

FRANKLY
SPEAKING
ABOUT CANCER

Coping with Side Effects

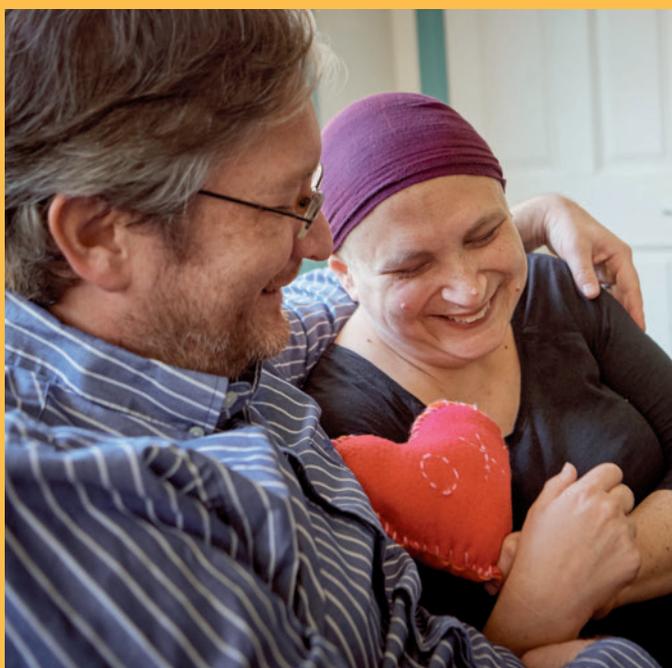


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The Empowerment Approach

I Receiving a cancer diagnosis and undergoing cancer treatment can be challenging for both you and your loved ones. Unwanted side effects can intensify the disruption in your life even further. Fortunately, great strides are being made in improving treatments for cancer and managing treatment side effects. If you or your loved ones have received a cancer diagnosis, know there are actions you and your health care team can take to improve your emotional and physical well-being during this experience.

The Cancer Support Community values the concept of empowerment to help all people affected by cancer.

To feel empowered:

- Partner with your health care team and loved ones through open communication.
- Access resources, information, and support.
- Talk with your doctor about what your goals for treatment are and what you value.
- Make changes in your life that you feel are important and beneficial.

There is no instruction manual that tells you how to deal with cancer, and there is no right or wrong way to do it. You decide what is best for you.



To ensure that all people impacted by cancer are empowered by knowledge, strengthened by action, and sustained by community.

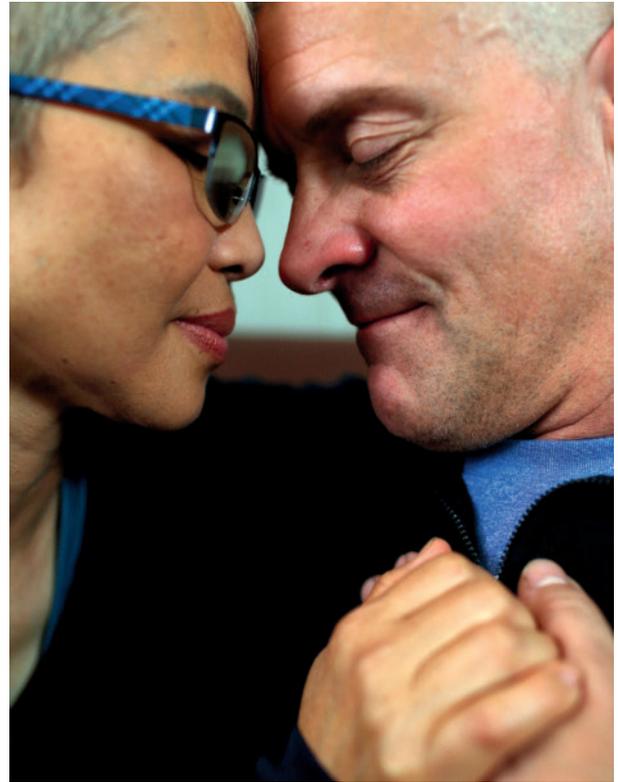
— The Cancer Support Community mission statement

HOW TO USE THIS BOOK

This book has a lot of information about coping with cancer treatment side effects. It may be too much to take in all at once. Feel free to use this book as a guide, and only refer to the content you need, as you need it. You may have opened this book because you have a specific question or concern. Take a look at the Table of Contents to find the information you need more easily.

We hope this helps you make each day better for yourself, and allows you to do what you can to live the best life you can. Many people have been where you are and many are there right now. You are not alone.

Call our Cancer Support Helpline (888-793-9355) Monday through Friday between 9am and 9pm Eastern Time to get questions answered, talk about your concerns, or find resources. We have English- and Spanish-speaking advocates available as well as translation into 200 languages. Or visit your local Cancer Support Community or Gilda's Club to get support and wellness services in person (www.CancerSupportCommunity.org/FindLocation).



© Danny Wilcox Frazier

Ten Tips for Living Well with Cancer

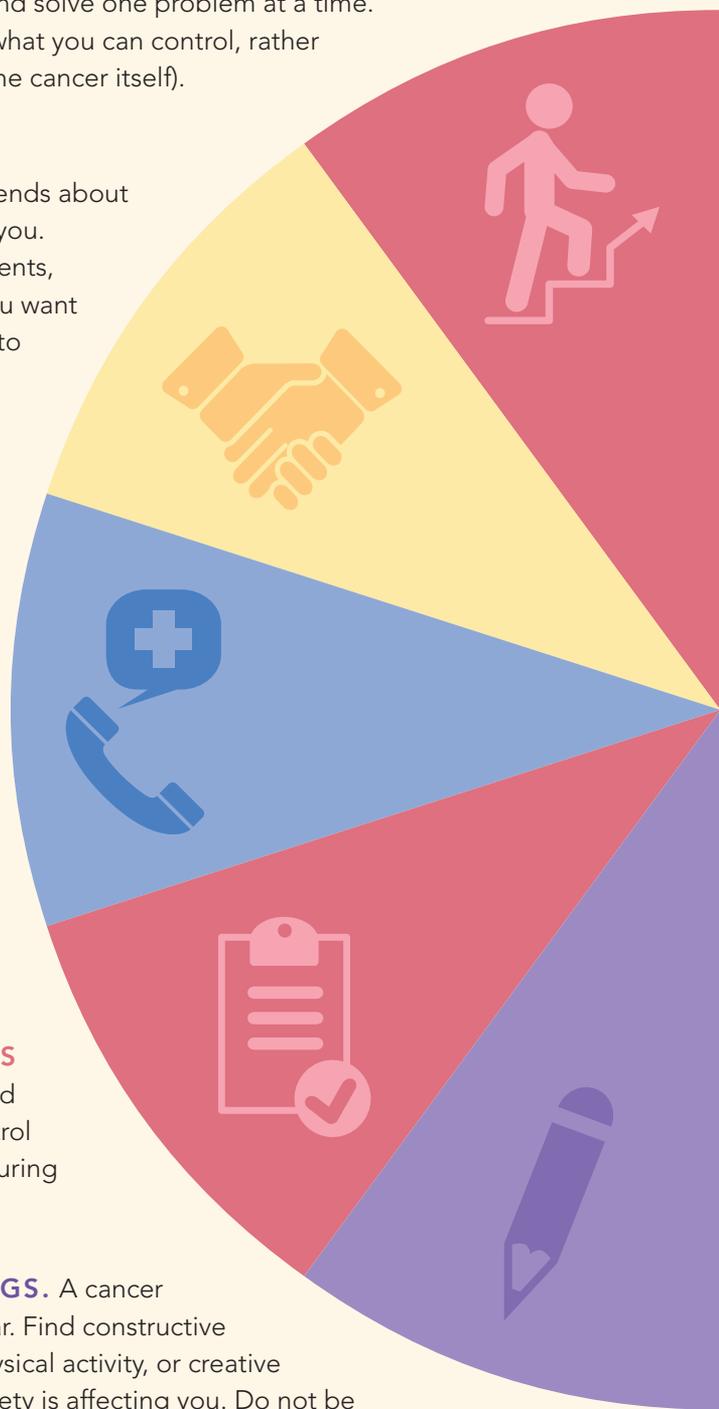
PACE YOURSELF. Try to take one moment at a time and solve one problem at a time. Accept your “new normal.” Allow your mind to focus on what you can control, rather than what you can’t control (such as the “unknowns,” or the cancer itself).

ASK FOR SUPPORT. Be open with your family and friends about how you feel and be honest about how they can support you. Offer specific examples, such as: driving you to appointments, researching insurance questions, or just listening when you want to talk. Take someone with you to medical appointments to take notes and help you remember instructions.

COMMUNICATE WITH YOUR HEALTH CARE TEAM. Your health care team may consist of medical oncologists, nurse practitioners, physician assistants, social workers, pharmacists, nutritionists, and patient navigators. Prepare your list of questions for each appointment and take the time you need to get answers. If you need more time with your health care team to get the answers you need, ask. Longer appointments may be available. It is also helpful to get a second opinion so you can feel informed and confident with your medical team. Your health care team wants to hear from you. If you are struggling with side effects at home, contact your health care team by phone.

RETAIN AS MUCH CONTROL OF YOUR LIFE AS IS REASONABLE. Work with your health care team and loved ones to develop a plan that gives you as much control over your life as you desire and can comfortably handle during and after treatment.

ACKNOWLEDGE AND EXPRESS YOUR FEELINGS. A cancer diagnosis typically triggers strong emotions, including fear. Find constructive ways to express your feelings through writing, talking, physical activity, or creative pursuits. Professional help is advised if depression or anxiety is affecting you. Do not be hesitant to express this to your team, so that you can obtain expert assistance. If you are unsure if you are suffering from depression or anxiety, talk to your doctor.



SEEK SUPPORT FROM OTHERS LIVING WITH CANCER. People gain comfort and strength when they talk to others coping with similar issues. Your doctor, nurse, or social worker can direct you to local support groups, or contact the Cancer Support Community.

LEARN RELAXATION TECHNIQUES. “Relaxation” refers to a calm, controlled physical state. Relaxation is not always easy, and you might have to learn how. Consider things that make you feel relaxed: music, a good book, walking, yoga, meditation, or cooking. The goal is to feel peace and enjoy the moment. Be patient with yourself, as relaxation takes practice.

DO WHAT YOU ENJOY. Try to find humor in the unexpected moments of each day. Consider activities that you enjoy and can do comfortably. Make activities you enjoy a priority.

MAKE HEALTHY LIFESTYLE CHOICES. It is never too late to make changes to increase your well-being. Set realistic goals and build on them. Improve your diet, include physical activity into your routine that feels good (your health care team can recommend safe exercises), rest, and maintain intimacy—these are all ways to feel better both physically and emotionally.

MAINTAIN A SPIRIT OF HOPE. Hope is desirable and reasonable. Even if your cancer experience is complicated, you can set small goals and enjoy daily pleasures. You can redefine how you experience hope by focusing on the activities and connections that give you happiness.



Cancer and Its Treatments

2 An important step in managing your cancer and its treatment is to be informed. Cancer is a complex and challenging disease that is treated in many different ways. The more you know about your specific cancer diagnosis, treatment options, and possible side effects, the easier it will be to talk with your health care team to determine the best treatment plan for you. Before making a decision about your treatment, it is helpful to know what the common short and long-term side effects are and how to manage them. Everyone experiences treatment and side effects differently, but it can help to feel prepared.

WHAT IS CANCER?

Cancer is a term used for diseases in which abnormal cells divide without control and may invade other tissues. Cancer cells can spread to other parts of the body through the blood and lymph systems¹.

The body is made up of many different types of cells, such as skin cells, muscle cells, and blood cells. Many normal cells are continually dividing in our body to create new cells. Normal cells have an internal system that knows when the cell is getting old and should die to make room for a new cell.

