keep me up at night. The right girl will understand.

Kenny Toye, Stage III colon cancer survivor

Males: The effects of some cancer treatments on the testicles can sometimes be reversible, although it isn't typical. Regaining full sexual function after treatment may take time, mostly because both psychological and physical factors are involved. Loss of function is permanent if these organs have been surgically removed or altered.

How you can manage fertility issues

Ask about the risk of fertility issues from each type of treatment you are considering. Also ask about preventive measures that are available. Making your treatment team aware of your life goals, such as becoming a parent or expanding your family, is very important and needs to be discussed before any treatments are started or even considered.

Addressing the emotions that come with fertility problems resulting from cancer and treatment is good for both you and your partner. Keep the lines of communication open as well, which will help you to understand what's important to each of you while making these important decisions. Consider counseling (individual, couples and/or sex therapy) and physical exercise, which can help lower your stress surrounding this situation. You may also find it helpful to talk with a spiritual advisor.

Adoption is another option that lets you legally accept the responsibility for a child. Get in touch with an adoption attorney or agency to learn more, especially because some agencies are more open than others when working with cancer survivors.

Females: Your health care provider may be able to prescribe medication to help stimulate ovulation; however, this type of treatment is usually only beneficial to women whose infertility is due to problems with ovulation.

Learn more about the fertility alternatives

that are available, including assisted reproductive technologies (ART), such as intrauterine insemination (IUI), in vitro fertilization and third-party-assisted ART. If you were unable to preserve your fertility before treatment, third-party-assisted ART may be an option. This involves the use of sperm donors, egg donors and/or surrogates.

A combination of treatments may be your best option. You may be able to use in vitro fertilization with donor eggs or have your frozen embryos carried to term using a surrogate. Talk to a fertility specialist about the options available to you.

Males: If you didn't pursue the use of sperm banks, testicular sperm extraction or gonadal shielding prior to radiation therapy, little can be done to reverse the effects afterward.

Donor insemination is a possibility that allows you to use someone's sperm that you know (such as a friend or relative) or the sperm of a random donor. The semen is then used to create a pregnancy via intrauterine insemination (IUI).

When to call your health care provider about fertility issues

From the start, as you consider your treatment options, see a fertility specialist to determine whether you are fertile and what precautions you can take to help preserve your fertility. Your health care provider should be able to give you a referral.

Regardless of whether you were able to take precautions before beginning treatment, if you and your partner have been actively trying to conceive for a year after treatment ends but have been unsuccessful, ask your health care provider or fertility specialist for referrals to help you explore other possibilities.

» LYMPHEDEMA

▲ **Lymphedema is an excess** of lymph fluid in body tissues that causes abnormal swelling of a part of the body. It is most common in an arm or leg, but it can also happen in the neck, face, mouth, abdomen, groin and other parts of the body. General swelling can also occur, depending on the type of disease and treatment. The amount of swelling ranges from a mild increase to extreme swelling that interferes with motion or function of the affected area (see Figure 1).

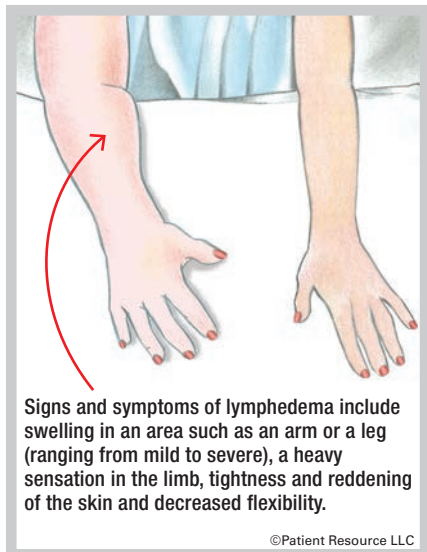
To understand lymphedema, it helps to understand the lymph system, which is a major part of your immune system. The lymphatic system helps to protect your body from infection and disease. It consists of lymph, lymphoid tissue, lymph nodes and lymph vessels.

Lymph is fluid that carries cells and travels through lymph vessels. Lymphoid tissue is mostly made up of white blood cells (lymphocytes). It is in many parts of your body, such as the lymph nodes, bone marrow, thymus, digestive tract, and adenoids and tonsils. Lymph vessels connect hundreds of lymph nodes, which are structures in your neck, underarm, chest, abdomen and groin that help filter substances through lymph.

The signs of lymphedema include the following:

- Swelling in the breast, chest, shoulder, arm, hand, leg or foot
- An extremity or affected area that feels full or heavy
- Changes in how the skin in an area looks (red) or feels (tight and hard)

▲ FIGURE 1
LYMPHEDEMA



- New aching or discomfort in an area
- Less movement or flexibility in nearby joints (shoulder, hand, wrist, hip or knee)
- Difficulty fitting your arm into a jacket or shirt, or tightness of jewelry on your hand or wrist
- For women, difference in how your bra fits

What causes lymphedema?

Lymphedema occurs when lymph cannot flow normally through lymph vessels because of damage to lymph nodes or lymph vessels or removal of lymph nodes. It is typically caused by surgery to remove lymph nodes, radiation therapy that affects the lymph nodes and lymph vessels, or a blockage of the lymph nodes or vessels caused by cancer.

