



Lung Cancer Handbook

Everything you need to know to create a more
confident cancer journey.

Brought to you by PearlPoint Cancer Support

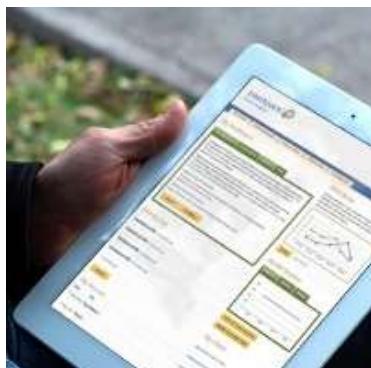
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Introduction

Welcome to the Lung Cancer Handbook presented by PearlPoint Cancer Support.

About The Lung Cancer Handbook

Having just been diagnosed with lung cancer, you probably have a lot of questions. The Lung Cancer Handbook from PearlPoint Cancer Support contains everything you need to know to more confidently manage your cancer journey from diagnosis through treatment and survivorship. The Handbook can be your guide.

With the internet and search engines, it's easy to find information about any lung cancer topic, but not all of it is reliable and trustworthy. But don't worry! PearlPoint's Lung Cancer Handbook is a reliable source of information. All of the content in the Lung Cancer Handbook has been reviewed and approved by medical professionals across the U.S. who participate on PearlPoint's Scientific Advisory Team.

Like the content in the Handbook?

There is more online at mypearlpoint.org. We encourage you to register on the site for a free, personal dashboard where you can bookmark, save, and reference articles, videos, and worksheets.

Using the Handbook, you will first learn how to talk about cancer with your healthcare team, family, and friends. As a cancer patient, being able to speak openly and honestly with your healthcare team is important. Communication with your caregiver and loved ones is important as well. You are not alone in your cancer journey.

Next, you will learn about lung cancer and the available treatment options. No two cancer diagnoses are the same. The best treatment for you may not be the best treatment for another patient. Use the information in the Handbook to talk with your healthcare team about your options to create the best treatment plan for you.

Cancer and cancer treatments cause side effects, but most side effects are manageable. Know what to expect. Different treatments have different side effects, and people may respond to treatment in unique ways. The Handbook will walk you through all the possible side effects and tips for managing them.

Nutrition is also a big part of any cancer patient's journey and a large part of the Handbook. Proper nutrition during your cancer treatment can help you feel better, maintain your strength, and speed your recovery. After treatment, good nutrition will continue to be an active part of your life in survivorship.

As you likely may imagine, a cancer diagnosis brings with it many practical life concerns—health insurance, finances, transportation, advanced directives. The Handbook contains information and content that will help you learn to manage the practical concerns of cancer during your treatment. But even when treatment ends, the cancer journey is not over. During survivorship, there are many things you can do to promote wellness and help you readjust to life after cancer. The Handbook will provide help and information.

We hope you find the Handbook to be a valuable, frequently consulted tool as you manage your cancer journey. We encourage you to make it your own! Ask your nurse navigator or another member of your healthcare team to highlight the sections that most apply to your specific diagnosis and treatment plan. Use the worksheets in the back to keep track of all your information such as medical history and appointments. And finally, never hesitate to talk with your healthcare team—frequently, proactively, and openly.

Nurse Navigator

What does a nurse navigator do?

Nurse navigators work directly with cancer patients to help guide them through their cancer care journey. Nurse navigators serve as a constant point of contact for patients to coordinate care, answer questions, and provide resources. Nurse navigators usually specialize in a certain type of cancer to help patients with their specific needs.

As a cancer patient, your healthcare team may include a large number of people including:

- A medical oncologist
- A radiation oncologist
- Surgeon
- Pharmacist
- Dietitian
- Physical therapist
- Other healthcare professionals
- Your caregiver, family, and friends

Your nurse navigator will work closely with every member of your healthcare team to keep the lines of communication open.

Nurse navigators understand the medical, practical, and emotional needs of cancer patients. If you have questions about treatment, medications, appointments, or anything else related to your cancer journey, start by asking your nurse navigator.

Who is my nurse navigator, and how do I contact him or her?

| My Nurse Navigator | |
|--------------------|--|
| Name | |
| Phone Number | |
| Email | |

Talking About Lung Cancer

With Your Healthcare Team

When going through cancer treatment, your healthcare team is very important. Your healthcare team may include your oncologists, surgeon, nurse navigator, a dietitian, a social worker, or other medical professionals. Every member plays an important role. Use the tips below for talking with your healthcare team:

- Establish your main point of contact.
 - Your main point of contact will probably be a nurse navigator, but it may be another member of your healthcare team. Who should you contact first with questions?
- You need to always be open and honest with your healthcare team about your physical and emotional well-being.
- Do not be afraid to ask questions.
 - Cancer is usually not a medical emergency. There is time to ask your healthcare team any questions you may have and to consider your treatment options.
- Write your questions down before your appointments. Take a pen and paper to write down the answers. You can use the “Appointment Notes” worksheet at the back of the Handbook.
- Before beginning treatment, ask your healthcare team the following:
 - What are all my treatment options?
 - What are the long term and short term side effects of treatment, and how can I manage them?
 - Will my fertility or ability to have children be affected?
 - Am I eligible for clinical trials?
 - For more questions to ask your healthcare team, read “Questions for Your Healthcare Team” in this Handbook.
- If you develop any new problems or symptoms during treatment, tell your healthcare team immediately. You are not complaining. This is valuable information for your doctors.

- Do not change your diet, start an exercise program, or take any new medications, including vitamins and supplements, during treatment without talking to your healthcare team first.

With Your Caregiver

Your primary caregiver may be with you when you receive your diagnosis. Your primary caregiver may be your spouse, partner, adult child, parent, or friend. Your primary caregiver is the person who may come with you to appointments, take care of you after surgery or treatment, and support you throughout your cancer journey.

- Everyone reacts to the news of cancer differently. You may feel upset, shocked, or angry. It may take you some time to process the information. Your caregiver may react the same way you do, or your caregiver may not. Even if your caregiver does not react the same way you do, it does not mean that he or she does not care deeply.
- Establish your role and your caregiver's role early. For example, will your caregiver be the one scheduling most of your appointments, or do you prefer to take an active role? Find what works best for you and your caregiver.
- Be open and honest with each other about how you both feel. Overly positive attitudes may hinder honest communication. It's okay to be upset.
- Encourage your caregiver to take time to care for his or her own physical and emotional well-being. Being a caregiver comes with its own hardships.
- If your primary caregiver is your spouse or partner, your intimate and physical relationship may change. To learn more about intimacy issues and discussing them with your partner, read the "Sexual Side Effects" section of the Handbook.

With Your Children

Children are very perceptive, no matter their age. While you may wish to protect your children by not telling them about your diagnosis, even young children may be able to tell that something is wrong. Not knowing what is wrong may cause them more stress and anxiety. Here are some tips to talk to your children and teens about your cancer diagnosis:

- Wait until your emotions are under control and decide what to say ahead of time.
- Tell the truth and answer questions honestly. Depending on your children's ages, it may not be appropriate to give them all the details, but do be truthful.
- Let them know what to expect. For example, let them know that after surgery you will need a lot of rest and may need to stay in the hospital. If your chemotherapy may cause you to lose your hair, let them know. Keep your children in the loop as much as possible.
- Explain to your children, especially younger children, that they cannot "catch" cancer.

- Let your children know that it is okay to cry or be upset. This may be especially important for your teens to hear.
- Tell teachers, babysitters, and others with responsibilities with and around your kids about your diagnosis in case they see behavior changes you may need to know about.
- Maintain normal schedules as much as possible.
- Let your kids help. Allow them to help with chores, and let them know that their help is important. Teens may want to take an active caregiver role. Let them do so, at appropriate levels.
- Look for support groups in your area. Many places offer support groups for children and teens whose parents have a cancer diagnosis.
- Know when to seek professional help. If your child begins to demonstrate unusual behavior such as angry outbursts, nightmares, or poor grades in school, ask your healthcare team for a recommendation for a counselor.

With Family and Friends

You may choose to keep your cancer journey private, or you may choose to share your story with others. The choice is yours. Remember when family, friends, coworkers, or other acquaintances ask about your diagnosis, they are genuinely concerned about your well-being. You can share with them as much or as little information as you like. These suggestions may help you talk about your diagnosis:

- Decide how much information you want to share before you start telling people about your diagnosis.
- If you chose to keep your journey private, make sure to let people know that you appreciate their concern, but you hope they respect your privacy.
- Choose someone close to you, like your caregiver, to spread the word about updates and treatment progress. After a long day of treatment, you may not feel like calling and texting people, but your friends and family will probably want to know how you are.
- If you want to share your story, consider starting an email chain or a Facebook group. This way you can update everyone with one message instead of needing to answer a lot of emails and phone calls.
 - You can also create your own private website at MyLifeLine.org.
- When people offer to help with things, let them. Your family and friends could cook dinner, drive you to an appointment, or babysit.
- If you lose your hair due to treatment or have visible surgical scars, strangers may ask about your diagnosis. Have a response prepared. Again, you may share as little or as much as you like.

Learn About Your Cancer Diagnosis

If you or someone you know has just been diagnosed with cancer, you may have a lot of questions. In the next few pages, you will find basic information about cancer and questions to ask your healthcare team.

Understanding Lung Cancer: What Is Cancer?

To understand lung cancer, it's first important to understand what cancer is: basically, the production of abnormal cells.

The body is programmed to routinely replenish cells in different organs. As normal cells age or get damaged, they die off. New cells take their place. This is what's supposed to happen. Abnormal cell growth refers to a buildup of extra cells. This happens when:

- New cells form even though the body doesn't need them or
- Old, damaged cells don't die off.

These extra cells slowly accumulate to form a tissue mass, lump, or growth called a tumor. These abnormal cells can destroy normal body tissue and spread through the bloodstream and lymphatic system.

Benign vs. Malignant: What's the Difference?

Benign means not cancerous. A benign tumor can get larger but does not spread to other tissues or organs.

Malignant means cancerous. A malignant tumor's cells can invade nearby tissue and lymph nodes and then spread to other organs. These cells are destructive.

| | |
|-------------------|---|
| Benign tumors: | <ul style="list-style-type: none">• Can be removed• Usually don't grow back• Are rarely fatal• Don't spread to other tissues or body parts |
| Malignant tumors: | <ul style="list-style-type: none">• Can often be removed• Sometimes grow back• Can invade other tissues and organs and cause damage• Can spread to other body parts• Can be fatal |

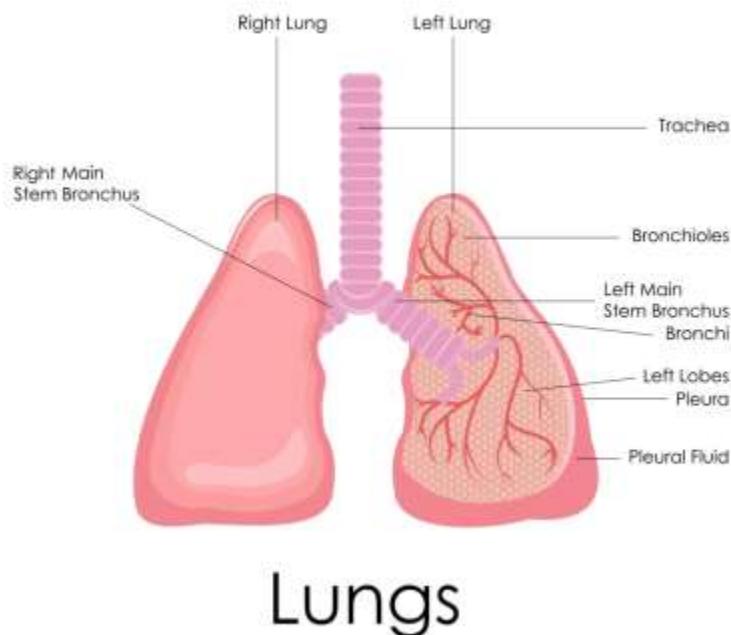
Lung Cancer

Lung cancer is the leading cause of cancer related death. It occurs in both men and women. It is more common in older adults.

To understand lung cancer, it's helpful to understand how your lungs work.

When you breathe, you take in air. It goes through your nose, down your trachea (windpipe) and into your lungs. There it spreads through tubes that are called bronchi. Most lung cancer begins in cells that line these tubes.

You don't have to smoke to get lung cancer. There are many different types of lung cancer.



Non-small-cell lung cancer (NSCLC) and small-cell lung cancer (SCLS) make up 96% of lung cancers.