When an error occurs in the making of a new cell, that cell can become a cancer cell. In addition to an error in development of the cell, cancer cells do not have the internal system that causes the cell to die after a certain time. This causes a buildup of the abnormal cells. When this occurs, it can form into a mass of tissue, called a *tumor*, or it can crowd out the good, healthy cells, like with leukemia or other cancers that affect the blood. If cancer cells leave their original site and move to other parts of the body, this is called *metastasizing*.

Cancer types can be grouped into categories, which describe where the cancer originally started from. The main categories of cancer are:

- **Carcinoma:** This is the most common kind of cancer and is generally known by the place in the body where the cancer begins, such as the lung, breast, or colon
- **Sarcoma:** Cancer found in supporting tissue, such as bone, muscle, or fat
- **Leukemia:** Cancer that starts in the blood or bone marrow; an abnormal production of blood cells
- **Lymphoma:** Cancer that starts in immune system cells within the lymphatic system
- **Central nervous system cancers:** Cancer that starts in the brain or spinal cord

Within these categories, there are many different types of cancer. It is important to know the cancer type (primary location) and stage. Stages are classified as Roman numerals I-IV (1-4). The higher the number, the more the disease has spread.



QUESTIONS TO ASK AT THE START

1. What type of testing will I need in order to confirm my diagnosis and stage of cancer?
2. What type of cancer do I have?
3. What is the stage of my cancer?

¹ National Cancer Institute

GOALS OF CANCER TREATMENT

Treatment may be used to achieve different goals, depending on the stage and type of cancer you have at time of diagnosis:

- **Cure the cancer:** Destroy cancer cells to the point that they can no longer be detected and will not grow back.
- **Control the cancer:** Keep cancer from spreading, slow its growth or destroy cancer cells that have spread.
- **Improve symptoms:** Ease pain or pressure by shrinking tumors or managing other symptoms that cancer may cause.

It is important to help set and understand the goal(s) of treatment.

Most cancer is treated with a combination of treatments. In general, treatments are divided into two main groups:

- local and regional control of the cancer
- systemic control of the cancer

Local and regional treatments focus on the immediate area where the cancer is located, whereas *systemic treatments* focus on any potential cancer cells throughout the entire body.

Decisions about your cancer treatment are based on several things:

- type and subtype of cancer
- location of the cancer
- whether or not the cancer has spread (or stage of cancer)
- your age, general health, and other individual circumstances
- results of biomarker tests
- your personal goals for treatment

You may be asked to consider and choose from several different treatment options, or you may be advised that a single type or combination of therapies would be best.

You will receive a lot of information, and it can be overwhelming. You typically have time to make decisions, so it is okay to take time to discuss the options with your family and health care team before making a decision. Make sure that all of your questions have been answered before making a decision about what treatment you want to receive.

I learned more about my cancer and started asking my doctor more questions.

— Thomas

YOUR HEALTH CARE TEAM

In addition to you and your loved ones, key members of your cancer treatment team may include:

- Surgeon
- Oncologist or Hematologist
- Radiation Oncologist
- Oncology Nurse
- Nurse Practitioner or Physician Assistant
- Patient Navigator
- Primary Care Doctor
- Social Worker
- Palliative Care Provider

It is helpful to choose a cancer treatment team with experience in your type and stage of cancer.

Get the most out of each visit by preparing ahead of time. You can prepare by:

- Asking members of your health care team to help you plan for your treatment dates and follow-up appointments in advance.
- Writing down your questions before each visit. Throughout this booklet, you will find questions that are helpful to ask.
- Writing down any side effects you are experiencing or any side effects you have questions about. Record the time and date of side effects using the *Coping with Side Effects Planner*.
- Bringing a friend or family member with you to appointments to help you write down information and ask questions.

A SECOND OPINION

Some people find it difficult to speak to their doctor about getting a second opinion.

A second opinion is recommended before starting treatment. In some cases, insurance companies require it before starting treatment. A doctor should be comfortable with this request and should support you in the process of seeking a second opinion.

When you hear the words, “you have cancer,” it’s easy to feel like you need to make decisions within days of your diagnosis. But in most cases you have time to learn about your treatment options. I learned the importance of taking a proactive role in my decision-making.

— Sharishta

CANCER TREATMENTS

Common forms of cancer treatment include: surgery, radiation, chemotherapy, targeted therapy, hormonal therapy, and immunotherapy. A clinical trial can also be a way to access new or existing treatments.

This book discusses many types of treatment for cancer but does not include every type. You or your loved one may learn more specifics about treatments available to you by visiting www.CancerSupportCommunity.org. As always, when making a treatment decision, it is important to consult with your health care team and seek a second opinion if you don't feel comfortable with your suggested treatment plan.

Help with Making a Treatment Decision



If you are facing a cancer treatment decision, CSC's Open to Options® research-proven program can help. Our Open to Options® team can help you create a list of questions for your doctor in English or Spanish. Call 888-793-9355 to make an appointment or to find a local CSC or Gilda's Club near you.



QUESTIONS TO ASK ABOUT YOUR CANCER TREATMENT(S)

1. What is the goal of the treatment you are recommending?
2. What is the standard treatment for this diagnosis?
3. Why do you recommend this particular treatment?
4. What are the benefits and risks?
5. How long will this treatment last?
6. How will the treatment be given?
7. Are there other options available?
8. Is a clinical trial an option for me?
9. Where will I receive treatment? Will I need to be in the hospital or will I be able to receive treatment as an outpatient?
10. What side effects can I expect now or later?
11. Will the side effects go away when the treatment is over?
12. How will side effects be managed?
13. How can I communicate with you between appointments?
14. How do I obtain a copy of my medical records for my own files?

SURGERY

Surgery is an operation used to diagnose and/or treat cancer. Surgery is the most common form of cancer treatment. It may be used alone or in combination with other treatments.

Surgery has several different purposes:

- **Diagnosis:** in a surgical procedure called a biopsy, all or part of a tumor is removed so it can be studied under a microscope.
- **Staging:** staging surgery can help determine how advanced the cancer is by evaluating the size of a tumor and the spread of the disease.
- **Primary Treatment:** for tumors that are localized (found in one place) and show no evidence of spread, surgery is usually the primary treatment. The goal of this surgery is to completely remove all visible signs of the cancer.
- **Debulking:** a surgical procedure may be used to reduce the size of a tumor that cannot be completely removed, allowing chemotherapy or radiation therapy to work more effectively.
- **Palliation:** is surgery done to relieve symptoms caused by pressure of a tumor on a nerve or other body part, such as the intestines.
- **Reconstruction:** reconstructive surgery helps restore the function or appearance of an area of the body where a tumor was located.

Common side effects from surgery are specific to the type of surgery done. Examples could include pain (often temporary), fatigue, the risk of infection at the surgical site, scarring, and numbness (often temporary).



QUESTIONS TO ASK ABOUT SURGERY

1. What should I do to prepare for surgery?
2. How should I expect to feel after surgery?
3. What physical limitations may I expect during my recovery?
4. If there is a risk of infection at the surgical site, what can I do to prevent a problem?
5. What is the expected length of recovery? Will I need a caregiver during my recovery period?
6. Will I have any drains or devices to learn to care for after recovery?
7. Who can I contact with any questions?
8. What should I do in the event of an emergency?

RADIATION THERAPY

Radiation therapy (or radiotherapy) is the use of high-energy rays (ionizing radiation) to kill or damage cancer cells. For some, radiation is given before, during, or after other treatments. The goal of radiation is to damage as many cancer cells as possible without harming healthy tissue. To minimize damage to healthy cells, radiation doses are calculated very precisely and treatment is often spaced out over time.

How Is Radiation Therapy Given?

External radiation therapy is delivered by a machine that aims high-energy rays at the specific area of the body to be treated. Before treatment begins, a radiation oncologist conducts simulation tests to confirm measurements on the precise area of the body where radiation is to be delivered.



QUESTIONS TO ASK ABOUT RADIATION THERAPY

1. What kind of radiation will I get?
2. How long will my treatment last?
3. Should I arrange for help driving to and from treatment appointments?
4. How should I take care of the area being treated?
5. What side effects should I expect and how will we manage them?
6. Who do I contact with issues during my radiation therapy—my radiation team or my primary oncology team?
7. Should I take my routine medication prior to my radiation appointment?
8. How will we know if the treatment has worked?
9. Will there be any restrictions on my activities while I am receiving radiation therapy?

Common side effects from radiation therapy include nausea, fatigue, and skin changes, such as redness, dryness, or itching at the site of treatment. Other side effects are specific to the part of the body being treated. Side effects can be progressive and can last after treatment is complete. Discuss any side effects with your health care team.

Treatments are typically given once a day, five days a week, for several weeks. Sometimes treatment is given in smaller doses twice a day. Radiation does not hurt while it is being given and people receiving external radiation are not radioactive.

Treatment usually occurs in an outpatient clinic or radiation treatment center. Some people feel very tired as they proceed further along in their course of radiation, but many people are able to arrange their daily radiation appointments around work or other activities.

Internal radiation therapy involves the placement of a radiation source inside your body. Seeds, ribbons, or capsules are placed in or near cancer cells to deliver a dose of radiation directly to the tumor site. Internal radiation can also be given in a liquid form, which is swallowed by mouth or injected through a vein.

Depending on the type of internal radiation therapy, some individuals may need to stay in the hospital until their body no longer gives off radiation at a high level. If you receive this therapy, very specific instructions about how to take care of yourself and others will be given to you and your family. This type of radiation is only done for certain types of cancer. Your doctor will tell you if this is required for your type of cancer.

CHEMOTHERAPY

Chemotherapy involves the use of drugs to destroy cancer cells. More than half of all people treated for cancer receive chemotherapy, and many different types are available. Doctors choose specific types of chemotherapy based on a number of factors, including the type of cancer you have, and its stage. Each person has a unique response to chemotherapy. Side effects will also vary depending on which drug or drug combination you receive, the dose of your drugs and the frequency of your treatments.

Chemotherapy is a *systemic* (whole body) treatment. This means it can destroy cancer cells almost anywhere in your body. Chemotherapy is most effective against fast growing cells, like cancer. However, some healthy, normal cells may also be damaged by this treatment.

How Is Chemotherapy Given?

Chemotherapy may be given intravenously (through a vein), in pill form (by mouth), through an injection (a shot), applied directly on the skin into the area around the tumor, or placed directly into the tumor site. Most often, chemotherapy is administered in an outpatient clinic on a regular schedule for a specific period of time. Some individuals may receive a prescription for a chemotherapy medication to take at home, while others receive chemotherapy in a hospital or at their doctor's office.

Because chemotherapy is a systemic treatment, side effects associated with chemotherapy often result from the damage of healthy cells, even in areas that are not sites of your cancer. Because previously healthy cells usually repair themselves after chemotherapy, many side effects are temporary and resolve themselves soon after treatment stops.

Some common side effects from chemotherapy include mouth sores, hair loss, nausea, “chemo brain,” and low white blood cell counts.



QUESTIONS TO ASK ABOUT CHEMOTHERAPY

1. What are the names of the chemotherapy drug(s) I will be receiving?
2. How will I get these drugs (in an IV, a pill, etc.)?
3. How much time is there between treatments?
4. How long will each treatment take?
5. Will I receive this treatment as an inpatient or as an outpatient? If as an inpatient, how many days will I be in the hospital?
6. How long will I need to receive this treatment?
7. Will there be any restrictions on my activities while I am receiving chemotherapy?
8. Will I need to have a catheter or central venous line implanted/inserted? If so, how long will this stay? Will I receive training about how to take care of it?
9. How will I know if the treatment worked?
10. Should I plan to have help driving me to and from treatment appointments?
11. What side effects should I expect and how will we manage them?
12. Are there long-term side effects that I should consider (i.e., related to fertility or other issues)?