Treatment of lymphedema is determined by the stage and severity of the condition.

Stage 0: The lymphatic system may have been damaged but swelling may not be visible yet. People may feel a heaviness or aching in the affected body part.

Stage I: Swelling is now visible but there are no signs of skin thickening or scarring. It can be reduced by keeping the affected limb raised and using compression.

Stage II: Skin may or may not indent when pressed. Moderate to severe skin thickening is present. Compression and keeping the limb raised may help but will not reduce swelling.

Stage III: The skin is now very thick and hardened. The limb is swollen in size and volume, and the skin has changed texture. This stage is permanent.

When does lymphedema typically occur?

Lymphedema can develop from weeks to many years after treatment begins.

How you can manage lymphedema

Management of lymphedema focuses on ways to minimize swelling and control discomfort. Avoid constriction of the area by only wearing loose clothes and loose jewelry on the affected side, carrying a handbag or backpack on the unaffected side, keeping legs uncrossed while seated and avoiding socks or stockings with tight bands. If you have lymphedema of an arm, avoid having

injections (blood draws or vaccines) and blood pressure measurements in that arm. It is also important to keep blood from pooling in the affected limb. When possible, elevate the affected limb to a point higher than the heart; do not swing the limb quickly in circles or let the limb hang down; and do not apply heat to the limb.

Prevention of infection is an important part of managing lymphedema because infection causes your body to respond by making more lymph, and if the lymph nodes and/or vessels are damaged, the excess fluid has nowhere to go. Keep your skin and nails clean and well-maintained.

To decrease your risk of developing lymphedema after treatment, it is important to regain full range of motion by using exercises suggested by your physician.

When to call your health care provider

You should talk about the possibility of lymphedema when discussing the risks and benefits of treatment, then report symptoms that persist for 1 to 2 weeks so treatment can begin promptly. If left untreated, it can cause more swelling, weakness, difficulty moving your arm or leg. You may also develop itchy, red, warm skin, wounds that do not heal, an increased risk of skin infections causing pain, and thickening or hardening of the skin.

A certified lymphedema therapist (CLT) may develop a treatment plan for you that includes some or all of the following:

- Complete decongestive therapy (CDT): a combination of skin care, manual lymphatic drainage, exercise and compression
- Compression garments to put pressure on affected areas
- Elevation
- Exercise
- Manual lymphatic drainage (MLD), a special type of gentle skin massage
- Medications for infection or pain
- Physical therapy
- Skin care to keep the area clean and moisturized

Contact a member of your health care team immediately if you have one or more of these signs of lymphedema:

- The affected limb or body area feels hot, looks red or swells suddenly.
- You have a fever (oral temperature of 100.4 °F or higher) that is not related to a cold or flu.

» MOUTH SORES

▲ **Mouth sores**, or oral mucositis (myo-koh-SY-tis), are tiny sores that begin in the mucous membrane lining in the mouth and become red, burn-like or ulcer-like. They can also affect the gums, tongue, roof of the mouth or lips, a condition called stomatitis. Mouth sores sometimes begin as mild pain or burning, followed by white patches that may become large red lesions. Pain may range from mild to severe, making it difficult to talk, eat or swallow. Also, infection may develop if bacteria enter the open sores.

What causes mouth sores?

Mouth sores can occur when mucous membranes become inflamed. The cells of the mucous membranes in the mouth divide rapidly, so they may be damaged by cancer treatments. Some drug therapies are more likely than others to cause mouth sores. The cells lining the mouth are also sensitive to radiation therapy. People who receive a bone marrow/stem cell transplant are at high risk for mouth sores because of the chemotherapy or radiation therapy that typically accompany those treatments.

When do mouth sores typically occur?

Mouth sores usually develop within a few days after treatment begins and heal within 2 to 4 weeks after it ends.

Sometimes, you can take steps to prevent mouth sores from developing or from becoming severe. Before beginning treatment, if possible, visit your dentist to help get your gums and teeth healthier. Taking good care of your teeth and gums is essential, and you should brush your teeth and floss several times a day.

If your treatment plan includes a therapy with a high likelihood of causing mouth sores, ask about intravenous medication that may be used before treatment to help prevent them. Your health care provider may recommend that you suck on ice chips during the first half-hour of your treatment. This will reduce the likelihood of mouth sores because the cold limits the amount of the drug that reaches your mouth.

How you can manage mouth sores

Managing mouth sores involves taking steps to minimize pain or discomfort and to help them heal. The following may help:

Perform oral care

- Find a dentist who is experienced in treating people with cancer, and schedule regular visits.
- Check your mouth more than once a day using a small flashlight and a mirror, and let your health care provider know if you see or feel anything different or notice taste changes.
- Brush your teeth, tongue and gums with a soft-bristled toothbrush 30 minutes after eating, every 4 hours and at bedtime.
- Avoid toothpastes that contain additional ingredients such as whiteners. Use a nonabrasive fluoride toothpaste or a solution of 1 teaspoon baking soda in 2 cups water.
- Brush your teeth gently with a soft bristle toothbrush; if using a toothbrush is painful, use a soft foam swab (available at drug stores).
- Rinse your mouth several times a day and after eating. Use a mixture of 1 tablespoon of baking soda in 1 quart of warm water, or ask your medical team to recommend a solution that may work best for you.
- Keep lips moist with unscented lip balm. Do not use petroleum jelly or other oil-based products as they may promote infection.