Non-small-cell lung cancer (NSCLC) is the most common type of lung cancer. It is very slow growing. NSCLC makes up about 80% of lung cancer diagnoses. Here are the common types of NSCLC:

- Adenocarcinomas
 - In Situ Pulmonary Adenocarcinoma (AIS) (previously known as Bronchioloalveolar carcinoma)
- Squamous cell carcinoma/ Epidermoid
- Pancoast/ Pulmonary sulcus tumor

- Large cell undifferentiated carcinoma

Adenocarcinomas: To better understand what an adenocarcinoma is, consider the word: Adeno means gland; Carcinoma is a malignant tumor. These tumors are usually found in the outer area of the lung. This is the most common type of NSCLC.

Adenocarcinomas are usually slow-growing and are often found before the cancer has spread to areas outside of the lungs.

AIS tumors are “*in situ*” meaning the cancer is localized or not spread. Patients with this type of lung cancer tend to have a better prognosis, due to the ability to remove this small tumor.

Squamous cell carcinomas: Squamous cells are flat cells that line the airways of the lungs. Squamous cell tumors are usually found in the center of the lung near the air tube (bronchus). These tend to grow more slowly than other types.

Pancoast tumor: A type of lung cancer that begins in the upper part of a lung and spreads to nearby tissues such as the ribs and spine. Surgery for this type of tumor can be very difficult because of its location. Less than 5% of all primary lung cancers are Pancoast tumors.

Large cell carcinomas: Large cell carcinomas can occur in any part of the lung. The cells of large cell carcinomas are actually larger than normal cells. This type of lung cancer often grows quickly, sometimes making it difficult to treat.

Small-cell lung cancer (SCLC) is less common, and is very uncommon among non-smokers. Only about 15-25% of all lung cancers are SCLC. This tends to be a faster growing type of lung cancer. SCLCs are also referred to as oat cell cancers or neuroendocrine cancers.

SCLC usually spreads more rapidly than non-small-cell lung cancer. In most cases, SCLC has metastasized or spread to other parts of the body before it is diagnosed.

Some lung cancer consists of both NSCLC and SCLC. These are referred to as mixed small cell/large cell cancers. This is not common.

There are also rarer types of lung cancer including:

- Mesothelioma: A tumor found in the lining of the chest or abdomen often linked to asbestos exposure.
- Carcinoid: A slowing-growing tumor. Carcinoids are most often found in the gastrointestinal system, but they can sometimes appear in the lungs.
- Sarcoma: Sarcomas are a type of tumor that begins in the soft tissues such as fat, muscle, connective tissue, or blood vessels.

Sometimes cancer starts somewhere else in the body and spreads to the lungs. If that is true, it is called metastatic cancer to the lung, not lung cancer.

For more information on these rarer forms of lung cancer, visit the National Cancer Institute's website at www.cancer.gov.

Risk Factors and Screening Recommendations for Lung Cancer

If you have a lung cancer diagnosis, share this section with your friends and family. If you do not have a lung cancer diagnosis, use this section to understand your risk for lung cancer and learn screening recommendations.

Risk Factors for Lung Cancer

The following increase your risk for lung cancer:

- Smoking
- Second-hand smoke
- Expose to carcinogens, cancer causing agents, such as:
 - Radon
 - Asbestos
 - Coal smoke
 - Diesel fumes
- Personal history of cancer
 - Radiation of chest
 - Some treatments for Hodgkin lymphoma
- Family history of lung cancer
- Personal history of lung diseases such as:
 - Chronic Obstructive Pulmonary Disease (COPD)

Symptoms of Lung Cancer

Early stage lung cancer is usually asymptomatic, meaning the person has no symptoms. Some common symptoms of lung cancer include:

- A persistent cough
- Coughing up blood
- Chest pains
- Difficulty breathing or swallowing
- Fatigue
- Shortness of breath
- Pneumonia
- Wheezing
- Hoarseness
- Weight loss or loss of appetite

These symptoms could also be signs of other medical issues. Tell your doctor if you experience any of these symptoms.

Recommended Screening for Lung Cancers

The following guidelines are from the National Comprehensive Cancer Network's 2015 guidelines for patients. To learn more, visit www.nccn.org.

Lung cancer screening is recommended for people who meet the following criteria:

| | |
|----|--|
| 1. | <ul style="list-style-type: none">• 55 years of age or older• Smoked for 30 or more pack years*• Stopped smoking less than 15 years ago |
| 2. | <ul style="list-style-type: none">• 50 years of age or older• Smoked for 20 or more pack years*• Family history of lung cancer• Personal history of chronic lung disease (COPD, emphysema, bronchitis, pulmonary fibrosis)• Personal history of cancer• Jobs that expose you to arsenic, nickel, asbestos, beryllium, soot, cadmium, diesel fumes, chromium, or coal dust |

*Pack years are equal to number of packs smoked a day multiplied by number of years smoking.

Lung cancer screenings are not recommended for people who do not fit the above criteria. Lung cancer screenings are also not recommended for people in poor health who are not well enough to undergo curative treatment for lung cancer, such as lung surgery.

Low-dose computed tomography (LDCT) scans are used to screen for lung cancer. These scans are similar to CT scans but use a lower dose of radiation to create the images of the lungs.

The first LDCT scan is used as a baseline to determine a screening schedule. Follow up scans will depend on the patient's other risk factors.

Always follow your doctor's recommendations. The earlier lung cancer is discovered the easier it is to treat.

The Diagnosis

If you have a symptom that suggests lung cancer, your doctor must find out whether it's from cancer or something else. Your doctor may ask about your personal and family medical

history. Your doctor may order blood tests, and you may have one or more of the following tests:

- **Physical exam:** Your doctor checks for general signs of health, listens to your breathing, and checks for fluid in the lungs. Your doctor may feel for swollen lymph nodes and a swollen belly.
- **Chest X-ray:** X-ray pictures of your chest may show tumors or abnormal fluid.
- **CT scan:** Doctors often use CT scans to take pictures inside your chest. In a CT scan, an X-ray machine linked to a computer takes several pictures. Your doctor may want you to have a spiral CT scan. In this procedure, the CT scanner rotates around you as you lie still on a table. The table then travels through the center of the scanner. The pictures can show tumors, abnormal fluid, or swollen lymph nodes.

These are the first steps in diagnosis. However, lung cancer can only be completely diagnosed by checking samples of cells or tissue. The doctor collects a sample. Then that sample is examined under a microscope.

There are many different ways to collect samples:

- **Sputum cytology:** You cough up thick fluid (called sputum) from your lungs. The lab checks samples of sputum for cancer cells. This may be collected either at home or in your doctor's office.
- **Thoracentesis:** Your doctor uses a long needle to take fluid from your chest. This fluid is called pleural fluid. The lab checks the pleural fluid for cancer cells. This is a short procedure performed in your doctor's office.
- **Bronchoscopy:** Your doctor inserts a thin, lighted tube (called a bronchoscope) through your nose or mouth into your lung. This lets your doctor examine both the lungs and the air passages that lead to them. Your doctor may take a sample of cells with a needle, brush, or other tool. This procedure will be done at a hospital or special clinic. You will be given medicine to help you relax so you will need someone to drive you home. You may also be asked to restrict food and water intake the night before a bronchoscopy.
- **Super Dimension Bronchoscopy/ Electromagnetic Navigational Bronchoscopy (ENB):** This is less invasive than a traditional bronchoscopy, and allows your doctor to biopsy tumors or lymph nodes in harder to reach places, such as deep inside the lungs. This is usually done with local anesthesia and sedation.
- **Endobronchial ultrasound (EBUS):** Your doctor uses a special bronchoscope equipped with an ultrasound to help better see the tumor or lymph node that needs to be biopsied.
- **Fine-needle aspiration:** Your doctor uses a thin needle to remove tissue or fluid from your lung or lymph node. Sometimes the doctor uses a CT scan or other imaging method at the same time. This helps your doctor guide the needle to a lung tumor or lymph node. You will be sedated for the procedure so you will need a ride home afterwards. You may also be asked to restrict food and water intake the night before the procedure.
- **Thoracoscopy:** Your surgeon makes several small incisions in your chest and back. Then he or she looks at your lungs and nearby tissues. This is done with a thin, lighted

tube. If the surgeon sees an abnormal area, then a biopsy may be needed to check for cancer cells. You will be sedated for the procedure so you will need a ride home afterwards. You may also be asked to restrict food and water intake the night before the procedure.

- **Thoracotomy:** Your surgeon will open your chest with a long incision. Then, he or she will remove lymph nodes and other tissue. You will be sedated for the procedure. You will likely need to stay in the hospital for a few days after surgery to recover. You may also be asked to restrict food and water intake the night before the procedure.
- **Mediastinoscopy:** Your surgeon makes an incision at the top of your breastbone. Then he or she uses a thin, lighted tube to see inside your chest. The surgeon may take tissue and lymph node samples. You will be sedated for the procedure. You will need someone to drive you home. You may also be asked to restrict food and water intake the night before the procedure.
- **Lymph node biopsy:** A lymph node biopsy checks the lymph nodes for abnormal cells. A lymph node biopsy can be done in a few different ways. A needle can be inserted into the lymph node to collect a sample. This can be done alone or during a bronchoscopy or mediastinoscopy. Lymph nodes can also be completely removed during surgery.
- **Core needle biopsy:** Your surgeon uses a needle that is larger than the fine-needle aspiration needle to remove a cylindrical piece of tissue about $\frac{1}{2}$ inches long. A CT scan may be used to help guide the needle into the tumor or lymph node. Your doctor will numb the area first.
- **Video-Assisted Thoracoscopic Surgery (VATS):** Your surgeon will make an incision in the chest wall and insert a thoracoscope. A thoracoscope is a thin tube with a light and a camera that allows your surgeon to examine your lungs and the inside of your chest. You will be asleep during the procedure.

You may want to ask these questions before the doctor takes a sample of tissue:

- Which procedure do you recommend? How will the tissue be removed?
- Will I have to stay in the hospital? If so, for how long?
- Will I have to do anything to prepare for it?
- How long will it take? Will I be awake? Will it hurt?
- Are there any risks? What is the chance that the procedure will make my lung collapse? What are the chances of infection or bleeding after the procedure?
- How long will it take me to recover?
- How soon will I know the results? Who will explain them to me?

Understanding Your Pathology Report

What is a pathology report?

In order to make a cancer diagnosis, a doctor needs to collect a sample of the tumor cells to be tested and examined in a lab by a pathologist. A pathologist is a doctor who identifies cancer and other diseases by studying cells under a microscope. After the pathologist studies

a sample, he or she prepares a pathology report that explains the findings. Doctors use these reports to diagnosis and stage cancer.

What will be in the pathology report?

The pathology report provides all the pathologist's findings. Your pathology report may include some or all of the following:

- Your identification information
- Your important medical history
- Details on how the sample or biopsy was taken
- Description of how the sample looked under the microscope
 - Size, color, grade, margins, etc.
- Genetic markers, biomarkers, and other molecular considerations
- A written summary of the full report

What do the words in my pathology report mean?

Here is a vocabulary list to help you through your pathology report:

Angliolymphatic: means cancer has spread to the lymph nodes

Antibody: a protein produced by the immune system to fight foreign substances

Atypia: an abnormal cellular structure

Benign: not cancerous

Cell Density: the number of cells in a single sample

Cytology: the study of a single cell or a small group of cells

Differentiation: how close the cells look to normal cells

Dysplasia: the presence of abnormal cells

Florescence In Situ Hybridization (FISH): a test used to find genetic mutations

Granulomas: inflammation of the tissue, often from infection

Grade: how abnormal the cells look and how quickly the tumor is likely to grow

Histology: the way the cells look under a microscope

Hyperplasia: increased cell production

Inconclusive: with the current sample and tests, it cannot be determined if cancer is present

Invasive: the cancer has spread to surrounding tissues

In Situ: abnormal cells have not spread; the abnormal cells are only where they started

Malignant: cancerous

Metastasis: cancer that has spread to other parts of the body

Necrosis: cell death

Neoplasm: a growth made up of abnormal cells

Pleomorphic: able to change shape

Stage: how advanced the cancer is

Stains: used to color the tissues and cells so the pathologist can see them better

Tissue Block: the sample of tissue removed during a biopsy or surgery

For a more complete glossary, visit mypearlpoint.org/glossary.

Use your pathology report or ask a member of your healthcare team to fill out the “About My Diagnosis” worksheet included in this handbook.

Understanding Your Pathology Report was adapted from the Lung Cancer Alliance’s “Your Lung Cancer Pathology Report” brochure. Visit the Lung Cancer Alliance at LungCancerAlliance.org.

Stages of Lung Cancer

What “Stages” Mean

The TNM staging system is used for all types of cancer, not just lung cancer. The letters TNM describe the tumor size and if the cancer has spread to other areas:

- T: indicates how big the tumor is
- N: indicates number of lymph nodes with cancer cells in them
- M: indicates metastasis, which means that cancer has spread to other body parts.