TAKING ORAL CANCER THERAPIES (PILLS) AT HOME

It's very important to take pills as prescribed. Even when you have a reason, a missed pill can lead to serious outcomes. The cancer may be more likely to spread or return. Here are some tricks that may help you take drugs as prescribed:

- Set reminders on your phone or watch.
- Use a pill calendar or a pillbox to organize your pills by day and time. This will help you see if you have missed a dose.
- Sometimes drugs will come in a blister pack that helps you see whether you took your dose at the right time.
- Store pills in a place you will see them every day.
- Follow your doctor or pharmacist's instructions on what to do if a dose is missed.
- Tell your doctor about any missed doses at your regular appointments.
- Oral cancer drugs may need to be pre-approved through your insurance company. This may take days or weeks to complete.
- Based on the drug ordered, your insurance company will tell you where you can purchase these drugs (such as through a specialty pharmacy, mail order, or a local pharmacy).

TARGETED THERAPY

Targeted therapy is a type of cancer treatment that targets specific genes or proteins to more precisely attack cancer cells. Some targeted therapies may interfere with the tumor's ability to grow its own blood supply; others interrupt the signaling system within the cancer cell to prevent it from growing and dividing. There are many different types of targeted therapies and new ones are being researched every day.

Targeted therapy is given in the same ways that chemotherapy is given: as a pill (by mouth), as an IV (through a vein), or as an injection (shot). Targeted therapy can be given in combination with chemotherapy for some cancer types. You will want to ask specifically what side effects to expect if you receive a combination of these treatment types and if targeted therapy is appropriate for you. Targeted therapy is better at treating certain types of cancers than others. It is important to note that not all cancer types can be treated with targeted therapy.

Some of the more common side effects from targeted therapies are skin problems such as a rash, dry skin, or itching. The rash is often mild, and is often worst within the first few weeks of treatment. Some other common side effects are fatigue and a flu-like reaction with fever, chills, and diarrhea.



QUESTIONS TO ASK ABOUT TARGETED THERAPY

1. What are the name(s) of the targeted therapy drugs that I could or will receive?
2. Where and how will I receive my treatment? Is there anything I should know about handling the drug (i.e. wearing gloves)?
3. How often will I get treatment?
4. What side effects should I expect and how will we manage them?
5. Will I receive targeted therapy alone or in combination with other treatments?
6. How long will I need to receive this treatment?



IMMUNOTHERAPY

Immunotherapy is a type of cancer treatment that uses the body's natural defenses (the immune system) to identify, attack, and kill cancer cells. The immune system's purpose is to attack any cell that it sees as unhealthy or abnormal. Cancer cells can hide from these defenses or even stop an attack. New knowledge about the complex interactions between the immune system and cancer is leading to new treatments. Although there are promising results, immunotherapy does not work for every cancer type or every patient. There is still a lot that researchers don't know.

Most immunotherapy is given using an IV (through a vein). You may receive immunotherapy in a doctor's office, in a clinic, or as an outpatient in a hospital. Different immunotherapies are given on different schedules. Some may be given in combination with other therapies or with a different immunotherapy.

We tend to think of immunotherapy as “natural”—as our body's own defense system. However, immunotherapy can still have side effects. These effects are generally different from those caused by chemotherapy or radiation therapy. In many cases, they are not severe and may be short-lived or easy to manage. Less often, side effects can be very severe and even life-threatening.

If you are on immunotherapy, it is important to let your health care team know right away if you notice any change in how you feel.

The most common immunotherapy side effects include:

- Fatigue (feeling tired)
- Skin problems like rashes, redness, or itching
- Muscle or joint pain

Alert your health care team immediately if you have:

- Diarrhea
- Problems breathing
- Eye problems
- Stomach pain, cramping, nausea, vomiting
- Fever
- Sudden change in energy or severe weakness
- Headaches
- Low blood pressure
- Chest pain
- Decreased urination
- Problems thinking or remembering things

Most side effects can be treated early and managed well. Sometimes a side effect will occur several months later. Having one or more side effects does not always mean that you must stop taking drugs that are working for you. Ask your health care team what side effects you may experience with your immunotherapy. If you are also being treated with a different type of anti-cancer drug, like chemotherapy or a targeted therapy, you will need to know what side effects those drugs may cause.



QUESTIONS TO ASK ABOUT IMMUNOTHERAPY

1. What are the name(s) of the immunotherapy drugs that I could or will receive?
2. Where and how will I receive my treatment?
3. How often will I get treatment?
4. What side effects should I expect and how will we manage them?
5. How long will I need to receive this treatment?
6. How will we know if the treatment is working?

Clinical Trials

A clinical trial is a research study that compares a new drug or treatment approach with the best known available therapy, or standard of care. Clinical trials are used to find out if the new treatment is safe and effective. Before the Food and Drug Administration (FDA) approves a new treatment for use, the treatment must move successfully through at least three phases of clinical trials.

Each study has specific conditions a person must meet in order to participate. Participation in a clinical trial is always voluntary and participants may choose to leave the study at any time.

PHASE I

Phase I trials are the first test of the dose and safety of a drug. Doctors work with small groups of patients who may have different kinds of cancer. Many phase I trials are for people with cancers that have spread to other parts of their bodies.

PHASE II

Phase II trials are done if a phase I trial showed that the treatment is safe and works against one or more types of cancer. A phase II trial is a larger study, often done with specific cancer types. It looks at how well a treatment can work in that type of cancer.

PHASE III

Phase III trials are large studies. They involve hundreds or thousands of patients. These studies are often done in many cancer centers in the United States or around the world. For this phase, you will be assigned to get the new treatment or the “standard of care” (current best treatment). In order to give everyone an equal chance at the new treatment, a computer decides randomly which treatment you will get. The doctor does

not have any role in deciding which patients get which treatments and often does not know who is getting the standard of care.



QUESTIONS TO ASK ABOUT CLINICAL TRIALS

1. What is this clinical trial trying to find out?
2. What will I have to do as a participant?
3. What are the possible risks and benefits of the new treatment?
4. Why might the treatment being studied be better than standard treatment? Why may it not be better?
5. How does the treatment in this trial compare with other treatment choices?
6. Will my insurance cover my costs?
7. Will being in the study cost me anything? If so, will I be reimbursed?

TO LEARN MORE ABOUT CLINICAL TRIALS

Your health care team can provide you with information about clinical trials available at your treatment center.

National Cancer Institute

800-422-6237

www.cancer.gov/clinicaltrials

Cancer Support Community's Clinical Trials Matching Service

800-814-8927

www.CancerSupportCommunity.org/finding-clinical-trial



Managing Common Side Effects

3 Knowing what side effects to expect during and after treatment can help you prepare for them. More importantly, being better informed can help you and your health care team to proactively manage or possibly prevent side effects so they will not decrease your quality of life or disrupt your treatment. Some people decide they do not want certain side effects so they talk about a different form of treatment with their health care team. Others manage their side effects and continue to live as normally as possible. It is important to note that most people will not experience many of the side effects discussed in this booklet. However, it is helpful to be aware of possible side effects from your treatment options.

COMMON SIDE EFFECTS

Research indicates the most common side effects people experience due to cancer and cancer treatment include: fatigue, hair loss, anemia, stomach or bowel problems (like nausea, constipation, or diarrhea), pain and infection, rash, and flu-like symptoms.

Emotional distress is also very common. However, there are specific approaches you can take to help manage these side effects. The side effects discussed in this book are listed in no particular order.



GENERAL TIPS TO HELP MANAGE SIDE EFFECTS

- Good nutrition maintains energy, strengthens the immune system, and can decrease side effects.
- Adequate fluid intake avoids dehydration, helps decrease constipation, and decreases fatigue.
- Try to do some physical activity every day. Exercise combats fatigue, promotes restful sleep, and can elevate your mood. Talk with your health care team about what exercises may help you.
- Tell your health care team about all medicines that have been prescribed, as well as over-the-counter medicines like aspirin, cold remedies, vitamins, or herbal supplements you take. Some medicines and combinations of medications can contribute to side effects or interfere with your treatment.
- Wash your hands to decrease the risk of infection. Ensure that family members and friends do the same. Avoid having visitors who are sick or are exposed to young children who are sick.
- Relaxation techniques such as yoga, meditation, and deep breathing help to reduce stress and increase energy.
- Talking with others can help you understand and manage your feelings.
- Tell your doctor and nurse about all side effects you are experiencing. They often have resources and techniques to help you manage them.

ANEMIA, INFECTION & BLEEDING

Your body produces important types of blood cells, including:

- white blood cells to fight infection
- platelets to control bleeding
- red blood cells to carry oxygen

Chemotherapy and radiation therapy can slow the development of blood cells, making fewer available in the blood. During and after treatment, your blood will be checked regularly with a test called a complete blood count (CBC) to monitor how many of each of these cells you have. You may want to write down your CBC results or keep a printout of your blood test results from your clinic visits.

ANEMIA

If the number of **red blood cells** in your body decreases, you can develop anemia. When anemia becomes severe, you have fewer blood cells to carry oxygen to your body's cells and tissues so you may feel weak, fatigued, experience dizziness, shortness of breath and sometimes depression. If left untreated, anemia can interfere with treatment and strain the heart and lungs.

Fortunately, there are treatments for anemia including blood transfusions or medications

that encourage the growth of red blood cells, which supplies the body with oxygen. Treatment for anemia is determined by the cause and extent of the condition.

What Symptoms Should You Report to Your Doctor?

- shortness of breath
- feeling your heart pound or beat fast
- confusion or difficulty concentrating
- dizziness or fainting
- feeling very tired or unable to perform your daily activities



TIPS TO MANAGE ANEMIA

- Get plenty of rest.
- Ask your family and friends for help when your energy is low.
- Eat a healthy diet and drink plenty of fluids. Ask your doctor or nurse about iron rich foods that are important for you to eat if you have anemia.
- Stand up slowly. Anemia can cause you to feel dizzy when you rise quickly after lying or sitting.
- Report worsening fatigue to your doctor.
- Ask your doctor if you need medication or a transfusion to increase your red blood cells.

INFECTION

A low **white blood cell** count puts you at risk for infection, which is one of the most serious side effects of cancer treatment. Infection can lead to hospitalization, and may even be life threatening.



I try to stay away from situations where there are a lot of germs, because my immune system isn't very strong. I know that if you sneeze on me, then I'm down for the count, so I'm very careful with that.

— Cathy

How Can I Recognize the Symptoms of Infection?

Take your temperature daily or as your health care team recommends. Call your doctor or nurse immediately if you have a fever of 100.4° F (38° C) or higher. Fever is often one of the first symptoms of infection. If your immune system is weakened, a small infection can become a larger infection quickly if it goes untreated. Fever that occurs when your white blood cells are low (neutropenic fever) is considered an emergency and requires prompt medical attention.

HOW DOES INFECTION OCCUR?

When you come in contact with different bacteria, viruses, or other germs that don't normally live inside your body, your immune system needs to fight them off. If your white blood cells are low it can be a sign that your immune system is unable to prevent these germs from growing inside the body, causing an infection. If you develop a bacterial infection, you will be treated with antibiotics. In some cases, hospitalization may be necessary.



TIPS TO PREVENT INFECTION

- The most effective way to avoid infection is to wash your hands frequently and thoroughly. Take at least 15 seconds to wash your hands with soap and warm water. Dry your hands completely to prevent bacteria from growing and spreading.
- Wash your hands before cooking and eating and after using the bathroom, sneezing, or coughing. Carry hand sanitizer when you are not at home.
- Avoid people who are sick or who have just received a live vaccine (ex. a vaccine for chicken pox or polio). Stay away from large crowds. Avoid children who have received any live vaccines for 10-14 days.
- If you cut yourself, clean the cut well and apply an antiseptic.
- Wash fruits and vegetables well before eating.
- Avoid touching or eating raw or undercooked meat, chicken, eggs, and seafood.
- Ask your doctor if you need medication to increase your white blood cells.
- Ask your health care team about caring for pets during periods where your white blood cell count is low.