Avoid products that may dry or irritate the mouth

- Mouthwashes that contain alcohol.
- Glycerin swabs.
- Alcoholic beverages.
- Cigarettes, cigars, chewing tobacco and similar items.

Practice certain dietary habits

- Drink a large amount of fluids (aim for two to three quarts per day).
- Use a straw.

- Eat soft foods that are cut into small pieces and kept at room temperature or slightly warm.
- Avoid hot, spicy, greasy or fried foods; very salty or high-sugar foods; sharp or crunchy foods; citrus fruits and juices; caffeine and carbonated beverages.

Take special precautions with dentures

- Remove and clean dentures between meals regularly.
- Leave them out whenever possible to expose your gums to air.
- Wear dentures that fit properly. Loose-fitting dentures may irritate the mouth and gums. Be aware that dentures may become loose if you lose weight.
- Do not wear dentures if mouth sores are severe.

Relieve pain:

- Suck on ice chips.
- Apply topical, local anesthetic solutions or jellies, such as lidocaine.
- Use oral analgesia or intravenous analgesia with opioids as prescribed by your health care provider.
- Rinse with a medicated mouthwash prescribed by your health care provider to decrease inflammation and yeast infections.
- Use topical corticosteroids on irritated areas of the tongue, mouth or lips.

When to call your health care provider

Call when you first notice any type of sore in your mouth. A special mouth rinse, medication that coats the lining of your mouth or pain medication that can be applied topically may be options. The sooner you treat mouth sores, the easier it is to prevent them from becoming severe.

Call immediately if any of the following occurs:

- An oral temperature of 100.4 °F or higher
- Inability to take medications
- Redness or shininess in the mouth that lasts for more than 48 hours
- White patches on the tongue or inside the mouth
- Bleeding gums
- Inability to eat or drink much for 2 days. Getting the proper nutrients during and after cancer treatment is critical to promote healing and avoid dehydration and malnutrition.

I made sure to use a lidocaine rinse every four hours to help with the mouth and throat pain.



Rick Long, Stage IV tonsil cancer survivor

» NAUSEA AND VOMITING

▲ **Nausea is an unpleasant** sensation of feeling the need to throw up or being queasy. It's important to note that these two side effects are different from one another, but people often experience them together.

Nausea and vomiting usually cause distress (for the person with cancer as well as family members), and can limit activities. Be sure to share upcoming events that are important to you, such as weddings or graduations, with your medical team. Sometimes your treatment can be adjusted to make it easier for you to attend these special occasions without having to worry about feeling too ill to enjoy them. In general, when you are experiencing nausea and vomiting and you must be away from home, make sure you know where the nearest restroom is, just in case.

These side effects can also worsen other symptoms, such as pain, insomnia, cognitive dysfunction, fatigue and appetite challenges. If vomiting is not controlled and becomes severe, it can lead to dehydration which is a lack of essential fluids and minerals in your body. Most importantly, severe nausea and vomiting can interrupt your treatment plan. Thus, it is important to control these two symptoms.

What causes nausea and vomiting?

When treatment damages the cells lining the inside of the stomach, the cells send signals to a vomiting center (the fourth ventricle) in your brain, which then sends signals to trigger nausea and vomiting. Drug therapies may also trigger the vomiting center directly.

Drug therapy, surgery and radiation therapy to certain parts of the body can cause nausea and vomiting.

Chemotherapy drugs are the most common cause. The dose used, how often the drug is given, and how it is given (intravenously or orally) are factors in the likelihood of nausea and vomiting occurring. Your medical team may refer to it as chemotherapy-induced nausea and vomiting (CINV). In addition, some cancers, dehydration, infection, pain, other diseases and anxiety can also lead to nausea and vomiting.

Nausea and vomiting are also side effects of other types of medication, especially strong pain medications, such as opioids.

Radiation therapy in general and in high doses, as well as radiation aimed at the gastrointestinal tract, liver or brain, can also cause these symptoms.

When do nausea and vomiting typically occur?

Nausea and vomiting related to drug therapies are described as either acute or delayed depending on when they first occur.

- Acute: Begins minutes to hours after the drug is given, peaks in 5 to 6 hours and resolves within 24 hours.
- Delayed: Begins more than 24 hours after the drug is given, peaks in 48 to 72 hours and resolves within 3 to 7 days.

These side effects may also be described as anticipatory. They can occur before a drug dose is given and usually happen in people who have had severe nausea and vomiting during a previous experience with a drug therapy.

With prescription opioids, this side effect usually occurs within a few hours of a dose.

How you can manage nausea and vomiting

Taking supportive care drugs in conjunction with your treatment may help prevent nausea and vomiting. If possible, discuss this with your health care provider prior to starting treatment. These symptoms are easier to prevent than to control once they have started.