Using TNM, your doctor will diagnose your cancer according to one of the following stages:

| | |
|--------------|--|
| Occult Stage | Lung cancer cells are found in sputum or in a sample of fluid collected during bronchoscopy, but a tumor cannot be seen in the lung. |
|--------------|--|

| | |
|----------|--|
| Stage 0 | Cancer cells are found only in the innermost lining of the lung or airway. A Stage 0 tumor is also called carcinoma in situ. The tumor is not invasive. |
| Stage 1 | This is an invasive cancer. It has grown through the innermost lining of the lung. There are two categories: IA ($\leq 2\text{cm}$) and IB ($>2\text{cm}, \leq 3\text{cm}$). The difference is in the size of the tumor. |
| Stage 2 | Stage 2 is more invasive than Stage 1. Cancer cells are in nearby lymph nodes. Or, the lung tumor has invaded the chest wall, diaphragm, pleura, or main bronchus. There are two categories, IIA and IIB. The main difference is where the cancer has spread and how large the tumor is. |
| Stage 3A | The tumor is large ($>7\text{cm}$) or invades surrounding structures or has spread to the lymph nodes in the neck, above the clavicle, or near the other lung. |
| Stage 3B | The tumor may be any size and has invaded nearby organs such as the heart, esophagus, or trachea. |
| Stage 4 | Malignant growths may be found in the other lung. Cancer cells may also exist in other parts of your body, like the brain, liver or bone. This is the most advanced stage of lung cancer. |

Choosing and Oncologist and Treatment Center

If you've been diagnosed with lung cancer, it's important to explore all options related to lung cancer treatment. Learn what's next, what questions to ask the doctor, and what treatments are available.

Finding an Oncologist

The first step on the lung cancer treatment journey is to find an oncologist (medical or surgical) who inspires trust. You may want to discuss this with your nurse navigator. It may seem overwhelming to choose an oncologist. First, start with referrals from your primary care physician, specialist, or insurance carrier. Talk to family and friends who may have recommendations.

Here are some things to consider when choosing an oncologist:

- Is the oncologist board certified?
- How much experience does he or she have in treating lung cancer?
- Do you feel comfortable talking with this doctor? Does he or she listen well?
- Is the staff compassionate? Is the environment a good one or do you feel rushed?
- What hospital(s) does this oncologist see patients in?
- What are the office hours?
- What if you have an emergency? Can you call?
- Can this doctor be contacted after hours?

You will be spending a lot of time with the oncologist and staff nurses and technicians, so it's important to feel comfortable with them.

Choosing a Cancer Center

Choosing where to receive treatment is just as important as selecting an oncologist. It's good to know the differences between hospitals. Here are some guidelines:

- Academic cancer centers: These are affiliated with medical schools. At these locations, high priority is put on research. They are usually located in large cities.
- Community cancer centers: The main focus is on patient care.
- Cancer centers: These are noted for a high quality of science and research.

Some questions to ask before choosing where to get your treatment include:

- Volume: How many lung cancer surgeries does the surgeon do annually?
- Travel: How far do you want to travel? Would there be extra costs?
- Cost: Is the hospital covered by your insurance plan?
- Accreditations: What accreditations does the hospital hold?

Specific Questions To Ask Your Doctor

As you and your doctor explore the treatment options, make sure you find out the answers to the following:

- What are my treatment choices? Which do you recommend for me? Why?
- Will I have more than one kind of treatment?
- What are the expected benefits of each kind of treatment?
- What are the risks and possible side effects of each treatment? What can we do to control the side effects?
- What can I do to prepare for treatment?
- Will I need to stay in the hospital? If so, for how long?

- What is the treatment likely to cost? Will my insurance cover the cost?
- How will treatment affect my normal activities?
- Would a clinical trial be right for me?
- How often should I have checkups after treatment?
- What are the chances my cancer will come back after this treatment?
- What do we do if the cancer comes back or the treatment doesn't work?
- Will I lose my hair?
- Will you have to remove lymph nodes?
- Will it hurt?
- Will there be scars?

Treatment Options

It's helpful to understand all possible treatments for lung cancer. The following are overviews of the most common treatments. Reading these should help you know what to expect, what the potential side effects are, and what the advantages are to each.

Here are the common treatments for lung cancer:

- Surgery
- Chemotherapy
- Radiation
- Targeted Therapy

There are many different specialists who treat lung cancer. Typically, they work as a team. Often a lung cancer team includes:

- Thoracic (chest) surgeon
- Medical oncologist
- Radiation oncologist
- Pulmonologist (lung specialist)
- Respiratory therapist
- Oncology nurse
- Registered dietitian
- Psychologist
- Supportive Care Specialist
- Thoracic Nurse Navigator

The type of treatment you get depends on the type of lung cancer and its stage. Your doctor may recommend that you have surgery, chemotherapy, radiation therapy, targeted therapy, or a combination of several of these.

Treatment of lung cancer is either *local therapy* or *systemic therapy*:

- **Local therapy:** Local therapies remove or destroy cancer. Surgery and radiation are examples of local therapies. If lung cancer has spread to another part of your body, your doctor may recommend local therapy to control the disease there. For example, if lung cancer has spread to the liver, it may be treated with radiation to the liver.
- **Systemic therapy:** Systemic medications enter your bloodstream. They can destroy cancer throughout your body. Chemotherapy and targeted therapy are examples of systemic therapies.

Surgery

Surgery for lung cancer removes the tissue with the tumor in it. Your surgeon also removes nearby lymph nodes.

The surgeon removes either part or all of the lung:

- Wedge resection or segmentectomy: In this procedure the surgeon removes the tumor and a small part of your lung.
- Lobectomy or sleeve lobectomy: In this procedure the surgeon removes a lobe of your lung. This is the most common surgery for lung cancer.
- Pneumonectomy: The surgeon removes your entire lung.

What to Expect

Once surgery is over, air and fluid collect in your chest. You will need a chest tube to let the fluid drain out. A nurse or respiratory therapist will teach you coughing and breathing exercises. You'll need to do these exercises several times a day. These exercises will do several things:

- Keep your lung(s) inflated
- Help move fluid out of your lungs
- Help prevent pneumonia

You may be in the hospital for a week or longer after surgery. It will probably take several weeks before you can return to normal activities.

Your doctor will give you a prescription for pain medicine after surgery. It's important to get this prescription filled before you go home—in case you need it.

You may want to ask your doctor these questions before having surgery:

- What kind of surgery do you suggest for me?
- How will I feel after surgery?
- If I have pain, how will it be controlled?
- How long will I be in the hospital?

- Will I have any lasting side effects?
- When can I get back to my normal activities?

Chemotherapy

Chemotherapy (usually called chemo) uses anticancer drugs to destroy cancer cells. These drugs are given through a vein in your arm or a special IV port inserted in your chest. There are some chemotherapy drugs that can be taken by mouth. The chemotherapy drugs damage cancer cells all over your body.

Chemotherapy is not just one drug. There are many types of chemotherapy drugs. Your doctor may give you more than one chemotherapy drug.

Chemotherapy is given in cycles. You have a period of rest after each treatment. The length of the rest period and the number of cycles depend on what anticancer drugs are used.

You may have your treatment in a clinic, at the doctor's office, or at home. You may need to stay in the hospital for treatment.

What to Expect

The side effects of chemotherapy depend on which drugs are given and how much of the drugs are given. You may feel side effects from chemotherapy drugs because those drugs can harm normal cells as they destroy cancer cells. Possible side effects to watch out for include:

- Fatigue
- Hair loss
- Poor appetite
- Nausea and/or vomiting
- Mouth sores
- Hearing loss
- Pain in your joints
- Tingling or numbness in your hands and feet (peripheral neuropathy)

These side effects usually go away once treatment ends. Make sure you report any side effects. There are many medications and therapies that can make the side effects more bearable. Refer to the "Side Effects Management" section of the Handbook for more information.

You may want to ask your doctor these questions before having chemotherapy:

- What are the benefits of chemotherapy?
- What are the risks and possible short and long term side effects?

- What will my treatment schedule be?
- Will I receive one drug or a combination?
- Will I need someone to come with me to treatment?
- How will I know if the treatment is working?

Radiation

Radiation therapy (also called radiotherapy or radiation) uses high-energy x-rays to destroy cancer cells. Radiation damages cells only in the cancerous area and is a type of local therapy.

Radiation comes from a large machine outside your body. It is administered at a hospital or cancer clinic.

You will receive treatments of radiation which can take 2 to 9 weeks to complete. Radiation treatments are usually preformed Monday-Friday. The schedule depends on what is being treated.

Side effects of external radiation may include:

- Damage to the esophagus, causing problems with swallowing
- Fatigue
- Red, dry, tender skin in the area that has received radiation

Internal radiation (also called brachytherapy) is another option. The radiation comes from a wire, seed, or device put inside your body. Internal radiation is not commonly used for lung cancer.

You may want to ask your doctor these questions before having radiation therapy:

- Why do I need this treatment?
- What kind of radiation therapy do you suggest for me?
- When will the treatments begin? When will they end?
- How will I feel during treatment?
- How will we know if the radiation treatment is working?
- Are there any lasting side effects?

Targeted Therapy

Targeted therapy uses drugs to block the growth and spread of cancer cells. The drugs enter your bloodstream. They can then travel throughout your body and damage cancer cells.

Although this sounds like chemotherapy, targeted therapies work differently. They target specific biomarkers that help tumors grow and divide. They do not attack normal cells, like chemotherapy drugs do. Your oncologist will conduct molecular testing to find out which targeted therapy may be right for you.

What are biomarkers?

Biomarkers are molecules that are signs of a condition or disease. Many newer cancer treatments can target these biomarkers to destroy cancer cells or stop cell growth. Here are some of the common lung cancer biomarkers:

- EGFR (epidermal growth factor receptor): A protein found on the surface of cells which causes cells to divide and multiply.
- ALK (anaplastic lymphoma kinase) gene: If this gene is mutated, it may increase cancer cell growth.
- ROS1 (c-ros oncogene 1): When this gene is mutated, it causes cancer to grow.
- KRAS (Kristen RNA Associated Rat Sarcoma 2 Virus Gene): This gene makes the KRAS protein. This protein controls cell signaling pathways, cell growth, and cell death.

Not all lung cancers are the same. Your tumor may not test positive for these biomarkers, but your doctor can use the information to personalize your treatment plan.

Currently, there are only targeted therapies approved for non-small cell lung cancer.

There are two kinds of targeted therapy for lung cancer:

- Intravenous: This type is given through an IV in your vein. It's given at the same time as chemotherapy. It may be given at your doctor's office, hospital, or clinic. Side effects can include bleeding, coughing up blood, rash, high blood pressure, stomach pain, vomiting, or diarrhea.
- Oral: This type is taken by mouth. It is not given at the same time as chemotherapy. Side effects can include rash, diarrhea, and shortness of breath.

Targeted therapy is usually recommended for people with non-small cell lung cancer that has spread.

You may want to ask your doctor these questions before having targeted therapy:

- What drugs will I have? What are the expected benefits?
- When will treatment start? When will it end? How often will I have treatments?
- Where will I go for treatment?
- What can I do to take care of myself during treatment?
- How will we know the treatment is working?
- What side effects should I tell you about? Can I prevent or treat any of these side effects?

- Will there be lasting side effects?

Questions for Your Healthcare Team

If you've just been diagnosed with cancer, you may be confused and overwhelmed. You probably want answers, but you may not even know what questions to ask. As a cancer patient, being able to talk openly and honestly with your healthcare team is very important. Use these must-ask questions as a guide to start talking with your healthcare team.

What is my diagnosis?

This question may seem like a no-brainer, but in the rush of appointments, you may not receive a clear answer. If you are unsure of your diagnosis, ask your oncologist. Sometimes more specific tests are needed to make an exact diagnosis.

What is my prognosis? What stage is my cancer?

Knowing your prognosis can help you better prepare for the future and select your best treatment plan. In order to know the stage of your cancer, your doctor will need to do tests. These may include scans, genetic testing, and/or a biopsy. The answer to these questions may be difficult to hear. You may consider having a family member or friend with you at this appointment.

What are my treatment options? What would you recommend?

Ask your oncologist to explain all your treatment options, including possible side effects and cost. Ask your oncologist which treatment he or she recommends. If you are unsatisfied with your options, do not be afraid to seek a second opinion. If you need more information about finding a second opinion, contact the cancer supportive services professionals at PearlPoint Cancer Support.

Am I eligible for a clinical trial?

Clinical trials help improve the standard of care for all cancer patients. Based on your situation, a clinical trial may also be your best treatment option. Each clinical trial has its own eligibility requirements.

What are the possible short-term and long-term side effects of treatment? How will these affect my normal activities?

Always ask about short-term and long-term side effects before beginning treatment so you are prepared. You should also consider short-term and long-term side effects when deciding which treatment plan is best for you.