Call your doctor or nurse right away if you experience:

- Fever
- Chills, shaking
- Shortness of breath, chest pain
- Headache or stiff neck
- Dizziness or fainting

Call your doctor or nurse if you experience:

- Redness, swelling, rash, or skin that is warm to touch, especially around a wound or catheter site
- Cough or sore throat
- Mouth ulcers
- Sinus pain or earache
- Diarrhea or pain when you have a bowel movement
- Bloody or cloudy urine, pain or a burning sensation during urination, frequent urination
- Unusual vaginal discharge or itching

BLEEDING

Platelets are blood cells that help control bleeding. If cancer treatment lowers the number of platelets in your body (thrombocytopenia), bleeding can occur. Low **platelets** can cause bruising, tiny red dots on your skin (petechiae), or bleeding from any part of your body.

Many medications, including aspirin, over-the-counter pain relievers, and some herbal supplements, can also increase your risk of bleeding. Tell your doctor about any non-prescription medications you take. If your platelet counts become very low, you may need a platelet transfusion or a delay in your chemotherapy treatment to allow time for your blood counts to further recover.

Call your doctor or nurse right away if you notice any of these symptoms:

- Bruises, especially if you haven't injured yourself
- Tiny, red dots on your skin
- Bleeding from your nose or around your gums
- Headache or any change in your vision
- Feeling very sleepy or confused
- Pink or red urine; bloody or black bowel movements
- An extra-long or very heavy menstrual period or vaginal bleeding not caused by your period



TIPS TO PREVENT OR MANAGE BLEEDING

- Use a soft toothbrush, avoid toothpicks, ask your doctor about dental floss.
- Blow your nose gently.
- Use an electric shaver rather than a razor.
- Try to avoid injury. Be careful when using sharp objects. Do not participate in contact sports.
- Apply firm pressure to any cuts.
- Do not use suppositories, enemas, or rectal thermometers.
- Avoid constipation. Ask your doctor or nurse if you should use a stool softener.
- Ask your health care team about sexual intercourse if your platelets are low.

COGNITIVE CHANGES & CHEMO BRAIN

Cancer and cancer treatment can affect your thinking, memory, concentration and behavior. These “cognitive changes” can interfere with your ability to work or perform everyday tasks. It can be very upsetting to realize that your cancer has been successfully treated, but you still do not feel like your old self.

Not everyone will experience cognitive changes. For those who do, changes can be mild or more severe, and often improve with time or treatment. Pay attention to any changes you notice. Ask your family or friends to watch for changes as well. Talk with your doctor or a member of your health care team about these symptoms. Some changes are caused by an underlying condition, which may be treatable.

Whether cognitive changes will improve or be permanent depends on their cause.

If you notice changes in your thinking, memory or behavior, keep a record of the problems that you have and ask your family or friends to watch for additional problems. Make an appointment to talk to your health care team about these symptoms as soon as possible. Treating the underlying condition often reduces or removes cognitive problems.

CHEMO BRAIN

People often use the expression “chemo brain” to describe mild changes in their ability to think, concentrate or remember during and after cancer treatment. Symptoms may include:

- Difficulty concentrating
- Forgetfulness
- Confusion
- Inability to think clearly or find the right words
- Difficulty multitasking



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TIPS FOR COPING WITH CHEMO BRAIN

These tips can help you cope with mild cognitive changes. Be sure to talk with a health care professional in case there is an underlying condition that can be treated.

- Tell a family member or friend. Let people know what's going on so they can support you.
- Plan your day and schedule things that require the most concentration for when you feel best.
- Stay organized by taking notes, recording things, using a calendar for important dates and a pillbox for your medication.
- Make time for physical activity as it can increase mental alertness.
- Try to focus on one thing at a time. Whenever possible, avoid having conversations or working in an environment with distractions.
- Develop routines to stay on top of things.
- Get enough rest.
- Eat a healthy diet.
- Keep moving. Even a few minutes of exercise can be helpful.

MENTAL CONFUSION OR DELIRIUM

Delirium refers to the state of being very confused. It can come and go throughout the day. Some people with delirium act tired or withdrawn, while others seem agitated or hyper. Delirium is a side effect of certain medicines and generally improves when you stop taking the medicine.

Other causes of delirium may be more difficult to reverse, or there may be more than one thing causing delirium. These may include:

- Drugs such as benzodiazepines and opioids
- Drug withdrawal
- Infection
- Decreased oxygen
- Inability to completely empty the bladder

Get in touch with your health care team right away if you think that you or a loved one may be experiencing delirium. There are programs for cognitive changes that might help with your memory or other issues. Ask your oncology team for possible referral.

CONSTIPATION

Difficulty having a bowel movement may be a problem for people undergoing cancer treatment. Surgery, inactivity, eating a low-fiber diet, and not drinking enough fluid can contribute to changes in normal bowel function. Pain medications and some chemotherapy drugs can also cause constipation.

Call your doctor if you have prolonged abdominal pain, or lack of a bowel movement or gas for more than two days.



TIPS TO MANAGE CONSTIPATION

FOOD TIPS FOR CONSTIPATION

Increase foods that can help promote a bowel movement:

- Drink 8 to 12 glasses of water or fluid each day.
- Warm drinks and prune, apple or pear juice may also be helpful.
- Drink hot beverages, such as herbal tea and decaffeinated coffee.
- If recommended by your health care team, increase your fiber intake by eating bran, fresh fruit, prunes or other foods high in fiber.
- Check with your doctor to see if there are certain high fiber foods you should avoid if you are having gas and bloating.

NON-FOOD TIPS FOR CONSTIPATION

- Stay active. Try to get 15-30 minutes of moderate physical activity (such as walking) each day.
- Move more if you are able—walk, stretch, or do yoga.
- Talk to your health care team about drugs or other tips that can help with constipation.
- Always talk to your nurse or doctor before using fiber supplements, laxatives or stool softeners. Suppositories and enemas can be especially dangerous if your blood counts are low.
- Tell your health care team if you do not have a bowel movement within 72 hours or experience abdominal pains or cramping. These may be signs of a bowel obstruction.

To learn more and to find recipes to help with constipation, see www.CancerSupportCommunity.org/TreatmentNutrition and www.CancerSupportCommunity.org/TreatmentRecipes.

DIARRHEA

Frequent bowel movements that are loose or watery are called diarrhea. Some chemotherapy drugs cause diarrhea. Infections, certain surgical procedures, and radiation to the pelvic area can also cause diarrhea. If diarrhea is a side effect of your treatment, your health care team will discuss

how you can work together to manage it. **If you are experiencing more than three episodes of diarrhea in a day, call your doctor or nurse.** Diarrhea can result in dehydration or changes in the levels of potassium and sodium in your body. Changes in these levels can be dangerous if not corrected.



TIPS TO MANAGE DIARRHEA

- Drink 8 to 12 glasses of fluid each day to prevent dehydration. Fluids should be at room temperature and may include water, ginger ale without fizz, or sports drinks. Clear broth is another option for increasing your fluid intake.
- Avoid caffeine. Caffeine may stimulate the bowel, further irritating it. It also may cause you to become more dehydrated.
- Avoid very hot or very cold drinks and alcoholic beverages.
- Eat 5 or 6 small meals a day instead of 3 large meals.
- Avoid spicy or fatty foods, and milk products.
- Eat low fiber foods, like the BRAT diet. BRAT stands for bananas, white rice, apples/applesauce, and toast.
- Wipe gently after each bowel movement; baby wipes may be more comfortable than toilet paper. Wash your hands well.
- Do not take an over-the-counter Pepto-Bismol or other anti-diarrheal drugs before speaking to your health care team. In some instances, diarrhea can be a sign of an infection or virus, and your health care team will want to test a stool sample prior to allowing you to take medication.
- If your doctor gives you medication for your diarrhea, be sure you understand how to take it. Never take any drugs for diarrhea without first speaking to your doctor or nurse.

To learn more and to find recipes to help with diarrhea, see www.CancerSupportCommunity.org/TreatmentNutrition and www.CancerSupportCommunity.org/TreatmentRecipes.

FATIGUE

Fatigue is one of the most common and toughest side effects of cancer treatment. It is more than just being tired. Fatigue is feeling physically, emotionally or mentally exhausted. You may have trouble finding the energy for even the simplest tasks, and this feeling does not go away with rest. It is important to tell your health care team if your energy is low. Fatigue usually lessens over time, but it is sometimes caused by anemia or blood loss that can be treated with medication. Sometimes fatigue is confused with depression, a psychological condition treatable with counseling or medication.

Fatigue is a side effect that is cumulative. This means you may only experience a small amount of fatigue after your first treatment but the amount of fatigue will likely grow as your treatment continues. Fatigue does improve after treatment has finished but it does take some time to feel like you did before your treatment. There are strategies your doctor or nurse can discuss with you to help manage fatigue.

Be sure to tell your health care team if you:

- have difficulty sleeping
- are experiencing symptoms such as shortness of breath or feelings of a “racing” heart as these are symptoms of anemia
- are unable to exercise
- are experiencing pain
- take other medications
- are experiencing emotional distress, anxiety, or depression

It is difficult to predict how fatigued you will feel because every side effect is different for each person. Also, some therapies cause more fatigue than others. In most cases, you will gradually begin to feel less fatigued when your treatment ends.



TIPS TO MANAGE FATIGUE

- Ask others to help you.
- Set realistic goals for what you want to accomplish for the day.
- Identify the time of day when you have the most energy and consider scheduling or doing things during this window.
- Be as physically active as you can tolerate, starting slowly and building up to 150 minutes of activity spread over at least 3 days a week.
- Aim to sleep at least eight hours each night.
- Take time to rest or take a short nap (no longer than 45 minutes) early in the day, so you don't disrupt your nighttime sleep.
- Eat a nutritious diet.
- Drink at least 8 glasses of water or fluid a day, unless instructed otherwise by your doctor.
- Try meditation, guided imagery, prayer, or other strategies to help you relax and decrease stress.

To learn more about coping with fatigue, visit www.CancerSupportCommunity.org/fatigue.

HAIR LOSS

Hair loss is often the most visible indicator that a person has cancer and it can be a deeply personal and challenging experience for both men and women. It is important to discuss your concerns with your health care team so you may find ways to manage the distress related to hair loss.

Not all treatment for cancer will cause hair loss and most hair loss is not permanent. Some chemotherapy drugs are known to cause hair loss; others do not. Ask your doctor if your treatment typically causes hair loss, and if so, when to expect it. You are likely to lose hair all over your body, including eyebrows, eyelashes, and pubic hair, if your treatment causes hair loss. In most cases, your hair will begin to grow back after treatment ends. Sometimes the texture and color of new hair may be different when it grows back.



How Can I Manage Hair Loss?

Many people who lose their hair choose to use some sort of head covering for comfort and privacy. You might choose to wear a wig, hat, scarf, or turban. If you plan to get a wig, try to visit your hairdresser or a wig store before you lose your hair. This allows you to match the wig to your hair color and style. Some people choose one or more wigs in a completely different style and color.

Certain insurance companies will supplement or cover the cost of a wig, but you must submit a prescription from your doctor for a “cranial prosthesis” or “hair prosthesis.” Frequently, cancer treatment centers will have wig banks where you can get a refurbished or new wig for free or a small fee.

Many people will choose to get a very short haircut or shave their head before they begin to lose their hair. This is an opportunity to control how the hair loss will occur.