You may want to supplement your anti-nausea drugs with a non-drug approach such as progressive muscle relaxation, biofeedback, guided imagery, self-hypnosis and acupuncture.

Some changes to your eating habits may also be helpful:

- Eat several small meals throughout the day rather than three big meals.
- Try eating a light meal a few hours before your scheduled treatment.
- Drink plenty of fluids in small amounts throughout the day.
- Avoid unpleasant odors, as they can trigger nausea. Surround yourself with pleasant scents.
- Rest after eating, but don't lie flat.
- Eat bland foods such as toast or crackers.
- Try ginger chews, drinks or capsules to settle an upset stomach.
- Smell peppermint in some form. Essential oils are often used.

Before treatment begins, talk about the potential for your planned treatment to cause nausea and vomiting. Ask about ways to prevent it. Anesthesia given during surgery can cause nausea and vomiting. Before surgery,

certain anti-nausea medications can be given preventively by IV.

Your health care provider will prescribe anti-nausea drugs on the basis of the specific drug or drug regimen you receive. Because these drugs work in different ways, a combination of them is often the best approach, especially for people who are receiving medication that has a high likelihood of causing nausea and vomiting. In these situations, anti-nausea drugs are prescribed to be taken before drug therapy starts and at specific intervals after treatment for as long as the risk of vomiting is expected. For example, an anti-nausea drug is prescribed to be taken for 24 hours if the chemotherapy drug is associated with acute nausea and vomiting and for 3 to 7 days if the drug is associated with delayed nausea and vomiting. Prevention of nausea and vomiting related to radiation therapy follows a similar approach. If you are to have total body radiation or radiation to the upper abdominal area, your health care provider will prescribe an anti-nausea drug to be taken before your scheduled treatment and for a period of time after treatment. For them to be effective, it is important that they are taken at the prescribed intervals and not on an as-needed basis.

Some are best for mild nausea and vomiting, and others are appropriate for more severe cases; some are effective for acute symptoms and others for delayed symptoms. Most can be given as either a pill or an injection. Although both forms are equally effective, intravenous drugs usually act more quickly.

When to call your health care provider

It is important to let a member of your health care team know whether you are still experiencing nausea and vomiting even after taking the anti-nausea drug as prescribed. This type of nausea and vomiting is known as breakthrough, and you may need a different drug or an increased dose in order to control these symptoms.

Call your health care provider right away if you experience any of the following:

- More than 3 episodes of vomiting per hour for at least 3 hours.
- Vomiting blood or something that looks like coffee grounds.
- Inability to take more than 4 cups of fluid or ice chips in 24 hours or any solid foods for more than 2 days.
- Inability to keep your medications down.
- Weakness or dizziness.

» NEUTROPENIA

▲ **Neutropenia is a condition** in which you have a low number of neutrophils, one type of white blood cell. Neutrophils play an important role in preventing infection throughout the body, so having an abnormally low number of them increases your risk of infection. The lower the neutrophil count, the greater the risk for infection. Neutropenia also makes it more difficult for an infection to resolve if bacteria enter the body. It is important to note, however, that most people who are treated for cancer with some types of radiation therapy and chemotherapy have neutropenia but do not get an infection.

What causes neutropenia?

White blood cells divide and grow rapidly, making them vulnerable to damage from cancer treatments. Treatments that typically affect neutrophils include chemotherapy, radiation therapy, bone marrow/ stem cell transplantation, immunotherapy and steroids.

Many factors contribute to the development of neutropenia, including the dose and type of the therapy and the overall health of an individual. Combination therapies tend to further increase the risk.

When does neutropenia typically occur?

The neutrophil count usually starts to drop about 7 days after a treatment begins and reaches the lowest point between 7 and 14 days after treatment. This may vary based on the type of treatment, dose and schedule.

During treatment, your health care provider will order blood tests frequently to check your absolute neutrophil count (ANC). It must be at a certain level for it to be safe to have your next scheduled treatment. Generally, the count rises again on its own. Sometimes, however, it does not.

If the neutrophil count is extremely low

and you hear that you are “neutropenic,” your health care provider may delay your next treatment until the count has increased. For the time that the count is low, you will be instructed to follow neutropenic precautions to prevent infection. These precautions include:

- Taking your temperature 4 times each day, or as advised by your health care provider.
- Not eating uncooked foods.
- Staying away from fresh flowers, plants and gardening.
- Avoiding enemas, rectal suppositories and rectal thermometers.
- Postponing dental work.

In addition, your health care provider may prescribe growth factors. They are special proteins that can stimulate the bone marrow to produce more white blood cells and are usually given as an injection under the skin (subcutaneously). Preventive antibiotics may be another option.

How you can manage neutropenia

Although neutropenia is an expected side effect and cannot be prevented, you can take steps to reduce your risk of infection.

Along with staying current with your vaccinations, do the following:

Practice excellent personal hygiene:

- Wash your hands frequently.
- Do not cut or pick at cuticles (use a cuticle cream).
- Brush teeth after each meal and at bedtime. Use alcohol-free, antiseptic mouthwash daily.
- Use a deodorant rather than an antiperspirant.
- Use a water-soluble lubricant during sexual intercourse, and perform good hygiene immediately following intercourse.