How can I manage these side effects?

Some side effects can be easily managed through diet, exercise, or over-the-counter medication. Other side effects may require prescription medication, occupational therapy, or physical therapy which your oncologist can prescribe as needed.

How can I keep myself as healthy as possible during treatment?

Your own immune system plays a big part in your fight against cancer. It is important to stay as healthy as possible while undergoing cancer treatment. Refer to “Nutrition” section of the Handbook.

Where can I find help with financial concerns?

Evaluate your financial situation as soon as possible. You will not want to deal with financial stress in the middle of treatment when you may not feel well. See the “10 Financial Assistance Tips for Cancer Patients” section of the Handbook.

Where can I find help with lodging or transportation?

When beginning cancer treatment, planning ahead is key. Some treatment centers have lodging coordinators or social workers to help you with the logistics of treatment. See the “Living with Cancer” section of the Handbook.

What will my follow-up care plan include?

After you finish treatment, make sure you and your oncologist create a follow-up care plan. You will need to check for recurrence. You may also need follow-up care for long term side effects. See the “Follow-Up Care” section of the Handbook.

When can I call myself a survivor?

According to the National Cancer Institute’s definition of a cancer survivor, “a person is considered to be a survivor from the time of diagnosis until the end of life.”

Clinical Trials

Clinical trials are medical research studies that test new ways to prevent, screen, diagnose, or treat a disease. Cancer clinical trials determine if a treatment shows an improved way of caring for patients. Clinical trials improve cancer care for all. Talk to your doctor about clinical trials. Depending on your specific diagnosis, a clinical trial may be your best treatment option.

All About Cancer Research

Cancer research involves very highly trained doctors and scientists trying to figure out how cancer works. Research is always done by a set of rules, called the “scientific method” that ensures the information will be valid. Researchers begin by looking for answers to questions like these:

- What causes cancer?
- What makes cancer cells keep growing?
- What destroys cancer cells?
- What stops cancer cells from growing?

By studying how cancer cells behave in animals, researchers can develop theories, or ideas, about potential treatments for humans with cancer. Once a treatment is ready to be tested on humans, researchers conduct clinical trials.

What are clinical trials?

A clinical trial is a medical research study that tests new ways to prevent, screen, diagnose, or treat a disease. The word “clinical” means related to examining and treating patients.

Cancer clinical trials help to determine if a treatment, drug, or procedure shows a better way of treating a particular cancer or provides a way to treat a condition for which there wasn’t a treatment before.

It takes years of thought and planning to have a clinical trial accepted by the U.S. Food and Drug Administration (FDA). The FDA must approve the trial before researchers can recruit patients. Clinical trials allow patients access to the latest research treatments before they are available to the public.

Who sponsors clinical trials?

Medical or research institutions, pharmaceutical and biotechnology companies, the government, and nonprofit groups who want to improve current cancer treatment can all sponsor clinical trials. Some trials are "investigator initiated," which means a researcher or doctor created the trial, but these trials face the same strict requirements.

What do the phases of clinical trials mean?

Phase I trials answer the questions: Is the drug or treatment safe? What is a safe dose? What are the side effects? Phase I trials are small, each only involving 20-80 participants. These trials are usually the first time a drug or treatment has been tested in humans.

Phase II trials tell researchers if the drug or treatment is effective in a larger group (100-300 participants) and help identify safety concerns.

Phase III trials determine within a large group (1,000 – 3,000 participants) if the experimental drug or treatment works better than what is currently used and if there are additional side effects. Most Phase III trials are randomized, meaning some participants will receive the experimental drug or treatment while others will receive the standard drug or treatment currently accepted by the medical community as best for their cancer type (standard of care).

Phase IV trials allow researchers to learn more about the drug or treatment and its risks, benefits, and best use.

Usually FDA approval comes after large phase III trials. However; sometimes special consideration is given to treatments that show great promise in early trials.

After enough data is gathered to prove that the new treatment is effective or more effective than current treatments, the FDA will investigate the findings and approve the treatment for use. After FDA approval, doctors can prescribe treatments to their patients without enrolling patients in clinical trials.

For a participant, what happens in a clinical trial?

Each clinical trial recruits and screens participants through participating treatment centers. In order to learn if a drug is effective, the participants must be similar in the type of diagnosis and other factors. Trials are designed to be very specific so researchers can know that the drug or treatment being studied is causing changes. For example, a clinical trial may be designed to answer a specific question, such as this: “Is this treatment effective for non-small-cell lung cancer in patients who have not received previous treatment?”

Participants must be eligible in order to qualify for the trial. Some possible requirements for eligibility include:

- Cancer type
- Stage
- Specific tumor types or genetic markers
- Treatment history
- Age
- Other medical conditions

If you qualify for a trial, your healthcare team will provide you with all the information about the trial. They will tell you, in a process called informed consent, how the trial will be conducted and the possible risks and benefits of the trial. You will then sign a document stating that you understand the details of the trial and that you are willing to participate. Even after signing the document of informed consent, you may withdraw from the trial at any time for any reason.

The way you receive treatment depends on the specific clinical trial. Clinical trial treatments can come in many forms. These include but are not limited to the following:

- Intravenous (IV) medications given through a port or IV line
- Shots
- Oral medications

- Surgery
- Radiation

As with any cancer treatment, clinical trial treatments may come with side effects. Your healthcare team will help you manage these side effects. It is very important to report to your healthcare team any side effects that you experience. Part of what researchers are studying is how the treatment affects the whole body, not just the cancer cells.

How is a clinical trial treatment different from other treatments?

Patients who decide to participate in clinical trials receive excellent care and attention. Throughout the trial, your healthcare team will closely monitor you for improvements and adverse side effects.

Researchers want to control as much about your care as they can to make sure it is the treatment that is helping your cancer improve, and not something else. Because of this, you may have restrictions on what you can eat and what other medicines you can take.

Although you should always follow your treatment plan and not miss appointments, doing so is especially important with a clinical trial. Clinical trials must have consistency among the participants to know if the treatment really is working.

Are clinical trials a “last resort” for cancer patients?

Patients who are no longer helped by existing standard of care treatments may find that a clinical trial provides hope, but many patients begin their treatment program with a clinical trial because the treatment best suited to their situation is still being tested. Some clinical trials even exclude patients who have already received another form of treatment.

When participating in a clinical trial that evaluates if a new treatment is better than the current standard treatment for your cancer type, you will always receive treatment – either the standard of care or the new treatment being studied. By being in a clinical trial, you may receive the added benefits of a new treatment before it is available to the public.

In many cases, cancer research moves at a faster pace than the FDA treatment approval process. Researchers have made important discoveries about biomarkers and mutations that affect how cancers respond to treatment. Because of the long time it takes for a treatment to be tested through the clinical trials process, many of these breakthrough treatments are still only available through participating in a clinical trial.

Why Should I Consider A Clinical Trial?

A clinical trial is a medical research study that tests new ways to prevent, screen, diagnose, or treat a disease. The first step is to speak with your oncologist to find out if a clinical trial is right for your cancer journey. The National Comprehensive Cancer Network (NCCN), an alliance of 21 leading cancer centers, believes that “the best management for any patient with cancer is in a clinical trial.”

Why should I consider a clinical trial?

Here are the top reasons why you should consider a clinical trial:

Complete care

The "standard of care" is what the medical community agrees is the treatment for a specific type of cancer given the patient's overall health. Clinical trials ALWAYS provide treatment that is the standard of care or better. For example, in a randomized Phase III trial for a promising new chemotherapy drug, some patients would get the treatment under study while others get the standard of care. Or some patients would get the current standard of care plus the treatment under study while others get just the current standard of care.

Personalized Medicine

Many of the newest clinical trials focus on very specific tumor types such as tumors that carry specific genetic mutations, markers, or DNA sequencing. Basically, these treatments are tailored to individual cancer diagnoses. Many of these treatments are only available through clinical trials.

Careful monitoring

Because the promising new treatment is being carefully studied, patients are also carefully monitored by health care professionals to see how they are doing and to watch for side effects. So, patients enrolled in clinical trials tend to talk with their health care professionals more often and are watched more carefully than patients not involved in a trial.

Safety first

Requirements for clinical trials are strictly managed by the Food and Drug Administration. Before a drug is approved for testing in humans, the FDA ensures that it has gone through strict testing protocols in laboratory animals.

Close to home

Most people are familiar with the tremendous research being conducted all over the country at research institutions, but in fact, many community cancer centers offer opportunities for their patients to participate in clinical trials. Depending on the type of clinical trial you seek, you may have many options that do not require you to travel.

Scientific advancement

Without clinical trials, there is no progress toward cures for cancer. By participating in scientific research through a clinical trial, you can help future cancer patients access new, better treatments. You can play a more active role in your own health care. People who are treated through clinical trials have access to the best new treatments before the general public.

Now that I know the benefits of clinical trials, what are the risks?

There are risks involved with the treatment for any life-threatening illness, including treatment offered through clinical trials:

- There may be difficult side effects from medications or treatments.
- The treatment may not be effective.
- The clinical trial may require extra time for trips to the study site, treatments, hospital stays, or complex dosage requirements.

However, through the process of "informed consent," your medical team will make sure you understand all the risks and benefits.

How can I find a clinical trial?

If you are interested in participating in clinical research, your first conversation should be with your doctor. She or he may be able to suggest trials or help you search for appropriate options.

My PearlPoint's Clinical Trial Locator (my.pearlpoint.org/clinical-trials/search) uses clinicaltrials.gov for our search data, as all clinical trials have to be registered with them. Be aware that the information may not be up-to-date. Your best source of information will be with the facility that is conducting the clinical trial. Their contact information will be clearly noted.

Next Steps: How To Talk to Your Doctor About the Latest Cancer Research

If you are interested in participating in a clinical trial, the first step is to talk to your healthcare team.

How To Start the Conversation

Here are some tips for talking to your doctor about clinical trials:

- Don't be afraid to ask. Your doctor may not bring up clinical trials, but you are the person being treated so you should be involved in planning your treatment.
- Do not feel that you are second-guessing your doctor. Your doctor should be willing to discuss options with you and answer all your questions without feeling insulted.
- Do not be afraid to seek a second opinion if necessary.
- If possible, talk to your doctor about clinical trials before you begin treatment. Some trials require that participants have not received any other treatments.
- Write down your questions and what you want to talk about before your appointment. Organize your thoughts and your notes so you don't forget anything.
- You may wish to have your caregiver go with you to your appointments. Your caregiver can take notes or ask any additional questions if you happen to forget.
- Search **My PearlPoint's Clinical Trial Locator** (my.pearlpoint.org/clinical-trials/search) to find possible trials on your own. If you've done some research, beginning the conversation with your doctor may be easier, especially if your treatment location is not a large research center.
- Keep in mind that while a clinical trial may be one patient's best option, there may not be a clinical trial option for your diagnosis. You should discuss ALL your treatment options with your healthcare team to create the best treatment plan for you.

What To Ask Before Starting a Trial

Once you find a trial and meet the eligibility requirements, you will go through a process called informed consent. During this process, your healthcare team and members of the research team conducting the trial will tell you all you need to know about the trial. Make sure you receive answers to the questions below:

- What is the purpose of the trial?
- How will the trial treatment be better for me than other treatment options?
- How will the healthcare team learn if I am eligible for the trial?
- Where will I receive treatment?
- What type of treatment will the trial involve?
- What will happen at my appointments? (For example, will I have scans, blood tests, and/or examinations?)
- During the treatment, who should I contact with questions and concerns?
- What are the risks and benefits of this trial?
- Will my insurance cover the cost of the trial?
- Will I receive any financial assistance for travel and lodging?
- What will my follow-up care be?

Side Effect Management

Most cancer patients experience some side effects as a result of their diagnosis or treatment. The type of side effects depends on your diagnosis, treatment type, and overall health. Some of the most common side effects for cancer patients include: fatigue, loss of appetite, nausea, pain, and weight loss. Talk to your healthcare team about your risk for side effects—which side effects are you most likely to experience?

Side effects can be managed a variety of ways with lifestyle changes, nutrition, exercise, and medication. Read through the following sections to learn tips for managing your side effects to help improve your cancer journey.

Changes in Taste and Smell

Changes in taste and smell can interfere with maintaining good nutrition during treatment. Here are some ways to manage changes in taste and smell.