The scalp can become quite tender during the period of active hair loss. Sleeping on a satin pillowcase can be soothing. Use gentle cleansers and lotions on the scalp during this time. Once hair loss occurs, protect your head from the sun by applying sunscreen and wearing a scarf or hat. To stay warm in cold weather, cover your head to prevent loss of body heat.

COOLING CAP SYSTEMS

Ask your doctor about prescribing a cooling cap system to prevent hair loss. They can be costly and are not covered by all insurance companies.

Most of all, do whatever feels right to you. The more you prepare for losing your hair, the easier it will be if and when it happens. Nonetheless, when hair loss occurs, it can be upsetting. Be kind to yourself and allow time and space to cope with this loss. Reach out for the support you need.



TIPS TO MANAGE HAIR LOSS

- Avoid hair products that contain harsh chemicals (permanents, dyes, and relaxers), hairdryers and curling irons, hair bands and clips, and braiding your hair or pulling it back tightly.
- Use a mild shampoo, pat your hair dry, and brush with a soft hairbrush.
- Avoid any products that suggest they prevent hair loss from cancer treatment.
- Find new ways to feel good after hair loss with hats, scarves, makeup, and other accessories.
- Talk to your nurse about resources and programs that are available to you.

HOT FLASHES

During hot flashes (or hot flushes and night sweats) a person feels very hot and may start sweating, feeling anxious, and feel like their heart is beating faster than normal. Hot flashes are unpredictable, can come on quickly, and may be mild to severe. People getting hormone therapy to treat breast or prostate cancer often get hot flashes. They can occur because these treatments change the amount of sex hormones in the body.

Be sure to tell your health care team if you are experiencing hot flashes that get in the way of your sleep or normal activities.



TIPS TO MANAGE HOT FLASHES

- Avoid spicy foods, smoking, and alcohol.
- Avoid drinking very hot beverages.
- Avoid saunas and hot baths or showers.
- Dress in layers; cotton clothing and bedding may be helpful.
- Cooling bandannas and electric fans may be helpful.
- Practice stress reduction techniques, like deep, slow abdominal breathing.
- Try acupuncture—some people find that this can help relieve a number of their symptoms. However, it isn't always covered by insurance.
- Talk with your health care team before taking any medications or therapies.

LYMPHEDEMA

Lymphedema is swelling that is caused by a buildup of fluid beneath the skin. Cancer and cancer treatment can damage or remove lymph nodes, which lead to lymphedema. Anyone who has had cancer or cancer treatment is at risk for lymphedema.

Lymphedema is most common among people who have had breast cancer, melanoma, lymphoma, head and neck cancer, or cancers affecting the pelvic area including gynecologic, urinary tract, and prostate cancers. Procedures that put you at greater risk for developing lymphedema include:

- Biopsy
- Lumpectomy or mastectomy
- Surgery that affects the groin or armpit area, including surgeries for prostate and gynecological cancers and melanoma
- Radiation therapy
- Procedures to find cancerous lymph nodes that use dyes and radioactive substances

Other factors such as obesity, skin that is slow to heal, diabetes and the use of certain medications such as steroids may also increase your risk of lymphedema.

SIGNS OF LYMPHEDEMA

Lymphedema can develop soon after treatment, or appear weeks, months, or even years later. Talk with your health care team if you notice any of these signs:

- Swelling in any part of the body
- Tingling feeling in the arms or legs
- Changes in the color, feeling or texture of your skin
- Muscle weakness or difficulty bending or moving
- Itchiness, burning sensation or heavy feeling in the arms or legs

Ask your health care team if manual lymph drainage or compression garments could help you.



TIPS TO PREVENT LYMPHEDEMA

There is no sure way to prevent lymphedema, but it can help to take special care of your arms and legs. Use these tips to help prevent and manage lymphedema:

- Maintain a healthy weight.
- When possible, avoid shots, needles, finger sticks, blood pressure checks, or blood draws in the arm or leg that might be at risk for lymphedema (the post-surgery side).
- Keep the skin of the at-risk limb clean and gently moisturized.
- Make sure the at-risk arm or leg gets proper circulation. Avoid sitting or standing in the same position for long periods of time.
- Lift the arm(s) or leg(s) above the heart occasionally.
- Wear loose-fitting clothing. Avoid tight clothing and jewelry around the affected area.
- Avoid heavy lifting, rigorous movements, or too much pressure on the affected limb.
- Exercise. Work with a lymphedema specialist or physical therapist to develop a safe exercise program.
- Limit time in extreme temperatures, such as very hot showers. Avoid saunas, hot tubs, and the use of ice or heating pads in affected areas.
- Try to avoid injury and infection to the affected area.
- If a prosthesis is needed, choose one that is lightweight.
- Take special precautions when traveling—ask for guidance from a lymphedema specialist.

MOUTH & THROAT CHANGES

Because chemotherapy is a systemic treatment and targets rapidly dividing cells, the normal cells in your mouth and throat can be damaged. This might lead to the development of mouth sores, dry mouth, or changes in taste and smell. Also, individuals who receive radiation to the head and neck area may experience mouth and throat changes. Ask your doctor or nurse if you should expect this side effect.

Mouth Sores (Mucositis)

Mucositis is the term for inflammation and/or sores in your mouth, on your lips or in your throat. When, and if, mouth sores develop and how long they last depends on the treatment you are receiving. If your doctor or nurse has indicated that mouth sores are a likely side effect of your treatment you will want to start good mouth care habits early on in your treatment. If mucositis becomes painful or makes you not want to eat or drink, you may need medication to control the pain. Call your doctor or nurse if you experience pain when swallowing, eating, or drinking.

Dry Mouth

Sometimes chemotherapy and radiation therapy can decrease the amount of saliva in your mouth so that your mouth becomes very dry and your saliva becomes thick. Dry mouth can make it difficult to chew and swallow. If radiation has decreased the amount of saliva in your mouth, the problem may persist after treatment is over. Ask your health care team about saliva substitutes if your mouth is very dry.

Changes in Taste and Smell

Cancer treatment can make food taste like metal or chalk, have no taste at all or just taste different than before treatment. You may find you no longer enjoy the same foods or tastes that you did before. In most cases, this goes away after treatment is over. Taste and smell are an important part of eating. Changes in your taste and/or smell are commonly temporary, and routinely resolve within three months of treatment completion. If you find that changes in your taste and smell are affecting your eating, tell your doctor or nurse.



TIPS TO MANAGE MOUTH AND THROAT CHANGES

- Before starting treatment, talk to your doctor about making dentist appointments. It might be necessary for you to have dental work completed prior to treatment if there is a risk of infection, or it might be necessary to avoid routine dental appointments for a specific period of time after treatment is completed.
- Check your mouth and tongue every day for mouth sores, red areas, or white patches. White patches may indicate infection.
- Drink plenty of fluids, chew gum, or suck on hard candies to keep your mouth moist. Use lip moisturizer to keep lips moist.
- Brush with an extra-soft toothbrush and use fluoride toothpaste.
- Rinse your mouth four times a day with salt water, baking soda solution, or a mixture of the two. Avoid mouthwash that has alcohol because it can dry out your mouth.
- Avoid sharp, crunchy, spicy, or citrus foods, alcoholic beverages, and tobacco when your mouth is sore.
- Consider switching to plastic utensils to reduce metallic taste.
- Eat cool or room temperature foods and foods that are soft and easy to swallow, like cooked cereals, soft-boiled or scrambled eggs, yogurt and puddings.
- Ice chips or popsicles may reduce pain, but tell your doctor or nurse if you need pain medication for your mouth sores.
- If changes in taste and smell affect your ability to eat, ask your doctor for a referral to a nutritionist who can help.

To learn more or to find recipes that help with mouth and throat changes, visit www.CancerSupportCommunity.org/TreatmentNutrition and www.CancerSupportCommunity.org/TreatmentRecipes.



Changes in your taste and/or smell are temporary and resolve within three months of treatment completion for many people.

NAUSEA AND VOMITING

Nausea (feeling sick to your stomach) and vomiting (throwing up) are side effects that many people associate with cancer treatment, especially chemotherapy, but not all treatments cause nausea. There are many medications available to effectively control, and even prevent this side effect. Ask what your health care team can do to prevent and manage nausea and vomiting, and how you can help.

What Should I do if I am Experiencing Nausea or Vomiting?

- Try sucking on popsicles or ice chips.
- Drink carbonated beverages that have lost their fizz (cola and ginger ale) to help settle your stomach.
- Eat toast, crackers, or gelatin.
- Eat cool or warm (but not cold or hot) foods.
- Avoid foods that are spicy, fried, fatty, or have strong aromas.
- Tell your doctor or nurse if you are having nausea so they can consider alternative antiemetic (anti-nausea) medications or different combinations of drugs.
- Ask your doctor about acupuncture or acupressure. Some people find that it can assist in nausea relief.



TIPS TO MANAGE NAUSEA

- Eat a light meal or snack before your treatment. Eat 5 or 6 small meals during the day rather than 3 large meals.
- Choose bland foods, such as plain pasta or rice. If dry mouth isn't a problem, you can also try dry food such as crackers and pretzels.
- Try to relax before and during treatment by listening to music, meditating, or practicing deep breathing exercises.
- Understand how to take your anti-nausea drugs (antiemetics). You may take these drugs before your treatment and may also continue to take them for several days after treatment is over.
- Take your anti-nausea medicines as soon as you begin to feel sick to your stomach—don't wait until your nausea is bad. You can also take the anti-nausea medicines before doing something that has made you feel sick before, such as before eating or riding in the car.

To learn more or for recipes that help with nausea and vomiting, visit www.CancerSupportCommunity.org/TreatmentNutrition and www.CancerSupportCommunity.org/TreatmentRecipes.

Nausea and food smells really bothered me—but I took anti-nausea drugs and worked with a dietician who helped me find more mild foods to eat.

— Rochelle

NERVE PROBLEMS (NEUROPATHY)

Nervous system side effects can be common and can be caused from the cancer itself or from cancer treatments. The nervous system is made up of the central nervous system (CNS) and the peripheral nervous system (PNS).

The CNS includes the brain and spinal cord. If the central nervous system is affected by the cancer and/or treatments, changes may include difficulty concentrating, memory problems, confusion and hearing loss. See the “Cognitive Changes” section on page 25 for more information on changes to thinking, concentrating, memory, and behavior.

The peripheral nervous system (PNS) includes nerves outside of the CNS that transport information between the body and the brain. The PNS is involved primarily in movement and sensation. **Peripheral neuropathy** is a set of symptoms caused by damage to nerves in the PNS. The most common sensation is numbness, tingling, and burning in the fingers and toes. People with peripheral neuropathy can also experience increased sensitivity to touch or pain in their hands and feet. Peripheral neuropathy can often be managed with short breaks from treatment, medications, or changing the dose of your treatment.

It is important to tell your doctor or nurse if you have trouble feeling the ground when you walk, or find it difficult to perform activities like picking up a penny off the table or

buttoning your shirt. Usually these symptoms gradually get better after your treatment is over, other times the symptoms persist even after treatment ends.



TIPS TO HELP MANAGE NEUROPATHY

- Tell your doctor or nurse right away if you have problems with movement or sensation.
- Discuss medication options with your doctor if you are experiencing pain.
- Avoid alcohol. Even small amounts can increase nerve damage from chemotherapy.
- If you are diabetic, control your blood sugar. High blood sugars can also cause nerve damage.

TAKE SAFETY PRECAUTIONS SUCH AS:

- Wear gloves when washing dishes.
- Use handrails to help avoid falls.
- Wear supportive shoes.
- Check water temperature.
- Be sure to use gloves and potholders.
- Keep rooms, outside paths and stairs well lit.
- Clear walkways and floors.
- Use non-skid mats in showers and bathtubs.
- Ask your doctor or nurse what actions make sense for you, at home and at work.