Avoid situations that could increase the risk of infection, such as the following:

- People with colds or other infections, such as COVID-19, influenza and RSV, and people who live with others who have these and other infections.
- Young children who may appear healthy but could be harboring colds, flu, chickenpox or other contagious ailments.
- Anyone, including infants and young children, who were vaccinated recently.
- Crowds and public transportation as much as possible (when necessary, go out at off-peak times and wear a medical-grade mask). Ask a caregiver or friend to do the errands that you absolutely do not have to do yourself.
- Disposal of animal waste (including cat litter and fish tank water).

Use extra precaution to reduce injuries:

- Always wear shoes.
- Protect your hands (wear gloves when doing dishes or gardening).
- Prevent constipation.
- Wear sunscreen with a sun protection factor (SPF) of at least 15.
- Use an electric razor rather than a blade razor to shave.

When to call your health care provider

Before treatment begins, talk to a member of your health care team about the possibility of neutropenia with the therapies in your treatment plan. If you are at risk, ask for specific symptoms to watch for and any other precautions to take.

Infections during cancer treatment can become serious very quickly. Immediately call your health care provider if you have any signs of infection, which include:

- Fever (oral temperature over 100.4 °F, or as advised by your health care provider), chills and sweating.
- Flu-like symptoms (body aches, general fatigue) with or without fever.
- Cough, shortness of breath, painful breathing.
- Sore throat or sores in your mouth.
- Redness, pain or swelling on any area of your skin.
- Pus or drainage from any open cut or sore.
- Diarrhea (loose or liquid stools).
- Pain or burning with urination.
- Vaginal drainage or itching.

“My husband and sister took care of me right after my stem cell transplant for 30 days. My daughter and granddaughters couldn’t come around me for fear of infections, but we would FaceTime.”



Lou Sears, multiple myeloma survivor

» PERIPHERAL NEUROPATHY

▲ **Peripheral neuropathy is a disorder** of the peripheral nerves, which are the nerves outside the brain and spinal cord. These nerves control the sensations and movements of the arms and legs, and some control involuntary functions such as digestion and breathing. There are three types of peripheral nerves:

- Sensory nerves help you feel pain, heat, cold and pressure
- Motor nerves help your muscles to move
- Autonomic nerves control functions such as blood pressure, digestion, heart rate, temperature and urination

The signs of peripheral neuropathy depend on the types of nerves affected. Usually, sensory nerves are affected, and the signs typically begin at a point on sensory nerve fibers that are farthest from the center of the body (your fingers and toes) and gradually affect your feet and hands. These signs include:

- Numbness and tingling (“pins and needles”)
- Decreased sensation of hot and cold
- Unpleasant sensations when touched
- Muscle weakness and cramping
- Balance problems
- Ringing in ears or loss of hearing
- Changes in vision
- Constipation or difficulty urinating
- Sexual health issues

Pain may also occur and usually has a burning or electric shock-like feeling. These symptoms may make it difficult to carry out normal activities, such as buttoning clothes, picking up small items or writing. Muscle weakness and balance problems may cause an unsteady gait or difficulty with walking.

What causes peripheral neuropathy?

It is the result of damage to sensory nerves, which may be caused by chemicals in chemotherapy or targeted therapy drugs. Other causes include tumors pressing on nerves, infections that affect nerves, spinal cord injuries, diabetes, alcohol abuse, shingles, low vitamin B levels, some autoimmune disorders

and poor circulation. Knowing the cause of your peripheral neuropathy will help your health care provider determine the right treatment for it.

When does peripheral neuropathy occur?

Peripheral neuropathy caused by chemotherapy or targeted therapy drugs can be either acute (short term) or chronic (long term). Acute peripheral neuropathy usually begins during or shortly after administration of the drug and most often goes away on its own after several days. Chronic peripheral neuropathy may arise weeks or months after treatment and is sometimes irreversible. Whether peripheral neuropathy is acute or chronic depends on many factors, primarily the dose and combinations of drugs and the total dose of a drug given over time.

How you can help manage it

You can manage it in a variety of ways: with substances to protect against damage caused by drug therapy, exercises to ease discomfort and strengthen muscles, and treatments and medications to relieve pain.

In some cases, a substance known as a chemoprotective agent may be given prior to or with a chemotherapy drug likely to cause peripheral neuropathy.

Other treatments may include occupational therapy, physical therapy, relaxation therapy, guided imagery, acupuncture, massage and biofeedback.

Another strategy that may help to relieve pain in some people is transcutaneous electrical nerve stimulation (TENS). TENS involves a small electrical device with wires attached to the skin with electrodes; the device transmits a gentle current into areas of pain and stimulates the release of endorphins, the body’s natural painkillers.

Some medications that relieve pain include corticosteroids, topical medications (such as a lidocaine patch), and opioids or narcotics for severe pain. Antidepressants may relieve pain related to damaged nerves.

Stretching can help decrease pain related to neuropathy, especially in the morning. Moving your hands and feet in all directions before you get out of bed in the morning may be helpful, and strengthening your muscles with isometric exercises (exercises in which you hold a muscle in a flexed position for a period of time) can help you maintain balance and walk normally.