- Note which foods and liquids taste and smell different.
 - Any or all of the four tastes — salty, sweet, bitter, and sour — may be affected.
 - It is common for meats to taste especially bitter.
 - Sometimes one taste is specifically more pronounced. For example, everything may taste really salty, or sweets may taste so sweet they are not appealing.
 - Pay attention to changes in taste to be able to apply these tips appropriately.
- Take care of your mouth and teeth.
 - Dental issues may affect taste, so visit your dentist prior to treatment.
 - Rinse mouth thoroughly before eating using plain water or a baking soda/salt water mixture (1/4 tsp. baking soda, 1/8 tsp. salt, and 1 cup warm water).
 - Sometimes medications, chemotherapy drugs, and radiation cause a film to form inside the mouth, affecting the taste buds. Rinsing may help to clean away this film.
 - After meals, rinse with an alcohol-free mouthwash or the baking soda/salt water mixture.
- If meats taste bitter or are not appealing, try alternative protein sources such as eggs, beans, cheese, or nuts.
 - If beef tastes bitter, try chicken, turkey, or fish.
 - Marinades that are sweet are often able to counter the bitter flavor of some meats.
 - It is important to find high protein foods that are palatable to best meet the body's protein needs.
- Try to keep odors to a minimum.
 - Do not cook anything with a strong odor in the house where the person who is in treatment spends most of his/her time.
 - Use cups that have lids and use straws to limit the odor of any liquids that are not appealing.

- Serve foods at room temperature. Hot foods tend to have a stronger smell than cold foods.
- Limit exposure to metal.
 - Eat using plastic utensils instead of metal.
 - Prepare and store food in glass pans and containers.
 - Between meals, sour flavors such as lemonade or candy may help. Mint candy or gum may also give some relief.
 - Tart or bitter flavors may be more palatable. Try citrus and vinegar based foods. Seasoning food differently and more heavily may help to mask the metallic flavor. Try barbecue sauce, salad dressings, ketchup, mustard, relish, onion, garlic, rosemary, ginger, chili powder, basil, oregano, tarragon, curry, and cumin.
- Don't be afraid to try some new foods.
 - Sometimes foods you didn't like before cancer treatment become more appealing as tastes change.
 - Do not be surprised if favorite foods do not taste the same as they did before.
 - Be patient as these changes are usually temporary.
 - Try to make good nutrition a priority and stock your home with a variety of healthy foods.

“Chemo Brain” (Cognitive Issues)

Many cancer patients report issues during and after cancer treatment including:

- memory loss
- forgetfulness
- loss of concentration
- confusion

These side effects result from changes in the cognitive (thinking) processes of the brain. Even though these side effects are commonly referred to as “chemo brain,” factors other than chemotherapy can lead to cognitive side effects such as:

- brain cancer or brain metastasis
- brain surgery
- radiation to the brain
- medications
- fatigue
- anemia
- hypothyroidism
- stress and anxiety

Cognitive side effects can be short term or long term. This depends on the cause of the side effects, the age of the patient, and the overall health of the patient. If the cause is medication,

once the medication is stopped, cognitive issues should improve. If surgery or radiation damages the brain or nervous system, the side effects may not improve over time.

Cognitive issues present many challenges. Because the direct cause of cognitive issues can be unclear, they are difficult to treat. Healthcare professionals are still researching cognitive issues as they relate to cancer and cancer treatment.

Changes in memory and brain function can be distressing, but many patients share the same experience. There are some things you can do to manage cognitive side effects.

Plan Ahead

- Write to-do lists.
- Keep a detailed calendar of appointments and other important dates.
- Leave notes around the house to remind yourself to do things.
- Track your medications and use a weekly pill box.
- Lay out everything you need for the day the night before.
- Use your phone to set reminders.

Get Organized

- De-clutter your home and your workspace.
- Make sure everything has a place.
 - Put keys in bowl by the door every day.
 - Leave your cell phone on your nightstand.
- Use labels for storage areas and boxes.

Minimize Distractions

- Avoid multitasking; focus on one task at a time.
- Put your phone and other unnecessary electronic devices away when working.

Exercise Your Brain

- Do “brain exercises” by taking free online quizzes or playing along with game shows.
- Try Sudoku or crossword puzzles.
- Read.
- Learn a new hobby such as painting or writing.

Exercise Your Body

- Exercise is not only good for your body. It can make you feel better mentally, too. Exercising releases mood-boosting endorphins.
- Exercise also combats fatigue, which can contribute to cognitive issues.
- Try going for a daily walk or taking an exercise class.

- Ask your healthcare team before beginning any exercise program.

Eat Well

- Choose foods that promote healthy brain functioning such as fish (omega-3 fatty acids), dark leafy greens, fresh fruits and vegetables, and whole grains.
- Avoid alcohol and other substances that alter cognition.

Get Plenty of Rest

- Being tired can make you less focused.
- Fatigue and insomnia are common side effects of cancer treatment.

Check Red Blood Cell Counts

- Anemia is a condition that occurs when the body does not have an adequate amount of red blood cells.
- Anemia can cause cognitive issues.
- Ask your healthcare team to check your red blood cell counts if they are not doing so already.

De-Stress

- Anxiety and stress can cause or worsen cognitive issues.
- Try to relax in a way that works for you. Consider trying:
 - Deep breathing
 - Meditation
 - Taking a warm bath
- Your doctor may be able to prescribe medication to help with anxiety and depression.
- Try seeking emotional support from a support group or one-on-one partnering organizations.

Ask for Help

- Be honest with your friends and family about your “chemo brain.”
- If you explain what you are going through, they can be more understanding.
 - They can also help you manage your side effects by sending you friendly reminders or helping you organize your space.
- As always, talk to your healthcare team about your side effects and ways to manage them.

Constipation

Constipation is common during cancer treatment. It can be caused by many factors such as cancer type, food and liquid intake, surgery, or medications. Follow these tips to manage constipation and promote regularity.

- Soluble and insoluble fiber are both important for overall health and nutrition.
 - Soluble fiber is found in oats, beans, sweet potatoes, and fruits.
 - Soluble fiber is completely digested by the body. Soluble fiber reduces cholesterol, stabilizes blood sugar, and rids the body of toxins.
 - Insoluble fiber is found in wheat, nuts, seeds, and fruit and vegetable skins.
 - Insoluble fiber is not digested by the body and is excreted as waste. Insoluble fiber promotes regularity.
- Drink plenty of liquids.
 - Fluid helps your body process fiber without discomfort. A good starting goal is eight 8-ounce glasses of fluid per day.
- Gradually increase your fiber intake.
 - Your daily goal should be between 25-35 grams daily.
 - Fiber is mostly found in plant foods, such as fruits and vegetables, beans, legumes, whole grain cereals, breads, and oatmeal.
- Eat 3-5 servings of fruits and vegetables daily.
 - Choose whole fruit instead of juice.
 - Eat the skins and seeds for extra fiber.
 - Try to have a fruit or vegetable with each meal or snack.
- Choose foods that promote regularity.
 - Eat cereals, breads, and pastas that are made with 100% whole grain.
 - Have brown or wild rice in place of white rice or potatoes.
 - Choose hot cereals like oatmeal or cold cereals with at least 5 grams of fiber.
 - Choose whole wheat breads, whole corn or wheat tortillas, and whole grain crackers instead of refined products.
 - Eat more beans, lentils, and peas. Add them to soups and casseroles, or have as a main entrée.
 - Beans are also a great source of protein, so you can use them as a substitute for meat at mealtimes.
 - Beans can be gas forming, so add them gradually. If you experience bloating or discomfort, you may want to limit them in your diet.
- Try plum or prune juice.
 - Start with a small amount such as a $\frac{1}{2}$ cup.
 - Eating dried prunes may also help relieve constipation.
- Try to include exercise or physical activity in your daily routine.

- Physical activity is a natural way to help constipation.
 - Always discuss any exercise or physical activity with your healthcare team before making changes.
- Talk to your healthcare team about medication or supplements to help with constipation.
 - There are over the counter medications that may help with constipation but you should always check with your doctor first before taking anything.

Diarrhea

Diarrhea occurs when foods pass through the body too quickly. The body cannot absorb enough nutrients, vitamins, minerals, and water. Follow these tips to carefully manage diarrhea and prevent dehydration and malnutrition.

- Contact your healthcare team for advice managing diarrhea.
 - If you have sudden diarrhea, have diarrhea for more than 24 hours or are experiencing pain, cramping, or blood in your stools, call your healthcare provider immediately.
 - Take medications or supplements only if they are recommended by your healthcare team.
 - Always ask your healthcare team first before taking anti-diarrhea medications.
 - Always talk to your healthcare team or a dietitian before taking any supplements.
- Stay hydrated to replace fluid losses.
 - Be sure to drink plenty of clear liquids (water, ginger ale, sports drinks, or electrolyte replacement drinks) for 12 to 24 hours after a sudden bout of diarrhea.
 - Make a homemade electrolyte replacement drink by mixing the following ingredients: $\frac{1}{4}$ teaspoons salt, 8 teaspoons sugar, 3 tablespoons orange juice concentrate, and 4 cups water.
 - Let carbonated drinks lose their fizz before you drink them.
 - Drinking clear liquids helps the bowel rest and replaces lost fluids.
 - Healthy people need a minimum of 8 cups of liquid per day. You may require more to replace fluids lost with diarrhea.
- Eat 5 or 6 small meals per day instead of 3 larger meals.
 - Eating smaller meals may put less stress on your bowels and will make it easier for your body to digest food.
- Choose foods and drinks carefully.
 - Very cold foods and very hot foods can make diarrhea worse.
 - If your diarrhea gets worse after eating a certain food, stop eating that food until you recover.
 - Avoid foods and drinks that can make your diarrhea worse. High fiber foods, raw fruits and vegetables, full-fat dairy products, foods and drinks that contain caffeine, and spicy or high-fat foods can make diarrhea worse.
 - Choose foods that help manage diarrhea, like white rice, puffed rice cereal or other low-fiber grains, soft fruits like bananas and applesauce, cooked soft vegetables, and low-fat meats and dairy products.

Difficulty Breathing and Shortness of Breath

Shortness of breath and difficulty breathing are common among lung cancer patients.

Shortness of breath can be caused by obstructed airways, fluid build-up, damaged lung tissue, or other illnesses such as pneumonia. Here are some ways to help improve breathing:

- Do not smoke. If you need help quitting, talk to your healthcare team. See the “Smoking Cessation” section of the Handbook.
- Try using a humidifier.
- Keep yourself upright when sleeping.
- You may need home oxygen and an oxygen tank. Discuss your options with your healthcare team.

Difficulty Swallowing

Treatment to the head and neck can make swallowing difficult and painful. This may make it hard to eat well and maintain a healthy weight. Follow these tips to make swallowing easier.

- Chemotherapy or radiation to the head and neck can harm the cells that line the throat and cause discomfort.
 - Higher doses of radiation can cause more discomfort.
 - Chemotherapy and radiation treatment at the same time may make side effects worse.
 - Drinking alcohol or using tobacco can make side effects worse.
- Use mealtime tactics to make swallowing easier.
 - Eat 5 or 6 small meals each day instead of 3 large meals. It may be easier to eat a smaller amount of food at one time.
 - Cook foods until they are soft and tender.
 - Moisten and soften foods with gravy, sauces, broth, or yogurt.
 - Consume liquids with meals.
 - Sip drinks through a straw; this may make them easier to swallow.
- Avoid foods that are hard to swallow or irritating.
 - Avoid coarse foods that do not soften in the mouth.
 - Avoid sharp and crunchy foods like potato and tortilla chips.
 - Avoid spicy foods.
 - Avoid acidic foods like lemons, lime, oranges, and tomatoes.
 - Be careful eating hot foods to reduce the risk of burning your mouth. Cold foods may be soothing.
 - Avoid alcohol.
- Choose foods that are easy to swallow.

- Try breakfast foods like instant oatmeal, grits, pancakes, waffles, and cold cereal that has been softened in milk.
- For a main dish, try chicken, tuna or egg salad, soups and stews, soft cooked fish, tofu, and meatloaf.
- Pick side dishes like cottage or ricotta cheese, macaroni and cheese, mashed white or sweet potatoes, and rice or risotto.
- Try desserts like custard, tapioca pudding, ice cream, milkshakes, and sherbet.
- Choose snacks like creamy nut butters, applesauce, gelatin, smoothies, and yogurt.

Dry, Itchy Skin

When cancer treatments fight cancer cells, they can also affect healthy cells. This can result in certain side effects including skin changes. Side effects of the skin commonly occur with two cancer treatments: external beam radiation therapy and new targeted therapies.

External Beam Radiation Therapy

With external beam radiation therapy, high-energy radiation rays from outside the body are used to kill and shrink cancerous tumors. The radiation is targeted at a specific area of the body. This therapy usually consists of daily treatments over several weeks.

Skin side effects, such as the following, do not usually appear until about the third week of treatment and may continue after finishing treatment:

- The skin at the treatment area may become red, dry, and tender like a mild to moderate sunburn.
- The skin may also become very itchy, which is a condition called pruritus.
- In some cases, the skin may even darken, swell, blister, or peel away.
- If the skin becomes moist or cracked, you are at risk for an infection.