PAIN

Pain can be caused by the cancer itself, by treatment, or by tests done to diagnose and monitor cancer. Or, your pain may not be related to your cancer diagnosis. Routine headaches, muscle strains, aches, and pains will continue to occur even after a cancer diagnosis. Not everyone with cancer will develop pain. Whether you have pain will depend on a number of factors, including the type of treatment you receive, your cancer type, the stage of your cancer and your personal pain tolerance. When the cancer itself causes pain, it is commonly due to a tumor pressing on bones, nerves, or other body organs. In addition, people with more advanced cancer diagnoses are more likely to experience pain.

How Should I Describe My Pain?

You are the expert in your cancer experience, so your health care team will look to you to

provide information regarding your pain.

Be honest about how much pain you are in.

By talking about pain, you begin the process of controlling it. Recording details in your planner can also be helpful.

Some of the important characteristics of your pain to discuss are:

- **Severity:** How bad is the pain? Health care providers typically ask people to rate their pain on a scale of 0 to 10, with 0 being “no pain” and 10 being “the worst pain you have ever had.”
- **Location:** Where is the pain? Is it in more than one place?
- **Frequency and Duration:** When do you have pain? Is the pain always there or does it come and go? How long does it last? When did the pain start? Have you ever had this pain before?

WONG-BAKER FACES® PAIN RATING SCALE



0

No
Hurt



2

Hurts
Little Bit



4

Hurts
Little More



6

Hurts
Even More



8

Hurts
Whole Lot



10

Hurts
Worst

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- **Quality:** Describe the pain. Is it burning or stabbing? Sharp or dull? Cramping?
- **Change:** What makes the pain better (medication, a heating pad) or worse (moving, coughing)?
- **Onset:** Did you feel it all of a sudden or did the pain build gradually?

How Is Pain Treated?

With appropriate management, most pain can be controlled, so you can return to your everyday routine. There are many pain management options. Most people are treated with medications initially, or complementary therapy, like massage or acupuncture. If you would like to use a complementary therapy, talk with your doctor and nurse to make sure there are no restrictions for you. For people with advanced cancers, other pain management options may include surgery or radiation therapy.

For mild pain, over-the-counter medicines may be all that is needed. For more severe pain, prescription pain medications might be required. Other medications, like steroids, anti-seizure drugs, and anti-depressants can also be used to control specific kinds of pain.

Pain is best managed when you work in partnership with your health care team. Once you and your doctor have identified the reason for your pain, your doctor will typically choose



TIPS FOR PAIN MANAGEMENT

- Do not ignore pain. Use your planner to track your pain and use a scale of 0–10 to rate it.
- Do NOT wait until the pain is out of control to take your medication. It is easier to stop pain before it starts or prevent it from getting worse.
- Tell your doctor or nurse if your pain is worsening, if you develop side effects from pain medication, or if you experience bowel or bladder problems.
- Write down how much medication you are taking and the times you take it.
- Tell your doctor and nurse about all of the prescriptions and over-the-counter medications you are using. This will help reduce the likelihood of a potentially dangerous drug interaction.
- For some people, complementary therapy for pain may be effective. Mind-body practices such as acupuncture, breathing exercises, meditation, hypnosis, Tai Chi or yoga may provide relief from pain.
- Physical or occupational therapy, massage, and the use of hot or cold compresses can also help to relieve pain.

and prescribe medication based on the type and severity of your pain.

If your pain is still not well controlled, ask your oncologist to refer you to a **pain specialist**. This member of the health care team works specifically on managing your pain, using a variety of techniques that your oncologist may be less familiar with. A specialist in pain management may include a palliative care provider or chronic pain specialist.

Are There Side Effects from Pain Medications?

Opioid pain medications can cause side effects, including sedation or drowsiness, nausea, and constipation. For most people, these side effects eventually subside. Short-term nausea may be treated with anti-nausea medication, but is often managed by taking the pain medication with food. Constipation can become a serious issue, so your doctor may recommend stool softeners or laxatives and an increase in the amount of fiber you eat and fluids you drink.

Sometimes switching to a different pain medication can eliminate unwanted side effects. If you are experiencing side effects from pain medication, tell your doctor, as there are a number of different medications that can be used.



ABOUT PAIN MEDICATIONS

NON-OPIOID DRUGS

Non-opioid drugs do not contain opioids, and include acetaminophen (Tylenol), non-steroidal anti-inflammatory (NSAIDs), and cyclooxygenase-2 (COX-2) inhibitors that have anti-inflammatory properties.

- *Examples:* Aspirin, Acetaminophen, Ibuprofen
- **Uses:** Mild pain, anti-inflammatory response
- Most are available over-the-counter

OPIOID DRUGS

Opioids are drugs that are widely used for treatment of pain in patients with cancer because of their safety, reliability, and effectiveness in managing many types of pain. The role of opioid therapy in severe forms of acute pain and in cancer pain is well established.

- *Examples:* Morphine, Oxycodone, Fentanyl
- **Uses:** Moderate to severe pain
- Available by prescription

Talk to your doctor or nurse before starting or taking any new medication, prescribed or over-the-counter, as some medications should not be taken together or may not be right for you.

SEXUALITY & FERTILITY

Many types of cancer and their treatments can cause sexual problems. Some common sexual issues reported include:

- Loss of fertility or fertility problems
- Loss of sexual desire
- Problems getting or keeping an erection
- Discoloration of sperm or ejaculate after treatment with chemotherapy (short term)
- Pain with intercourse for women
- Vaginal dryness
- Early menopause

A cancer diagnosis can change the way you feel about yourself and how you relate to others. Your physical appearance may change because of your treatment. You may have short-term and long-term changes in your body.

Talk about these changes with your health care team. A referral to a sexual health specialist may be helpful.

You may experience feelings of grief and loss, anxiety and depression. It is helpful to talk with people you trust and feel comfortable with.

Having a conversation with your partner is particularly useful in clarifying concerns and feelings. Open communication with your partner can contribute to maintaining a healthy relationship.

Intimacy

If engaging in sexual intercourse has become challenging, it does not mean you can't engage in other intimate activities that may afford equally as much pleasure.



TIPS ABOUT SEXUALITY

- Communication is essential. Talk with your partner and your health care team.
- During active treatment, especially when blood counts are low, you may be at increased risk of infection and bleeding. Talk to your health care team about engaging in sexual activity at this time.
- Discuss the use of birth control. Many providers will advise women to stop using the pill during treatment.
- Talk about using contraceptives during active treatment. Doctors usually advise using condoms or other contraceptives during this time. This prevents infections such as urinary tract infections (UTIs) and yeast infections. It also prevents pregnancy. Some anticancer drugs can be excreted into the semen and vaginal fluid. Using condoms can also prevent exposing the patient's partner to the drug.
- Vaginal dryness is a common side effect. Your health care team can prescribe medications to help with this.
- Your health care team may be able to refer you to sexual health and fertility specialists.
- Be open to discovering new ways you and your partner can connect and feel close.



CANCER TREATMENTS AND FERTILITY

If you are thinking of having children, let your doctor know as soon as possible, even before treatment has begun. Some options such as sperm/egg banking or radiation shielding of ovaries/testicles may need to happen or be agreed on before treatment begins.

Before you begin any of these procedures, check with your insurance company to see if they will cover them. If banking or tissue freezing is not an option for you, you may want to talk to your health care team about alternatives such as adoption, surrogacy, or a donor.

For more information on fertility preservation, fertility treatment discounts, and becoming a parent after cancer, contact **LIVESTRONG Fertility** at 855-844-7777 or www.livestrong.org/fertility.

SKIN AND NAIL CHANGES

Most skin and nail changes resulting from cancer treatment are minor and will get better once you have completed treatment. If you experience any severe redness or blistering, however, you should let your doctor or nurse know immediately.

Rashes and Other Skin Changes

Some types of chemotherapy can cause redness, swelling, and blisters on your hands and feet called **hand-foot syndrome**. Tell your health care team right away if this occurs. This is a serious side effect and may require a delay in treatment.

Some targeted therapies can cause a rash with an acne-like appearance. Your nurse or doctor will probably recommend a mild, soap-free cleanser and daily application of sunscreen. Do not use over-the-counter products for acne unless your doctor recommends them. In serious cases, steroid creams and antibiotics may be prescribed. Those undergoing treatment with immunotherapy may require steroids and holding treatment.

Changes Related to Radiation

Radiation therapy can cause skin changes that include redness, dry or peeling skin, itching, blisters, and swelling. Talk to your radiation oncologist and nurse about skin care. Be gentle with your skin. Wash your skin in the treatment area with mild soap, apply an unscented moisturizer and deodorant as long as your skin is intact. Do not use baby powder, cornstarch, tape, or adhesive strips on your skin. Do not put anything hot, like a heating pad, or cold, like an ice pack, on the area being treated. Wear soft clothes and use soft sheets made of fabrics like cotton. Some chemotherapy following radiation treatment can cause radiation recall, where skin in the area where you previously had radiation turns red and may blister and peel. Tell your oncologist if you notice this is happening.

Changes Related to Immunotherapy

Immunotherapy can cause skin changes. It often starts as itching without a visible rash. Tell your doctor if you have unusual itching or if you see redness or spots on your skin. Treatment may include allergy medications or steroid creams. A less common treatment is oral steroids.

Sun Sensitivity

Radiation and certain chemotherapies can make you very sensitive to the sun, even if you have dark skin or do not burn easily. This increased sensitivity can continue even after you complete treatment. Use sunscreen, hats or other sun protective clothing. Avoid direct and prolonged exposure. Remember to use sunscreen even during winter months.

Nail Changes

Fingernails and toenails can become dark, turn yellow, or become brittle and cracked due to cancer treatment. The cuticles may become swollen. Notify your health care team if your nails are loose or have fluid or pus under them.



TIPS FOR SKIN & NAIL CHANGE

- Avoid soaking in hot baths or Jacuzzis, which can dry out your skin. Try showering in lukewarm showers rather than hot showers.
- Use a moisturizing soap, pat dry after washing, and apply cream or lotion while your skin is still damp.
- Try a colloidal oatmeal bath for itching all over the body.
- Wear sunscreen, including lip balm with sun protection.
- Cover your skin as much as possible when you are outside.
- Never use a tanning bed.
- Do not bite your nails or wear fake nails.
- Ask your doctor before you have a manicure/pedicure.
- Wear gloves when you wash dishes or do household chores.
- Moisturize your hands and feet frequently.
- If a nail becomes inflamed, talk to your nurse or doctor.
- Report any new rash to your health care team, even if you are not particularly concerned by its appearance. Viral infections, such as shingles, can appear as a rash and should be treated as quickly as possible in order to prevent complications.

SLEEP CHANGES

Getting enough rest is an important part of staying healthy. People with cancer often report problems with getting the right amount of sleep. Some people find that they are sleeping much more than usual. Other people share that they suffer from insomnia which is the inability to get enough sleep to feel rested. Excessive sleep, too little sleep, restlessness and increased dream activity or nightmares can significantly affect your ability to feel well and to cope with daily activities.

For some people going through cancer treatment, disruption in sleep can be one of the most distressing side effects they face. Feeling too tired or fatigued from cancer treatment and having sleep problems sometimes go hand in hand. Please talk with your doctor if you are upset or feeling affected by changes in your sleep patterns. There are treatments and support services that can help with sleep problems.



There are three main ways sleep can interfere with your life:

- **Hypersomnia:** You sleep for long periods of time (10 or more hours at a time), have trouble staying awake during the day, or constantly feel tired, even after a nap.
- **Insomnia:** You struggle to fall asleep or stay asleep.
- **Nightmares:** Your sleep is disrupted by scary, vivid dreams that feel real.

All three of these conditions can make it harder to function during the day, and may worsen other side effects or health concerns. Try these tips to help manage sleep problems.