Your health care provider may suggest that you see a physical or occupational therapist to help with strengthening exercises and finding ways to carry out everyday tasks with less discomfort.

Other simple strategies include avoiding snug shoes or socks and extreme temperatures as well as taking part in regular exercise, such as walking. Take safety precautions, as the decreased sensation in your hands and feet may increase the risk for injury.

Safety tips to prevent accidental injury due to peripheral neuropathy:

- Use caution when handling sharp objects.
- Wear protective gloves when doing household repairs or yardwork/gardening.
- Use potholders when cooking.
- Do not walk inside or outside with bare feet. Always wear rubber-soled shoes.
- Inspect your hands and feet on a regular basis for any breakdown in the skin. Keep skin moist with lotion to avoid cracking and peeling.
- Remove obstacles in your home that could lead to injury (power cords, throw rugs, etc.)
- Use an assistive device (cane, walker or wheelchair) if your gait is unsteady.
- Use nightlights to keep areas of your home well lit.
- Wear warm gloves, hats and scarves during cold weather.
- Test the temperature of water with a non-affected body part before exposing affected areas.
- DO NOT DRIVE if you are not able to feel the gas pedal or brake with your feet.

When to call your health care provider

Call when you first experience symptoms of peripheral neuropathy because early treatment offers the best chance of managing it. Some people have peripheral neuropathy prior to treatment due to having diabetes. If this is your situation, make sure your provider is aware of it before starting treatment.

I manage peripheral neuropathy with compression socks and cold therapy socks.



Lisa Boyer, Stage IV breast cancer survivor

» SKIN AND NAIL REACTIONS

▲ **Your skin and nails** may change during treatment. Common skin reactions include skin redness and irritation (similar to a sunburn), skin rash, and dry, flaky skin. Common changes to your nails include changes in growth, strength or thickness, different textures or color; and lifting of the nail plate off the nail bed.

What causes skin and nail reactions?

Chemotherapy destroys rapidly dividing cancer cells, but many normal cells in your body, such as blood cells and cells in your mouth, nails, hair and skin, also divide rapidly. Chemotherapy can affect these normal cells, resulting in changes to your skin and nails.

Targeted therapy and immunotherapy can also affect skin and nails because of their effect on the normal cells near the genes, proteins or cancer cells they target.

Some drugs cause photosensitivity of the skin – an inflammation of the skin caused by the combination of sunlight and certain medications or substances – that leads to redness of the skin similar to sunburn. Skin and nail reactions are usually mild to moderate but can become severe or lead to infections if not treated early.


In addition, you may experience the following effects.

Skin reactions due to leaks: Some drugs given through a vein or artery can leak into the skin tissue. As a result, the cells in the skin tissue die. Some cause veins and tissue underneath the skin cells to become inflamed while others result in severe damage to skin, as well as ulcers and scar formation.

Excessive darkening of the skin: This may occur either over large areas or localized to smaller areas, such as under the nails, inside the mouth or along a vein where the medication was infused.

Skin growths or bumps: Unexpected growths on the skin can occur. Most are cosmetic, but your health care provider may need to remove any suspicious growths to make sure they are not a form of skin cancer.

Rashes: Those that are in a limited area, that do not cause discomfort and are not infected usually do not need to be treated. However, if the rash spreads over a larger area and causes itchiness or pain, your health care provider may prescribe a mild corticosteroid cream, antibiotic gel, oral antibiotic or oral corticosteroid.



I was told that chemotherapy is dehydrating, so it was important to drink plenty of fluids. Water is vital for everything to function optimally – nails, skin, joints, GI system, etc.

Lynn Fowler, Stage III breast cancer survivor

Targeted therapy drugs can cause an acne-like rash on the face, scalp and upper trunk called acneiform rash. The rashes are not true acne; they are usually sterile and contain no bacteria. The rash is uncomfortable and can be severe enough that treatment is modified or adjusted. The pain, itching and effect on appearance can negatively impact quality of life for individuals receiving targeted treatments. Symptoms include a stinging or burning sensation, itching, irritation or pain. Topical and oral antibiotics and corticosteroids can help this kind of rash as well, but it's important that you do not use certain medicines given to treat acne, such as a topical retinoid, because these may dry or irritate the skin even more.

Most nail changes, such as a groove across your nail plate, a thickening and/or thinning of the nail, and pale or dark streaks across your nail, are only cosmetic and will not affect your treatment. Usually, these marks reflect the times you have received chemotherapy treatments. The medication reaches the nail cells for a brief period of time, and in this period it changes the texture or color of your nail, leaving a mark that grows out with time. These nail changes are almost always temporary.

When do skin and nail reactions typically occur?

With targeted therapy, a rash most often starts within the first few weeks after taking the drug and resolves about 1 month after treatment is stopped. Nail changes may start during treatment and last throughout the duration. Nail plate issues will grow out with the nail and usually will not affect the new nail that grows in.

How you can manage skin and nail changes

If you have a history of nail changes, you may be given cold gloves and slippers (or ice

packs) to wear during treatment if you are receiving certain cancer drugs. In some cases, the cold shrinks blood vessels in your hands and feet, resulting in less medication delivered to those areas.