If side effects become too severe, your radiation oncologist may stop or delay treatment to allow your skin to rest.

Targeted Therapies

Targeted therapies focus on or “target” a specific type of cell or molecule. Common types of targeted therapy drugs attack the epidermal growth factor receptor (EGFR) to stop cancer cells from continuing to grow. Because EGFRs are also important to normal skin cell growth, this may cause skin side effects.

The most common skin side effects with targeted therapies are rashes, dry and itchy skin, hair loss, redness, and inflammation around fingernails and toenails. These side effects most commonly appear after the second or third treatment.

The following are targeted therapies (drugs) that commonly cause skin changes:

| Drug | Type of Cancer |
|--|---|
| Erlotinib, Gefitinib, Cetuximab, Panitumumab | Colorectal, Head and Neck, Lung, Pancreatic |
| Sorafenib, Sunitinib | Kidney, GIST, Liver |
| Ipilimumab | Melanoma |
| Vemurafenib | Melanoma |
| Everolimus and Temsirolimus | Kidney, Pancreatic |

Source: American Society of Clinical Oncology

How can I manage my skin side effects?

First, always tell your healthcare team about any skin changes you notice. Some side effects can be easily managed with prescription creams or oral medications. Here are some tips to help take care of your skin while undergoing cancer treatment:

Avoid irritants.

- Use unscented bath and household products including soap, shampoo, lotion, detergent, and dryer sheets.
- Do not use bath products containing alcohol. Alcohol dries the skin, making irritation worse.
- If your facial skin is affected, avoid using makeup, or switch to a sensitive skin brand.
- Always wear gloves when cleaning, and avoid skin contact with cleaning products.
- Do not shower or bathe with extremely hot or extremely cold water.
- Stay out of the sun, or wear protective clothing and sunscreen if you must be outside.
- Do not use tanning beds.
- Do not use chlorinated pools or hot tubs.

Let your skin rest.

- Do not scratch or pick at your skin.
- Do not pop blisters.
- Wash skin with care.
- Use a mild, fragrance-free soap.
 - Do not scrub the skin.
 - Let warm (not hot) water gently run over the affected area.
- Do not wear tight clothing over the affected areas.
- Do not use adhesive bandages.

Moisturize.

- Ask your doctor before using anything on your skin.
- Keep skin well moisturized.
- Use petroleum-based skin protectants or unscented lotions.
- Look for moisturizers specifically for sensitive skin.
- Ask your doctor which over-the-counter moisturizer is best for you.

- Use a humidifier while you sleep, and keep the temperature cool.
- If you are having radiation treatment, do not apply moisturizers right before treatment. It's better for your skin to be clean and clear during actual treatments.

Watch for signs of infection.

- Signs of infection include:
 - swelling, redness, or warmth
 - cloudy drainage or pus instead of clear
 - fever
 - bad smells
- Tell your doctor immediately if you notice signs of infection. You may need an antibiotic. If left untreated, infections can become very serious and spread to other parts of the body.

Dry Mouth

Dry mouth is common during and following cancer treatment. Symptoms of dry mouth are thirst, sore mouth or throat, difficulty swallowing, and changes in taste. Follow these tips to manage dry mouth.

- Chew gum or suck on ice chips, hard candy, or popsicles to help relieve dry mouth.
 - Keeping gum, ice chips, candy, or popsicles in the mouth helps keep the mouth moist.
 - Choose sugar-free or low-sugar gum or candy for prevention of cavities.
 - In place of ice chips, try frozen grapes.
 - Use lip balm if your lips become dry.
- Choose foods that are easier to chew and swallow.
 - Choose soft foods like scrambled eggs, puddings, and ice cream.
 - Avoid dry foods.
 - Cut your food into small pieces to make it easier to chew and swallow.
 - Soups and stews are good options, as long as meats are soft or cut into small pieces.
 - Try mashed potatoes and rice instead of crackers or breads.
 - Choose canned fruits or applesauce instead of raw fruits.
 - Puddings, ice cream, and sorbet are also good options.
 - Serve foods with gravy, broths, or sauces. This will make them easier to chew and swallow.
 - Season your food with citrus and herbs instead of salt or hot spices.
- Drink at least eight to ten 8-ounce cups of liquid each day.
 - Drinking liquids with meals can make it easier to swallow foods.
 - Sip cool drinks in between meals to ensure adequate fluid intake.

- Tart drinks in small amounts, such as lemonade, may help your mouth produce more saliva.
 - Keep a glass of water next to your bed at night. Drink when you wake during the night.
- Eat small meals, and eat more often.
 - Eating small, frequent meals will ensure that you are meeting your nutritional needs.
 - Try to have a good source of protein with meals and snacks. Eggs, cottage cheese, yogurt, beans, lentils, and smoothies are good soft food choices that also provide protein.
- Promote a moist mouth.
 - Rinse your mouth every 1-2 hours.
 - Mix $\frac{1}{4}$ tsp. of baking soda and $\frac{1}{8}$ tsp. salt with 1 cup warm water. Rinse with plain water after using this mixture.
 - Do not use a mouthwash that has alcohol. Alcohol makes a dry mouth worse.
 - Ask your doctor if an artificial saliva product might help. Radiation and some medications can decrease saliva production.
- Avoid things that make dry mouth worse.
 - Alcoholic drinks can worsen dry mouth.
 - Do not smoke or use other tobacco products.
 - If you do smoke, talk to your healthcare team about quitting.
- Tell a doctor or nurse if you have white patches in your mouth.
 - White patches can be evidence of an infection.

Fatigue

Fatigue impacts quality of life and can make it hard to eat healthy meals. The body needs proper nutrition to function. Improper nutrition can make other side effects worse. These tips can help manage fatigue.

- Cancer-related fatigue primarily occurs because the body requires additional energy to heal.
 - Other side effects, medications, and stress can make fatigue worse.
- While rest is important, too much rest can make you feel more tired so stay as active as possible.
 - Try going for a daily walk.
 - Talk to your healthcare team before beginning any exercise program.
- Go no longer than 4-5 hours without eating throughout the day.
 - Try to eat a balanced breakfast every day.
 - Try to eat small meals and snacks rather than large meals.

- Eat foods that provide sustainable energy; avoid foods that do not.
 - Try to include a source of protein at every meal to sustain energy released from food.
 - Try to limit sweets and sugary foods.
 - Avoid alcohol, caffeine, and chocolate in the evening.
- Stay hydrated by drinking liquids throughout the day.
- Stock your kitchen with easy-to-prepare foods and meals.
 - Ask your family and friends to help you shop for food and prepare meals.
 - Prepare food when you feel your best, and save it for later.
 - Prepare large amounts of your favorite meals then freeze meal-sized portions for later.
- Try keeping a food and fatigue journal to find patterns that trigger fatigue.
- Discuss fatigue with your healthcare team.
 - Ask your doctor to check for nutrient deficiencies, such as protein, iron, B vitamins, and vitamin D.
 - Talk to your healthcare team about other side effects such as anemia, pain, or vomiting.

Feeling Full Quickly

Feeling full too quickly is a common side effect, especially after abdominal surgery. This can cause weight loss. Not eating enough weakens the body and delays healing. Below are some tips to ensure proper nutrition.

- Eat small, frequent meals throughout the day.
 - Smaller meals are easier to digest and will allow you to better meet your needs throughout the day.
 - Keep healthy snacks on hand to eat between scheduled meals.
- Avoid foods and actions that may cause gas or bloating.
 - High-fat foods take longer to digest. They can make you feel fuller between meals. Avoid fried or greasy foods.
 - Gas-forming foods include: broccoli, cauliflower, Brussels sprouts, cabbage, corn, turnips, onions, peas, garlic, cantaloupe, watermelon, apples, avocado, beans, lentils, and nuts.
 - Stop behaviors that involve swallowing extra air. Do not suck on ice or candy, chew gum, drink carbonated drinks, or drink through a straw.
- Drink liquids between meals rather than during meals.
 - Drinking with your meals and snacks can fill you up more quickly.
 - Avoid carbonated drinks. Carbonated drinks can make you feel fuller.

- Keep your head up after meals.
 - Lying down after meals will only make your discomfort worse.
- If you are underweight or losing weight too quickly, choose foods that are rich in nutrients and calories.
 - Try to have a source of protein with each meal and snack. Some examples of protein-rich foods include eggs, chicken, fish, meat, milk, yogurt, cheese, beans, nuts, and peanut butter.
 - Add extra calories, protein, and healthy fats to foods you already eat to help prevent weight loss. Try adding olive oil, nuts, nut butters, seeds, non-fat powdered milk, or protein powder to recipes.
 - Drinking nutrient-rich liquids like smoothies or milkshakes can provide nutrition without making you feel full. Liquids leave the stomach more quickly than solid foods.
 - Ask a registered dietitian if drinking a liquid nutrition supplement is needed to provide necessary calories and protein. If needed, a specific liquid nutrition supplement can be recommended that meets your needs.

Gas and Bloating

Excess gas is a common side effect, especially for colorectal and stomach cancer patients. Foods, drinks, behaviors, and medications contribute to gas. These tips may help with the pain, bloating, and discomfort that come with excess gas.

- Avoid gas-forming foods.
 - Avoid broccoli, cauliflower, Brussels sprouts, cabbage, corn, turnips, onions, peas, peppers, radishes, garlic, cantaloupe, watermelon, apples, avocados, beans, lentils, and nuts.
 - Avoid dairy products such as milk cheese or yogurt.
 - Avoid carbonated beverages.
- Avoid behaviors that cause you to swallow extra air.
 - Eat slowly.
 - Do not suck on ice or candy.
 - Do not chew gum.
 - Do not drink through a straw.
 - Drink liquids slowly with small sips.

Insomnia and Difficulty Sleeping

Many cancer patients report that they occasionally have trouble sleeping or that they can't sleep at all (insomnia). Lack of sleep can lead to other issues such as fatigue, loss of concentration, headaches, and irritability.

To minimize the impact of insomnia, focus on these three possible solutions: managing other side effects of cancer or treatment, creating a good sleep routine, and talking to your healthcare team.

Manage other side effects.

Some side effects of cancer treatment can lead to difficulty sleeping. If you can minimize those side effects, then your sleep may improve.

Nausea

Nausea may make it difficult for you to go to sleep, and vomiting may wake you up at night.

- Sleeping with your head slightly elevated may help you get more comfortable.
- If your doctor has prescribed medication for nausea, make sure you take it as recommended, especially before bedtime.

Pain

Any type of pain can keep you up at night and make it difficult to be comfortable.

- Make sure you take pain medication as recommended, especially before bedtime.
- For more information on managing pain, read the pain management section of this handbook.

Weight Gain

If you gained weight as a result of cancer treatment, you may have trouble falling asleep and staying asleep. The extra weight can make it difficult to get comfortable. It can also make sleeping more difficult because your body has to work a little harder to function normally, such as regulating breathing.

- Try using a body pillow to give you more sleeping positions.
- Read the weight gain section of this handbook for more information on how to maintain a healthy weight.

Hormonal Changes

Hormonal changes, such as menopause for women, can disrupt sleep, especially with side effects such as hot flashes and night sweats. Talk to your healthcare team about the best ways to manage hormonal changes. Your doctor may be able to prescribe medications to help manage hormonal changes.

- Cool temperatures can help promote sleep. Make sure your bedroom thermostat is set low and that your pillowcase feels cool to your skin.

- If night sweats are a problem, buy wicking sleepwear to keep you dry at night.

Stress and Anxiety

Stress and anxiety can keep you up at night. It may feel difficult to “turn off your brain.” Finding ways to cope with your stress and anxiety is very important.

- Enjoy a relaxing activity every night before bed to take your mind off cancer. Try working on a crossword puzzle, reading a book, or listening to music.
- Try simple stretches, yoga, or meditation to clear your mind.

At any point in your cancer journey, you may wish to seek emotional support. Support groups, peer matching programs, or individual counseling may help relieve stress and anxiety.

Create a good sleep routine.

Try to create a comfortable and relaxing sleep routine. For example, every night before bed take a hot bath or read a few chapters of a good book. If you do this every night, it will signal to your body that it is time for sleep. The most important thing is that this routine works for you. Here are some tips to get you started:

Tips for creating relaxing sleep environment:

- Make sure your mattress, bedding, and pillows are comfortable for you.
- Pleasant smells, like lavender, may help you sleep. Try an aromatherapy mist on your pillow.
- Buy a fan or white noise machine to drown out other distracting noises.
- Turn out all the lights, and use blinds or curtains to cover the windows.
- Do not leave the TV or computer on while you are trying to fall asleep.
- Silence all call, email, and text alerts on your phone.