Coping with Hypersomnia

- Try to exercise every day, preferably in the morning or early afternoon. Develop a sleep routine so that you go to bed and wake up at the same time every day. When it is time to get up, get out of bed.
- Avoid naps. If needed, adjust your regular bedtime or wake-up time to give yourself extra sleep time.
- Spend time on activities you enjoy and that take your full attention.
- Watch your diet. Avoid eating foods high in carbohydrates, or meals that might make you feel drowsy during the day.
- Avoid alcohol and caffeine.

Coping with Insomnia

- Work with your health care team to address underlying sources of insomnia, such as pain, anxiety, or medication.
- Develop a sleep routine. Go to bed and wake up at the same time each day.
- Start a bedtime ritual, such as reading or taking a bath, to signal to your body that it is time for sleep.
- Avoid caffeine, alcohol, and tobacco, especially at night.
- If you are hungry at bedtime, eat a light snack.
- Exercise regularly, preferably more than two to three hours before bedtime.
- Sleep in a quiet, dark room that is not too hot or cold.
- Medications are sometimes used to treat insomnia in the short-term if other approaches do not work.

Coping with Nightmares

- Discuss your fears and feelings with a close friend or family member. Have these conversations early in the day rather than the evening.
- Talk about the nightmares with a trusted family member or friend.
- Write in a diary or draw pictures to express the content or themes of the nightmares.
- Imagine different endings or storylines to the nightmares.
- Remind yourself that nightmares aren't real.

URINARY AND BLADDER PROBLEMS

Some cancer treatments may cause urinary and bladder problems. These include radiation therapy to the pelvis, some types of chemotherapy and immunotherapy, and surgery to remove the prostate or bladder cancer surgery.

Symptoms of irritation of the bladder lining include:

- Pain or a burning feeling when you urinate
- Blood in your urine
- Trouble starting to urinate
- Trouble emptying your bladder completely
- Feeling that you need to urinate urgently or frequently
- Leaking a little urine when you sneeze or cough
- Bladder spasms, cramps, or discomfort in the pelvic area

Symptoms of a urinary tract infection include:

- Pain or a burning feeling when you urinate
- Urine that is cloudy or red
- A fever of 100.5 °F (38 °C) or higher, chills, and fatigue
- Pain in your back or abdomen
- Difficulty urinating or not being able to urinate

To prevent or manage urinary or bladder problems, drink plenty of liquids—at least 8 cups of fluid daily. Avoid caffeine, alcohol, spicy foods and tobacco—they can all make bladder problems worse.

Ways to reduce the risk of a urinary tract infection can include:

- Going to the bathroom often
- Wearing cotton underwear and loose-fitting pants
- Taking showers instead of baths
- Quickly changing out of wet bathing suits or damp exercise gear

Medications can sometimes cause problems emptying your bladder. These include some antihistamines, antidepressants, benzodiazepines, and opioids.

WEIGHT CHANGES

It is common to experience weight changes before, during and after cancer treatment. Perhaps you lost weight prior to your cancer diagnosis. Or you may have struggled with weight for many years. You may find that you have gained weight as a result of surgery, chemotherapy, treatment side effects, new medications, less physical activity, or depression. Some of these changes will be temporary and some may last much longer. Please talk to your health care team if you are concerned either about weight loss or gain. They will have suggestions to help determine the causes of your weight gain or loss and then work with you to find solutions that are specific for your situation.

Weight issues can be a very personal thing. If you want to lose weight, you might find that being on a strict diet and exercise plan may not blend well with your cancer treatment at this time. Your doctor may not want you to lose or gain too much weight during treatment. Above all, focusing on good nutrition and reasonable physical activity may be your best approach to a weight issue. Research has shown that obesity can result in cancer recurrence in some types of cancer. Eating healthy during and after cancer is an excellent way to improve your health and well-being with and beyond cancer.

Exercise can help you in many ways before, during, and after cancer treatment. These include:

- Less fatigue
- Reduces muscle wasting
- Less nausea
- Improved blood flow to the legs, which can lower the chance of blood clots
- Improved mood
- Better quality of life

Before starting exercise, ask your doctor how much exercise is safe for you.

Talk with your doctor about what concerns you and work together to identify the reasons for your weight loss or gain and talk about solutions. You may want to consult with a registered dietitian to develop an eating and nutrition plan that works well for you.



COPING WITH WEIGHT GAIN

CHOOSE HEALTHIER FOODS

- Fill up more of your plate with lower calorie fruits, non-starchy vegetables, and high-fiber whole grains.
- Avoid higher calorie foods made with rich creamy sauces, cheese, oils, and fried foods.
- Choose baked or broiled fish and lean meats like skinless chicken and turkey breast over high fat meats like hamburgers, steak, pork, and roasts.
- Eat smaller portions of food.
- Eat only when you are hungry.

KEEP A FOOD JOURNAL AND MEAL PLAN

- Planning ahead and tracking what you eat can help you to stick with your goals. Food journals and meal planning help can be found at: www.CancerSupportCommunity.org/SurvivorNutrition.

- Identify parts of your diet that can be improved and set goals to work on them.

AVOID EMPTY CALORIES

- Avoid high-calorie sugar-sweetened beverages, baked goods, and processed foods which offer little or no nutrition benefit.
- Choose beverages like water, seltzer, and plain tea. Flavor them with your favorite fruits.

INCLUDE MORE PHYSICAL ACTIVITY

- Aim for at least 150 minutes of moderate physical activity per week.
- Find a friend to stay active with you.
- If you are able, consider including cardio, stretching, and resistance training to help maintain or increase your muscle mass.



To learn more or for recipes that help with weight loss or gain, visit www.CancerSupportCommunity.org/SurvivorNutrition and www.CancerSupportCommunity.org/TreatmentRecipes.



COPING WITH WEIGHT LOSS

ADD HEALTHY HIGH-CALORIE ADDITIVES TO THE FOODS YOU EAT REGULARLY:

- Avocado
- Olive oil or butter
- Nuts and seeds
- Cheese
- Sauces and gravies
- Dried fruit
- Peanut butter, almond butter, or other nut butters

INCLUDE HIGH-PROTEIN FOODS TO HELP YOUR BODY HEAL AND PREVENT FURTHER MUSCLE MASS LOSS:

- Nuts, seeds, and nut butters
- Beans
- Meat
- Fish
- Poultry
- Eggs
- Dairy products

INCLUDE MORE PHYSICAL ACTIVITY

- Aim for a total of 150 minutes per week.
- Talk to your health care team about physical therapy if you feel weak or unable to maintain your daily routine.

EAT SMALLER, MORE FREQUENT MEALS

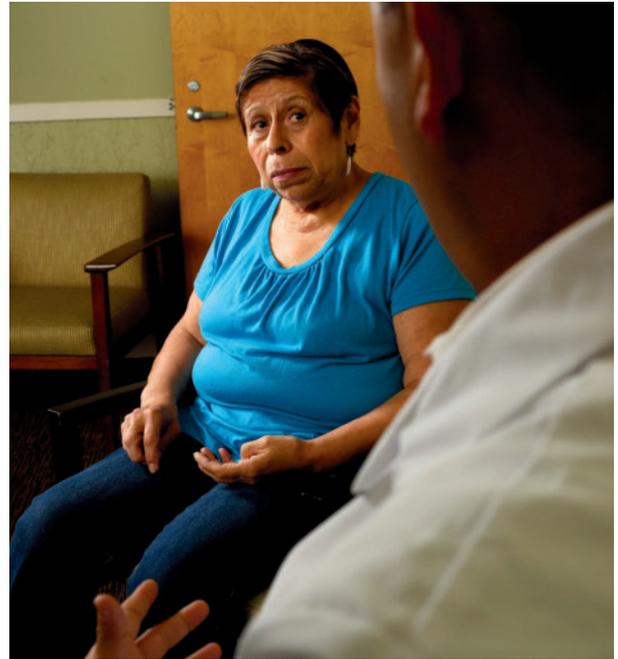
- Aim to eat 5-6 small meals daily, instead of 3 big meals.
- Keep high calorie foods and drinks nearby for times when you are hungry or have an appetite.
- Plan your largest meal for a time when you are likely to be hungriest.
- Snack regularly even when you are not hungry.
- Exercise to increase your appetite.
- Drink beverages containing protein between meals rather than with the meals.
- Include high-calorie smoothies or nutritional drinks to your daily routine.
- Set an alarm or reminder to eat.
- If nausea is making you eat less, try taking your nausea pill 20-30 minutes before eating.

OTHER SIDE EFFECTS

You may experience other side effects not mentioned in this booklet. Some may be normal and expected, but others may not be. You are the best judge of your body. If you experience anything that does not feel right talk with your health care team.

If you experience a side effect that you feel is an emergency, call your health care team immediately or go to an emergency room.

You can also find out more information about side effect management at www.CancerSupportCommunity.org or through the National Cancer Institute at www.cancer.gov.



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Resources for Side Effect & Symptom Management

Your health care team has access to a number of services to help you manage potential side effects. Common services you may come across are:

PALLIATIVE CARE

Can start at any point in a patient's experience to treat pain and other symptoms. The goal of palliative care is to achieve comfort, manage symptoms, and improve quality of life. Palliative care is also called symptom management, comfort care, and supportive care. Many medical institutions have a palliative care team made up of doctors and other health care providers trained in pain and symptom management. Palliative care is not hospice.

COMPLEMENTARY AND INTEGRATIVE MEDICINE (CIM)

Today, many cancer treatment centers combine standard therapy with a broad range of other treatments that are considered complementary in approach. The most common CIM techniques are: nutrition techniques, relaxation, exercise, acupuncture, chiropractic techniques, guided imagery, or meditation, healing touch (such as Reiki), herbal medicine, and massage therapy.

To learn more about these services, talk with your doctor and nurse so you can find the best combination for you.



It is important to tell your doctor and nurse about the use of any vitamins and herbal supplements you currently use. Vitamins and herbal supplements can cause negative interactions with some cancer treatments, so it is very important to keep your health care team informed about what you use before and during treatment.



Quality of Life

4 Cancer not only affects your body, but it also has an impact on your thoughts, feelings, beliefs, and attitudes. Through your cancer experience you may re-prioritize things in your life or find a new perspective on how to live in the present. Being diagnosed with cancer can bring up many different emotions. As you begin to make decisions regarding your medical care try to remain aware of how you feel on a social, emotional, and spiritual level.

EMOTIONAL DISTRESS

Finding out you have cancer can be very challenging. Allow yourself time to adjust to the news. The emotional impact of a cancer diagnosis on an individual or family can vary greatly.

There may be shifts in different aspects of your life including issues related to self-esteem and body image, family and friendship roles, financial resources, and day-to-day activities. Because of these changes, you may experience a wide range of emotions including shock, fear, anger, sadness, thoughts about death, and helplessness.

However, when these feelings interfere with your ability to carry out normal daily functions, you may consider whether you are experiencing depression and/or anxiety. Some people experience depression and anxiety after a diagnosis of cancer, while others may already have a history of depression. Caregivers and family members may also experience depression and/or anxiety.

While it may be difficult, it is important to acknowledge whether you think you might be experiencing symptoms of depression and/or anxiety. If left untreated, depression and anxiety can impact your quality of life. For example, you may decide to skip doctors' appointments because you feel like you can't get out of bed or leave the house.

Talk with your health care team if you believe you are experiencing depression and/or anxiety to learn about treatment options. Treating emotional distress is just as important as treating your physical body. Do not neglect this important part of your care.



CSC's toll free
Cancer Support
Helpline
(1-888-793-9355)

is here to help you or your loved ones. Our advocates are available to assist you Mon-Fri 9 am-9 pm ET. They have been specially trained to answer your questions and link you to valuable information. Translation is available in 200 languages.

How Much Emotional Distress is Normal?