Over-the-counter antibiotics and antiseptics may help prevent infection. Soaking your fingers and toes in a solution of 1 part white vinegar and 1 part cool tap water once a day for 15 minutes may help. If your nail problems persist, see a dermatologist.

Always wear sunscreen to protect yourself from the sun. Use a broad-spectrum sunscreen with an SPF (sun protection factor) of at least 15, and look for titanium dioxide or zinc oxide on the label. Ask your dermatologist for a recommendation.

When to call your health care provider

Report any changes to your skin or nails, as early treatment can prevent the reaction from becoming severe. If the reaction becomes painful or if you notice any signs of infection, such as fluid draining from an affected area, call your health care provider right away.

When a rash is severe, your health care provider may reduce the dose of the targeted therapy drug or temporarily stop it. Then, if the rash gets better within approximately two weeks, your provider may restart the targeted therapy drug.

If you have a skin reaction from a leak, depending on the treatment you are receiving, you may be given cold packs or heat packs to help in wound healing.

If you experience excessive skin darkening, the reaction usually disappears gradually once treatment is stopped, but if hyperpigmentation is troubling, talk with your health care provider about whether there are ways to decrease the effect.

Sunscreen use, indoors and outdoors, is always a must because even indoor lights can cause darkening. ■

Prioritize your emotional health

A cancer diagnosis affects more than just your body. It also affects your emotional well-being, making it important to take advantage of the various supportive care services available. Support is accessible in many forms, both in person and online. Some organizations offer one-on-one buddy programs that pair you with another person who has the same type of cancer as you. It can be very impactful to share your feelings with others who can relate because they have been through something similar.

Following are some emotions you may experience and suggestions for ways to feel better.

Anxiety can be feelings of fear, dread and uneasiness that may occur as a reaction to stress. A person with anxiety may sweat, feel restless and tense, and have a rapid heartbeat. Anxiety can begin as soon as you receive your diagnosis. Moderate to severe anxiety is often treated with medication, therapy or a combination of both. Explore relaxation techniques, such as meditation, muscle relaxation, yoga or guided imagery.

Depression is a mental condition marked by ongoing feelings of sadness, despair, loss of energy, and difficulty dealing with normal daily life. Other symptoms include feelings of worthlessness and hopelessness, loss of pleasure in activities, changes in eating or sleeping habits, and thoughts of death or suicide. Depression can occur at any time during treatment. Before treatment, if possible, talk to your health care provider about the risk of depression occurring as a side effect of your prescribed treatment.

As a side effect of medication or the result of low hormones, depression is a physical reaction resulting from chemical imbalances in the brain — specifically, decreases in the levels of serotonin and norepinephrine, chemicals that regulate moods.

Certain ongoing treatments, such as chemotherapy or hormone therapy, can cause or contribute to depression. Don't avoid talking to your health care provider about it because you think depression is just part of having cancer — it isn't. Call your health care provider's office if you have 5 or more symptoms of depression that last for 2 weeks. If you feel hopeless, helpless

or numb for more than a few days or have thoughts of death or of attempting suicide, seek medical attention immediately.

Distress is an unpleasant emotion, feeling, thought, condition or behavior. People with cancer may have trouble coping with their diagnosis, physical symptoms or treatment. It is normal to experience some amount of distress when you have cancer, but when it interferes with treatment, makes it difficult for you to function or cope, or affects all parts of your life, talk with your health care provider.

Doubt can lead to confusion and questions about life and its purpose. Some people find strength in support from family, friends or spirituality. It may help to open up to a counselor or support group. You may also experience doubt about your treatment decisions. Getting a second opinion can provide reassurance that you are on the right track.

Fear is common. Making plans may become difficult because every ache and pain triggers a concern. Do your best to stay focused on the present.

Guilt may occur if you feel you've been a burden to loved ones or if you wonder why you survived when others with similar conditions didn't. Talk with a therapist about these feelings. You might find that you can lessen your guilt by giving back to the cancer community. Helping others may provide a sense of purpose and well-being that takes away some of the blame you place on yourself.

Scanxiety describes the anxiety that can happen when you are awaiting results from imaging scans or laboratory tests. You may feel anxious as the appointment nears and

stay that way until you get your results. These suggestions may help manage the stress:

- Set expectations with your medical team about when and how you will receive the results so you are not left waiting and wondering.
- Occupy your mind with things you enjoy. Staying busy gives you less time to worry.
- Try to calm your nerves with meditation or deep breathing.

BE OPEN TO SUPPORT

Supportive care services can connect you with resources to help you work through your feelings. These suggestions may also be helpful.