Tips for sleeping through the night:

- Try to go bed and wake up at the same time each day.
- Choose a small snack, not a large meal, before bed.
 - Digestion may wake you up, but a small snack will keep you from getting hungry during the night.
- Use the restroom right before going to bed.
- Exercise during the day, but do not exercise right before bed.
- The buildup of adrenaline and endorphins from exercise makes it difficult to wind down.
- Limit daytime naps to no more than 30 minutes.
- Avoid caffeine, alcohol, and tobacco products.

Talk to your healthcare team.

Always talk to your healthcare team if you are having insomnia or difficulty sleeping. Your doctor may recommend prescription medications or over-the-counter sleep aids to help you fall asleep and stay asleep. Do not take any medications without consulting your healthcare team

first. Some sleep aids can be habit-forming so only take these medications as directed by your doctor.

Lactose Intolerance

Lactose intolerance occurs when the body cannot digest milk sugar (lactose). Some patients experience lactose intolerance, with symptoms like diarrhea, gas, and stomach cramps after having dairy. These tips may help to relieve symptoms.

- Avoid dairy products and foods containing lactose and instead choose lactose-free or reduced lactose milk products.
 - Most grocery stores sell lactose-free milk and ice cream.
 - After asking your doctor, consider trying products made with soy or rice instead. Soy milk, rice milk, and almond milk are available at most grocery stores.
 - Yogurt with live active cultures and hard cheeses such as parmesan and aged cheddar are lower in lactose. You may find these to be better tolerated and less likely to cause symptoms
 - Avoid using butter, margarine, cream, or soft cheeses when cooking or preparing foods.
- Read labels carefully.
 - Avoid foods that have been prepared with milk, butter, milk solids, cream, casein, or whey.
 - Avoid products with ingredient lists that say “May contain milk”.
- Talk to your doctor about using over-the-counter enzymes.
 - Lactase enzyme products are available in capsule, liquid, or pill form.
 - Taking these enzymes with your meal may help you to digest the lactose in milk and prevent symptoms.
- Choose other calcium-fortified or high-calcium foods.
 - Read labels to find foods that have been fortified with calcium to ensure you are meeting your calcium needs.
 - There are many ways to meet your calcium needs from foods other than dairy products. Other good sources of calcium include leafy green vegetables, broccoli, fortified orange juice, fortified cereals, canned salmon, tofu, almonds, soy beans, and white beans.
 - Talk with your physician or a registered dietitian about whether you could benefit from taking a calcium supplement.
- Symptoms of lactose intolerance may improve overtime after treatment ends, but sometimes it can be a long-term problem.

Loss of Appetite

Loss of appetite interferes with good nutrition before, during, and after treatment and can contribute to dangerous weight loss. The following are some tips to optimize nutrition while dealing with appetite loss.

- Manage any other nutrition related side effects that may contribute to appetite loss.
 - Nausea, vomiting, diarrhea, constipation, dry mouth, sore mouth, swallowing difficulty, and heartburn may lead to loss of appetite.
 - Talk to a registered dietitian and your healthcare team for assistance with any of these side effects. It is important to get help managing any of these side effects to increase appetite.
- Take note of when your appetite is best.
 - For some people this is in the morning and appetite diminishes throughout the day. For other people it may be the opposite.
 - When you feel well, eat as much nutritious food as possible in case you do not feel well later.
 - Do not limit or restrict food intake when appetite is good.
- Eat 5-6 small meals per day and snack anytime.
 - Small amounts of food are typically easier to digest and are easier on the stomach. It is often easier to better meet nutrition needs while battling appetite loss with smaller amounts of food more frequently.
- Keep healthy snacks around, and do not go more than three hours without eating.
 - Pack a cooler or insulated lunch bag to take on longer trips or to appointments when the wait time is variable.
 - Keep small containers of fruit, dried fruit, trail mix, small bottles of juice, yogurt, cheese, whole grain crackers, cereal, granola bars, and other portable food items that are easy to eat and require little to no preparation.
 - Always keep snacks visible and available as a reminder that it is important to eat to get the body the nutrients it needs.
- If food is not appealing, have a nutritious beverage instead.
 - A high-protein shake or smoothie can have as many calories as a small meal or large snack.
 - Have a ready-to-drink liquid nutrition supplement when food is not appealing.
 - Milkshakes, smoothies, or protein shakes can be made with yogurt, milk, ice cream, protein powder, fruit, and other ingredients using a blender. Have these ingredients available for times when a drink sounds better than a meal.
- Drink liquids between meals.
 - Sometimes drinking liquids with meals causes the stomach to get full faster. This prevents eating enough and maximizing nutrition from food sources.

- If an early feeling of fullness is a problem, try waiting to drink any liquids until after a meal and do not drink any liquids for at least 30 minutes before a meal.
- Add calories and protein to foods to give their nutrient content a boost.
 - There are ways to add protein and calories to foods that are already eaten regularly.
 - Add a scoop of protein powder to a shake or smoothie.
 - Add healthy fat such as olive oil, nuts, or nut butter to recipes and other dishes to boost the calorie content.
 - Ask a registered dietitian for other suggestions on how to increase the protein and calorie content of foods.
- Exercise or do some physical activity at least an hour before a meal.
 - Always check with your doctor before beginning an exercise regimen.
 - Regular exercise may help increase appetite.
 - Go for a 20-minute walk before sitting down to a meal.
- Get in the habit of having a bedtime snack.
 - An easy-to-digest snack such as yogurt and fruit, cheese and crackers, or peanut butter and crackers is an easy way to get some additional nutrition and will not impact appetite for the next meal.
 - If reflux or heartburn is an issue, have this snack at least one hour before lying down.
- Emotions are often related to appetite. Talk to your healthcare team about managing your emotional well-being.
 - Depression, anxiety, fear, and stress can all affect appetite.
 - Trained health professionals such as social workers and psychologists can assist in managing these emotions.
 - Support groups are another resource that may help in processing these emotions.

Nausea

Nausea and vomiting are common side effects of cancer treatment that can cause dehydration, poor nutrition, and weight loss. Follow these tips to control nausea and vomiting.

- Take anti-nausea medications as prescribed by your healthcare provider.
 - It is important to take anti-nausea medications as prescribed.
 - Do not wait until the onset of nausea to take medication.
 - It is best to attempt to keep nausea managed with medication to allow for consistent eating and optimal nutrition.
 - Call your healthcare provider if you are taking the medication as prescribed and it is not providing any relief. A different medication may be needed.

- Track nausea to determine causes and trends.
 - Some nausea may be directly related to chemotherapy.
 - It is beneficial to know how soon after chemotherapy the nausea begins. Sometimes it is immediate and other times the onset is delayed.
 - Tracking may help to identify other triggers or causes of nausea.
- Keep odors to a minimum.
 - Odors can lead to nausea so it is best to choose foods with little or no odor such as oatmeal, cereals, canned fruit, shakes, and smoothies.
 - When preparing food at home, opt for foods with short cooking times and minimal odor such as pancakes, scrambled eggs, reheated soup, or other prepared foods that just require reheating.
 - Cool and room temperature foods usually have fewer odors than hot food.
 - Avoid cooking foods that have long cooking times such as casseroles, meats, and slow cooked meals.
 - Ask friends or family members to cook these items in an alternative location like a neighbor's kitchen.
- Eat several small meals or snacks during the day.
 - Eating small meals or snacks 5-6 times per day instead of 2 or 3 larger meals may help with nausea management. This keeps the stomach from getting too empty and prevents excess stomach acid.
 - Chew all foods very well. The digestion process begins in the mouth.
 - Keep bland, odorless snacks on hand for easy meals and snacking. Some examples are crackers, cheese, canned fruit, yogurt, toast, rice, and pasta.
 - Not all foods are appealing to everyone. The key is to find the foods that are tolerable and stock up on those.
- Create a relaxing environment for eating and snacking.
 - Lighting, temperature, and other external cues may make nausea worse.
 - Dim lighting and cooler temperatures tend to be better for nausea management.
 - The use of a fan or ceiling fan may also make a difference.
 - It is important to be removed from situations that contribute to anxiety when attempting to enjoy a meal or a snack. (i.e. loud voices, arguing, loud music, or non-relaxing television programs).
 - Soft relaxing music, a relaxing television program or another activity that is relaxing in a cool, dim room may be the best environment for meals and snacks.
 - Rest after meals but do not lie flat as this may trigger nausea.
- Experiment with different foods.
 - Everyone is an individual and not all foods work for everyone when nausea is an issue. Try to be patient and experiment with different foods.
 - Start with bland foods with minimal odor and introduce them one at a time.
- Avoid foods and behaviors that tend to trigger nausea.

- Some foods are triggers for nausea for unexplained reasons. Some of these reasons may be psychological. It is best to avoid these foods for optimal nutrition. The time that it takes to recover from an episode is time that the body is missing out on good nutrition.
 - Foods that are harder to digest and stay in the stomach longer can be triggers for nausea. These foods are usually higher fat foods such as fried foods and foods prepared with a lot of butter or oil.
 - Spicy foods are usually not tolerated well.
 - Some behaviors such as eating in a restaurant may trigger nausea. If this is the case, order food to carry out and eat it in a more relaxing environment.
 - Caffeine and smoking contribute to nausea.
 - Limit or avoid smoking, and drink only decaffeinated beverages.
- Try foods and drinks containing ginger.
 - Ginger is a spice that has shown some promise for relief from nausea.
 - Ginger snaps, ginger ale, ginger gum, or ginger tea may be options that can help manage nausea.
 - Ginger is also common in some Asian recipes.
 - Ginger supplements are available; however, they have not been studied extensively to determine an effective dose.
- Avoid drinking while eating.
 - Sometimes excess liquid in the stomach contributes to nausea.
 - It is best to drink any beverages at times other than meal times.
 - The best beverages to choose are water, 100% fruit juices without added sugar, and caffeine-free soda that no longer has carbonation.
 - Ginger ale specifically may help with nausea.
- Wear loose-fitting, comfortable clothing.
 - Clothing that is tight especially around the midsection can trigger nausea.
 - Soft, comfortable fabrics tend to be more relaxing as well.
- Stay hydrated if vomiting occurs.
 - Continue to drink clear liquids including water and other electrolyte containing beverages like sports drinks.
 - Attempt to eat bland foods such as crackers or toast.
 - If vomiting is continuous and cannot be controlled, contact your healthcare provider immediately.

Pain

Cancer and Pain

Pain related to cancer comes in many different forms. Pain can be caused by the cancer itself, or it can be a side effect of treatment.

For the best pain management, you and your healthcare team will first need to find out the cause of your pain. Be prepared to answer these questions:

- How severe is your pain?
- Is there anything that makes it better?
- Is there anything that makes it worse?
- What does it feel like—an ache or a sharp pain, dull, throbbing, or tingling?
- Is the pain in only one part of your body?
- How does the pain interfere with your daily life?

Keeping a pain journal can be helpful. Use the Treatment and Side Effects Log included in this handbook.

Is the pain a side effect of treatment?

Chemotherapy, radiation, and surgery are the three most common cancer treatments, and pain is a potential side effect for all three. However, the type of pain caused by each is different.

Chemotherapy can cause the following types of pain: muscle and joint aches, mouth sores, headaches, and neuropathy. Neuropathy is an unpleasant tingling or numbness, usually in the hands or feet. Damage to nerve endings causes this feeling.

Radiation causes the skin at the treatment site to become dry, red, and painful like a mild to moderate sunburn. Sometimes these burns blister. Depending on the location of radiation, there may be other side effects. For example, radiation to the brain may cause headaches.

Surgery causes pain at the incision site. Depending on the extent and location of the surgery, this pain could be mild to severe. Surgery can damage muscles and tissues leading to range of motion problems. Surgery can also damage nerves and cause neuropathy.

Is the pain a side effect of the cancer itself?

Depending on size and location of the tumor, pain could be from the cancer itself. If the tumor is pressing on nerves, joints, or bones, it can cause pain. This type of pain is more common with advanced or metastatic cancer, especially when the cancer spreads to the bones. Tumors in the bones can cause fractures as the tumors continue to grow.

Pain Management Plans

Your healthcare team can help create the best pain management plan for you. If the first plan you try does not work, tell your healthcare team. You may need to try a different plan. Open and honest communication with your healthcare team is very important. Pain is a difficult side effect to treat. It may take a few tries to find the best plan for you. Do not be afraid to seek a second opinion if needed. The pain experience can also be influenced by additional stressors such as fatigue and anxiety. Your doctor may refer you to a pain specialist, a doctor who specializes in pain management.

Your pain management plan may include:

Pain Medications

Your doctor may prescribe pain medications or suggest over-the-counter pain medications. Ask your doctor before taking any over-the-counter medications. Some pain medications can cause nausea or constipation. Your doctor may be able to suggest additional medications to help with these side effects. You may have to try a few different types of medications or dosages to find what works for you.

Physical Therapy

Physical therapy uses exercises to help improve strength and motion. If your pain is related to loss of range of motion or difficulty doing physical activities such as walking, physical therapy may help ease pain.