Some signs or symptoms that might indicate professional help is required to manage feelings of depression and anxiety are:

- Sadness or worry so severe that you miss or postpone your treatment appointments
- Fear that leads to panic or an overwhelming sense of dread
- An inability to make decisions or difficulty concentrating
- Extreme irritability or anger
- Feeling despair or hopelessness
- Constant thoughts about cancer or death
- Feeling worthless
- Lack of interest in activities that previously provided pleasure
- Sleeping less than 4 hours per night or having difficulty getting out of bed
- Having no appetite for a period of weeks

If you or a loved one has thoughts of suicide, help is just a phone call away. Call the National Suicide Prevention Lifeline at 1-800-273-8255 to talk to a skilled, trained counselor near you. This service is available 24 hours a day, seven days a week.



TIPS TO COPE

- Talk to friends, family, or spiritual advisors about your feelings and fears.
- Make an appointment with a counselor, therapist or psychiatrist to help deal with your thoughts and feelings.
- Join a support group.
- Ask your doctor about medications that can help.
- Focus on living in the moment.
- Use relaxation techniques to reduce stress.
- Engage in physical activity you enjoy several times a week.

It helps to find a good support group. Share with them, and they'll share back. It reminds you that you're not in it by yourself.

— Vicki & Paul

VALUE OF SUPPORT

Cancer and its treatment may pose profound challenges to any individual or family. Yet, the idea of knowing you are not alone can be meaningful and significant in learning to cope with a cancer diagnosis. It is helpful to find people with whom you can share and express your feelings.

People cope with their emotions in different ways. Whether it is talking with a family member or friend, through individual therapy, or in the context of a support group, expressing emotions with others can:

- Decrease anger
- Improve self-confidence and assertiveness
- Improve an individual's expression of support, empathy, interest, and humor
- Improve physical functioning
- Improve your overall quality of life
- Decrease feelings of isolation

TALKING ABOUT YOUR DIAGNOSIS

Many people find it difficult to talk about their cancer diagnosis with others. However, talking with your loved ones can help you feel better, and the people you talk with will also feel good as they find ways to help and support you. Children sense and know more than they are often given credit for. When a loved one has cancer, the natural desire is to protect the children through silence—but that usually backfires. Children will overhear conversations, pick up on anxiety and blame themselves and fear the worst if they are given no information.

Young children up to the age of eight will not need a great deal of detailed information; older children and adolescents will need to know more. In a two-parent household, try to talk to each other first, to determine the best way to talk to your children. If single parents are feeling a bit anxious about the conversation, they may want to ask a relative or friend to be present. If you are unsure of how to talk to your children about cancer, speaking with a social worker or counselor may be helpful. Visit www.CancerSupportCommunity.org/Kids for more information on talking to children and teens about cancer.

RELATIONSHIPS WITH OTHERS

When changes in relationships occur, it is important to remember it is not your fault. Different people will react differently to your news—some will be eager to help, while others will withdraw and not know what to do. It is not uncommon for a cancer diagnosis to change personal relationships.

This is because it is stressful and a cancer diagnosis for others can be hard to deal with. On the other hand, many feel their relationships with others are strengthened through the process of dealing with a crisis together. When friends and family want to help, it can be useful to put together a list of specific tasks that are easy to delegate.

“Whenever I wanted to reach out to my support group to share the emotional journey I was traveling, all I needed to do was access MyLifeLine.org. I could compose my message and experience instant emotional relief. I can honestly say MyLifeLine.org was critical to my survival.”

— Dave, Colon Cancer



[MyLifeLine.org](https://www.mylifeline.org) is CSC's digital community that allows you to keep your friends and family informed and involved, connect with others like you, and find educational resources.

MAKING PLANS

It is a good idea for all adults, no matter their health situation, to prepare for the future. While these conversations can be difficult, it is important at any point to talk with your loved ones and your health care team about your wishes. These conversations are just as important as having the appropriate documents. The following legal documents are important tools to prepare:

- A **living will** or **advanced directive** lets your doctor know what kind of medical care you want if you cannot speak for yourself. Enforcement of advanced directives vary by state. Check with your health care team to determine what documents are recognized in your area.
- A **durable power of attorney** is a person who will make health care decisions for you if you are unable to make them yourself. This person does not need to be an attorney. It can be anyone in your life who you trust and have discussed your health care wishes with.
- A **financial power of attorney** is a person who will make financial decisions for your home and medical care in the event you are unable to do so yourself. Many people choose separate people to be their financial and durable medical attorneys.
- A **do not resuscitate (DNR), do not intubate (DNI), or allow natural death (AND)** order is an order for your doctor if you determine that you would not like heroic measures to be taken in the event of cardiac or respiratory arrest. An example is deciding that you do not want a machine (a ventilator) to breathe for you or to have your heart shocked, if your lungs or heart stop working on their own.
- A **will** designates who will receive your money and belongings and who will be responsible for your children (in the absence of another parent). If there is no will in place, an agent of the state may make these decisions.

Your health care team can often refer you to someone experienced to help you prepare these documents. Most of these documents can be prepared without the use of a lawyer and without any cost to you or your family. These documents will help reduce confusion and your loved ones will feel more comfortable knowing that the legal and medical decisions made are yours.

It's good to have your will and advanced directives done just in case, so then family doesn't have to worry.

— Rafael

IMPORTANT THINGS TO CONSIDER

Humor

Is a cancer diagnosis humorous? No, but learning to laugh at life's challenges has been shown to help people cope better with difficult situations. Being able to find humor in life can be calming when dealing with cancer. Humor therapy is used to encourage relaxation and reduce stress. Finding the humor in life is something you and your loved ones can focus on anywhere, anytime.

Spirituality

The crisis of a cancer diagnosis often helps people gain insight into their beliefs and spirituality. Each of us holds beliefs about life, its meaning, and its value, whether we participate in a religious tradition or not. Prayer may be comforting and help you feel less alone. Some people find comfort in their spiritual beliefs while others question their faith, possibly feeling distressed by the idea that the illness might be a punishment for some past sin or lack of faith.

Having doubts and being angry are normal responses. It can be helpful to talk to your pastor, rabbi, imam, or a spiritual counselor in your community. Members of religious and spiritual communities also may provide practical help, such as assistance with transportation, meals, and visitation services.

Hope

Hope is a powerful concept and coping strategy that empowers people to look beyond the moment and into the future. Your sense of "hope" can change over time. It's not about being positive all of the time, but about viewing things from a positive perspective as much as possible.

When you make plans for the future, keep hope in mind. Make reasonable plans based on your well-being at the time. Patience is important. Simple plans can be appreciated just as much as larger goals for the future.

After I was diagnosed, I started living a spiritual existence, which simply was not there before. I also do a lot with my diet and Qi Gong. It's really put so many things into perspective for me.

— Amanda

Cancer Support Community Resources

Cancer Support Community's resources and programs below are available at no charge.

CANCER SUPPORT HELPLINE®



Whether you are newly diagnosed with cancer, a long-time cancer survivor or caring for someone with cancer, CSC's toll-free Cancer Support Helpline (1-888-793-9355) is available to assist you Monday-Friday from 9 am-9 pm ET. Our specialists have been trained to answer your questions and link you to valuable information. Translation is available in 200 languages.

CANCER EXPERIENCE REGISTRY



The Cancer Experience Registry is designed to help people who have had a cancer diagnosis share their story, to learn about the experiences of others and to help transform the cancer experience. People who participate are connected to a network of support and resources. Findings from the Registry help us all better understand the social and emotional needs of people living with cancer and improve the ways in which care is delivered. Join today at www.CancerExperienceRegistry.org.

OPEN TO OPTIONS®



If you are facing a cancer treatment decision, CSC's Open to Options® research-proven program can help. Our Open to Options® team can help you create a list of questions for your doctor in English or Spanish. Call 888-793-9355 to make an appointment or to find a local CSC or Gilda's Club near you.

SERVICES AT LOCAL CSCs AND GILDA'S CLUBS

Over 50 locations plus more than 120 satellites around the country offer on-site support groups, educational workshops, yoga, nutrition and mind-body programs for people affected by cancer. For a full list of affiliate locations, visit www.CancerSupportCommunity.org/FindLocation or call 1-888-793-9355.

MYLIFELINE

CSC's private, online community allows patients and caregivers to easily connect with friends and family to receive social, emotional, and practical support throughout the cancer journey and beyond. Sign up at MyLifeLine.org.

These services are made available with generous contributions from CSC supporters.

RESOURCES

HELP WITH FINANCIAL & LEGAL CONCERNS

The Air Care Alliance

www.aircareall.org
888-260-9707

Cancer and Careers

www.cancerandcareers.org/en
646-929-8023

CancerCare

www.cancercare.org
800-813-4673

Centers for Medicare and Medicaid Services

www.cms.gov
800-633-4227

Corporate Angels Network

www.corpangelnetwork.org
914-328-1313

Disability Rights Legal Center

cancerlegalresources.org
866-999-3752

Equal Employment Opportunity Commission

www.eeoc.gov
800-669-4000

Healthcare.gov

www.healthcare.gov

LawHelp.org

www.lawhelp.org

Needymeds

www.needymeds.org
800-503-6897

Partnership for Prescription Assistance

www.pparx.org
888-477-2669

Patient Access Network Foundation

www.panfoundation.org
866-316-7263

Patient Advocate Foundation

www.patientadvocate.org
800-532-5274

Patient Advocate Foundation Co-Pay Relief

www.copays.org
866-512-3861

Survivorship A-Z

[www.survivorshipatoz.org/
cancer](http://www.survivorshipatoz.org/cancer)

U.S. Social Security Administration

www.ssa.gov
800-772-1213

INFORMATION & SUPPORT

American Cancer Society

www.cancer.org
800-227-2345

Cancer Support Community

CancerSupportCommunity.org
888-793-9355

Imerman Angels

www.imermanangels.org
877-274-5529

LIVESTRONG Foundation

www.livestrong.org
866-673-7205

National Cancer Institute

www.cancer.gov
800-422-6237

National Center for Complementary and Alternative Medicine

www.nccam.nih.gov
888-644-6226

National Coalition for Cancer Survivorship

www.canceradvocacy.org
877-622-7937

Caregiver Action Network

www.caregiveraction.org
202-454-3970

CLINICAL TRIALS

CSC's Clinical Trial Search

[CancerSupportCommunity.org/
finding-clinical-trial](http://CancerSupportCommunity.org/finding-clinical-trial)
800-814-8927

Food and Drug Administration

www.fda.gov
888-463-6332

National Cancer Institute's Clinical Trials Registry

www.cancer.gov/clinicaltrials
800-422-6237



CANCER SUPPORT COMMUNITY

The Cancer Support Community (CSC) is a global non-profit network of 175 locations, including CSC and Gilda's Club centers, health-care partnerships, and satellite locations that deliver more than \$50 million in free support services to patients and families. In addition, CSC administers a toll-free helpline and produces award-winning educational resources that reach more than one million people each year. Formed in 2009 by the merger of The Wellness Community and Gilda's Club, CSC also conducts cutting-edge research on the emotional, psychological, and financial journey of cancer patients. In addition, CSC advocates at all levels of government for policies to help individuals whose lives have been disrupted by cancer. In January 2018, CSC welcomed Denver-based nonprofit MyLifeLine, a digital community that includes more than 40,000 patients, caregivers, and their supporters that will enable CSC to scale its digital services in an innovative, groundbreaking way.

For more information, please call the toll-free Cancer Support Helpline at 888-793-9355, or visit www.CancerSupportCommunity.org.

So that no one faces cancer alone®

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This booklet is available to download and print yourself at www.CancerSupportCommunity.org/SideEffects. For print copies of this booklet or other information about coping with cancer, call our Helpline or visit Orders.CancerSupportCommunity.org.