- Allow yourself to fully express your emotions when they occur to help you avoid releasing bottled-up feelings in unhealthy ways.
- Ask about cancer support groups available in your community, options for online support or phone-based peer support programs. Cancer survivors can be a great source of support, friendship and insight.
- Explore meditation, gentle yoga, massage therapy, deep breathing exercises or other relaxation techniques.
- Get outside, regardless of the season. Fresh air and nature can be therapeutic.
- Express your feelings by writing in a journal.
- Take charge of things you can control. If decision-making feels overwhelming, ask loved ones to handle routine decisions for now.
- Give yourself permission to grieve the loss of the life you had before cancer. Consider setting some new life goals to achieve after treatment is completed. This is a life-altering experience but also can be life-changing for the better for many people.
- Staying positive is important, but give yourself a break when you need it.
- Find something to laugh about every day.
- It's extremely important to talk with your health care provider about feeling depressed, hopeless or desperate, particularly if these feelings last more than a few days. Seek medical attention immediately for thoughts of suicide. ■



MENTAL HEALTH HOTLINE

➔ American Psychosocial Oncology Society Helpline: 866-276-7443

Recognizing the benefits of making healthy lifestyle choices

From diagnosis through survivorship, you will have a valuable role in side effect management. For the most part, you have control over how you choose to live your life. Making smart lifestyle choices will position you to better tolerate treatment and its effects as you also continue to actively manage and control any underlying health conditions, such as high blood pressure and diabetes.

Many cancer treatments can affect your nutrition. Some can even cause malnutrition because your appetite, taste, smell and ability to eat or absorb nutrients from food may be affected. Your body needs essential nutrients, including fruits, vegetables, carbohydrates, fats and proteins, to recover.

Healthy eating during and after your treatment may help reduce the risk of cancer recurrence or secondary cancers. It also assists you with improving other health conditions, such as obesity, heart disease and diabetes, which have been linked to cancer. Maintaining a healthy weight is important, especially if treatment caused you to lose or gain weight.

A registered dietitian can offer nutritional counseling. If your health care team doesn't include a dietitian, ask for a referral.

Being physically active is an important lifestyle choice for people with cancer. Before starting an exercise program, consult your health care provider about the exercises, intensity levels and duration of activities that are best for you.

Don't be concerned that you will only get the benefits of exercise if you run a marathon. Even a 10-minute daily walk can energize you and reduce stress, fatigue, depression and anxiety. And, it's a natural way to boost your mood, offering drug-free relief for many of the emotional side effects of cancer.

Rethink your daily habits. If you use tobacco, ask your health care team for resources to help you stop. Don't drink excessive amounts of alcohol. Get adequate sleep. Pay attention to your mental health.

Stay up-to-date with vaccinations. Talk to your health care provider about the vaccinations, including influenza, COVID-19, shingles, pneumonia and others, that are appropriate for you. Do not receive any vaccination without talking to your health care provider first. Keep COVID-19 test kits on hand, and occasionally check their expiration dates.

RECLAIM YOUR SEXUAL HEALTH

A cancer diagnosis and its treatment can change many aspects of your sexual health. You may face post-treatment sexual difficulties, such as a decreased sex drive, the inability to achieve or maintain arousal, pain during intercourse, the delay or absence of orgasm or feeling less desirable. Talking about these types of changes with a member of your health care team is crucial and you should not be embarrassed to bring them up. Your sexual health is a vital part of life. Don't be surprised if your provider actually has a sexologist on staff as part of the treatment team. You won't know, though, unless you ask.

Lastly, share your concerns with your partner and allow your partner to do the same. Do your best to set aside one-on-one time to rediscover and strengthen the intimacy in your relationship. Explore ways to be intimate other than intercourse. Depending on your situation, consider a discussion with a professional counselor or therapist.

INVOLVE YOUR HEALTH CARE TEAM

Report a new side effect or symptom as soon as it happens, and share detailed information, such as when it began, how long it lasted and whether anything made it better. Early medical attention can help manage or even prevent side effects in the future. Be sure to tell your health care provider how you feel physically, mentally and emotionally, and include the following:

- New or ongoing physical symptoms, including pain, bladder/bowel control; deep fatigue or insomnia; sexual dysfunction or lack of desire; mobility issues; signs of infection; tingling or numbness; fluid buildup; or changes in appetite, sense of taste, vision or hearing
- Cognitive (thinking-related) dysfunction symptoms
- Depression, anxiety, fear, anger, grief,



hopelessness, emotional numbness, feeling overwhelmed or other concerns

- New medications, over-the-counter remedies, vitamins, supplements or herbs
- Any visits to the emergency room, urgent care or other health care provider, even if not cancer-related ■

Recognizing late effects

Late effects may show up months or years after treatment. As with side effects, late effects result from certain types of cancer treatment, and your reaction to them can differ greatly from that of another person's, even when you have the same diagnosis and treatment.

Some are determined by the particular drug and how the body reacts to it. Late effects from surgery and radiation therapy typically involve only the areas of the body that were treated.

Some late effects disappear over time, while others may be permanent. Some can even develop without warning years later. Because they can be so hard to predict, being aware of them is a good course of action.

Most late effects can be treated more easily and with a better outcome if they're detected early. That's why it's so important to stick to the appointment schedule recommended in your survivorship care plan.

Following are common challenges that may occur. If you experience any of these, contact a member of your health care team:

- Balance issues
- Fatigue
- Limited range of motion
- Lymphedema
- Memory or other cognitive difficulties
- Mobility challenges
- Pain
- Problems chewing food
- Sexual health issues
- Swallowing difficulty
- Weakness

PATIENT RESOURCE

Where information equals hope