Exercise

Regular exercise, even something as simple as a daily walk, may also help with pain. Exercising is good for the body. It can also make you feel better mentally too. Exercising releases endorphins, natural chemicals that make you feel happier. Exercising also combats fatigue which is a common side effect along with pain. Always ask your doctor before beginning an exercise plan.

Complementary and Alternative Medicine

Some cancer patients find success at relieving pain with complementary and alternative medicine (CAM) such as acupuncture, guided imagery, massage, supplements and vitamins, or yoga. The phrase “complementary and alternative medicine” means treatments outside the standard scope of what you would find at a hospital or treatment center. Complementary medicine is used along with standard treatment. Alternative medicine is used instead of standard treatment.

Always discuss the pros and cons of each treatment you consider with your healthcare team. If you are considering a complementary treatment, inform your medical team BEFORE you are treated to make sure it will not negatively interact with your standard treatment. If you are considering quitting standard treatment for an alternative treatment, remember: standard treatments go through a long and careful research process to ensure that they are safe and effective, but less is known about most types of CAM.

For more information on CAM, visit the National Center for Complementary and Alternative Medicine website.

Palliative Care

A team of people may talk to you about palliative care, including a palliative care physician, a palliative care nurse, and a spiritual care representative. Palliative care provides relief from pain and other symptoms, but it does not provide a cure. For cancer patients, common palliative therapies include surgery, radiation, or chemotherapy as a method of shrinking tumors that are causing pain. Palliative care is most commonly used for advanced or metastatic cancers.

Emotional Support

Taking care of your emotional well-being can also help manage pain. There are a number of ways to find emotional support—peer partnering programs, support groups, and one-on-one counseling.

Your doctor may even prescribe antidepressants, which have been shown to help with nerve pain as well as emotional well-being.

Managing Other Side Effects

Other side effects of treatment, such as fatigue, nausea, or loss of appetite, may be making your pain worse. You may be able to manage many of these side effects with simple nutrition and habit changes.

Reflux, Heartburn, and GERD

Heartburn, reflux, and GERD (gastroesophageal reflux disease) may occur during cancer treatment. Cancer treatments or medications may affect parts of your digestive tract and cause the food and liquids in your stomach to reflux (travel back) into your esophagus (food pipe). Patients with reflux may have symptoms such as swallowing difficulty, a sore throat, sour taste in your mouth, heartburn and painful digestion.

Talk with your healthcare team for the best care for reflux. Here are some tips and guidelines to help control reflux:

Go small.

- Eat 5-6 small meals or snacks throughout the day. Smaller amounts of food are easier for the body to digest and absorb.
- Smaller amounts of food also mean there is less food that can travel back up the food pipe.

Choose lean.

- Avoid fried and fatty foods. These foods are hard to digest and stay in your stomach for a long time. Time increases risk for reflux.
- Choose baked, broiled, or grilled foods instead.

Dress for comfort.

- Wear loose-fitting clothes, especially clothes that are not tight around your stomach.
- Clothes that are tight around the stomach can trigger reflux.

Avoid smoking and alcohol.

- Smoking cigarettes (including e-cigarettes) and drinking alcohol can trigger reflux.
- Instead of after-dinner drinks and cigarettes, chew sugarless non-mint gum for 30 minutes after meals. This encourages food to move through your digestive system.

Sit up.

- Pay attention to your posture.
- Sit up at least 1 hour after eating.
- Good posture helps your breathing and may reduce fatigue during eating.
- Raise the head of your bed 6 to 9 inches by putting wooden blocks under the legs of the head of your bed.

Slow down.

- Eat slowly and chew food thoroughly. Digestion begins in the mouth.
- Smaller food pieces are much easier to digest and are less likely to cause discomfort.
- Meals eaten in calm, relaxed place seems to be better digested.
- Added stress from treatment can also trigger reflux; try to eat when you are feeling most relaxed.

Choose well.

- Some specific foods and drinks may cause reflux symptoms.
- Some common problem foods and drinks may be: chocolate, cocoa, mint, whole milk, caffeine, pepper, some fruits/juices, pastries and other high-fat desserts.

Write it down.

- Record in a log the times you eat, the foods and drinks you consume, and any reflux symptoms.
- If you eat a large portion of a problem food, you may have symptoms. Try a small portion and take notes in your log. Use your log to eliminate items that cause reflux symptoms.
- Avoid “problem foods” for a couple of days to see if symptoms disappear.

Avoid eating before bed.

- Avoid eating too close to bedtime.
- Have your last food or drink 1-3 hours before you recline.
- If still having trouble sleeping due to reflux, you may need to raise the head of the bed so that gravity helps keep food down in the stomach.

Ask for help.

- Consult a local registered dietitian for specific recommendations based on your level of food tolerance.
- Talk to your healthcare team if symptoms persist or get worse.

Sexual Side Effects

Female Sexual Side Effects

Many female cancer patients experience sexual dysfunction or changes in their sex lives after a cancer diagnosis. These changes can be physical or mental. Many women are not comfortable discussing these issues with their healthcare team or with their partners, but being able to speak openly is important.

Each type of cancer treatment—chemotherapy, radiation, surgery, and hormonal therapy—can cause possible sexual side effects. Side effects may vary depending on the type of cancer, the specific mode of treatment, and the individual's response to treatment. Talk to your healthcare team about what you should expect from treatment.

Managing Side Effects

Below are some of the most common sexual side effects and tips for managing each.

Lack of Desire

During and after cancer treatment, many women report a lack of sexual desire. Lack of desire may come from hormonal changes such as early menopause or other side effects, making sex unenjoyable.

- Rethink what sex and intimacy mean.
 - Do not expect sex after cancer to be exactly the same as sex before cancer. Your body has been through a lot of changes.
 - Be patient. It may take some time to discover what is comfortable and pleasurable for you.
- Ask your doctor about estrogen therapies to increase estrogen and if they are safe for you to use.
 - Low levels of estrogen can cause female sexual dysfunction.
 - Estrogen therapies can help with lack of desire and dryness.
 - Estrogen therapies come in pills, creams, patches, and vaginal rings.
 - If your cancer is hormone driven, estrogen therapy may not be safe for you.
- If you are taking anti-depressants or pain medication, talk to your doctor about adjusting your dosage.
 - Both these medications can cause lack of desire.
- Manage other side effects such as dryness, pain, nausea, or fatigue that may be causing your lack of desire.

Dryness

Early menopause, triggered by chemotherapy, adjuvant therapies, or surgery, can cause vaginal dryness. Radiation to the pelvic region can also cause dryness.

- Use a water-based lubricant during sex.
 - Stay away from scented and warming lubricants. These can irritate the vagina, actually making dryness worse.
 - Do not use petroleum jelly based lubricants.
- Try vaginal moisturizers to improve overall dryness.
 - Vaginal moisturizers are different from lubricants. You do not use them only during sex. If used regularly, they improve overall dryness and vaginal health.
- As mentioned above, ask your doctor about estrogen therapies and if they are safe for you to use.

Pain

Pain during intercourse may occur for a few reasons such as dryness or scar tissue. Radiation to the pelvic region may cause minor burns as well as scarring that causes the vaginal canal to shrink. Gynecological surgery can damage or result in the removal of sex organs.

- After surgery, ask your doctor if and when it is safe to have sex.
- If the shape of the vagina has changed from treatment, you may need to adjust the way you have sex by trying new positions or new activities.
- After gynecological surgeries that affect the vagina, reconstructive surgery may be an option.
- A vaginal dilator can be used to stretch the vaginal canal. Vaginal dilators are smooth plastic cylinders of different widths. By beginning with the smaller ones and inserting them into the vaginal canal regularly, the vagina begins to stretch, making intercourse less painful. Vaginal dilators also make medical pelvic exams more comfortable.
- Pain may come from dryness. If you are also experiencing dryness, try the tips above.

General pain in other parts of the body can also make sex uncomfortable and decrease your desire to be intimate. To learn more about pain management unrelated to sex, read the pain management section of this handbook.

Difficulty Reaching Climax or Orgasm

Surgery and other treatments that directly affect the pelvic region can result in loss of sensation if nerves are damaged. This can make achieving an orgasm difficult for some women. Actions that worked before treatment may no longer feel the same. Other side effects mentioned in this article such as pain, lack of desire, and emotional issues can also make achieving orgasm difficult.

- Work on managing all of side effects that may be affecting your sex life.

- For most women, vaginal penetration does not provide enough stimulation for orgasm. Extended clitoral stimulation may be needed.
- Use your mind. Make sure you are comfortable and in the right mindset for sexual activity. Try imaging sexual fantasies to get in the mood.
- Try using a vibrator to increase stimulation. Vibrators can be purchased at a drug store or discreetly online.

Managing Non-Sexual Side Effects

Other treatment side effects, such as nausea and fatigue, may interfere with your sex life. Manage these side effects by using the tips in this handbook.

Self-Esteem and Body Image

How you feel about yourself can affect your sex life. Cancer and cancer treatment can cause significant changes to your body. You may have hair loss, weight loss, weight gain, or scars. With these changes, you may not feel the same way about your body. This is all normal. Do not be critical of yourself. Your body battled cancer.

Below are tips for managing issues related to self-esteem and body image.

Hair Loss

- Hair usually grows back after treatment ends.
- In the meantime, try wigs, hats, and scarves.
- When your hair does begin to grow back, use a gentle shampoo such as baby shampoo.

Weight Changes

- Talk to your healthcare team about reaching and maintaining a healthy weight.
- Ask your healthcare team if it is safe for you to start an exercise program.
 - The endorphins released during exercise can also make you feel better emotionally.

Surgical Scars

- Most surgeries leave some scars. Try using over-the-counter lotions and gels to help minimize incision scars. Moisturizers made with cocoa butter also minimize scars.
- After surgery for breast cancer, some women choose to wear a breast prosthesis.
 - Insurance companies often cover a prosthesis.

Emotional Support

You have to care for your mental health as well as your physical health. If you are struggling with anxiety or sadness, you probably don't feel like having sex. Some options for emotional

support include: peer partnering programs, support groups, and one-on-one counseling. Look the emotional support section of this handbook for more information.

Talking to Your Partner About Sexual Dysfunction

Being able to talk openly with your partner about sex is very important. What worked for you both before cancer may not work now. You may need to try different things to find what works for you both. If it has been a while since you've been intimate, start slowly with simple kissing and touching. Here are some basic guidelines for talking to your partner:

- Be honest.
- Always tell your partner if something hurts or is uncomfortable.
- If something feels good, let your partner know.
- Be patient with yourself and your partner.
- Set the scene by going on a romantic date or watching a movie together at home.
- Since cancer treatment can compromise your immune system, be sure to always use condoms to protect against STDs.

Talking to Your Healthcare Team About Sexual Dysfunction

Your healthcare team is made up of health professionals. You should feel comfortable telling them anything. There is nothing embarrassing about sexual dysfunction, as it can happen following cancer and its treatment. After fighting cancer, you deserve to have a healthy sex life.

You may wish to talk to healthcare professionals who specialize in areas related to sexual dysfunction including:

- Gynecologist
- Endocrinologist
- Sex therapist
- Psychologist or counselor

Talking about sexual dysfunction can be difficult. Here are some sample questions to begin your conversation with your doctor:

- How will treatment affect my sex life?
- What can I do to manage sexual side effects?
- I have pain and dryness during sex. What can I do to manage this?
- I no longer feel any desire to have sex. What can I do to feel like myself again?
- Could you recommend a specialist?
- Will treatment affect my fertility?

Male Sexual Side Effects

Many males with cancer experience sexual dysfunction or changes in their sex lives after a cancer diagnosis. These changes can be physical or mental. Many men are not comfortable discussing these issues with their healthcare team or with their partners, but being able to speak openly is important.

Common Side Effects of Treatment

Each type of cancer treatment—chemotherapy, radiation, surgery, and hormonal therapy—can cause possible sexual side effects. Side effects may vary depending on the type of cancer, the specific mode of treatment, and the individual's response to treatment. Talk to your healthcare team about what you should expect from treatment.

Below are some of the most common side effects of each treatment type that causes sexual dysfunction.

Surgery

Surgery to the pelvic area including surgery for prostate, anal, bladder, or testicular cancer can lead to the following:

- Damage to blood vessels or nerve endings resulting in difficulty having and keeping an erection, known as erectile dysfunction or impotence
- Damage of sexual organs
- Orgasms that do not result in ejaculation

After surgery, ask your doctor if and when it is safe to have sex.

Chemotherapy

Chemotherapy does not usually directly affect sexual function, but the side effects of chemotherapy, such as nausea and fatigue, may lead to loss of sexual desire. Chemotherapy can also cause infertility.

Radiation

Radiation may cause the following side effects:

- Damage to blood vessels or nerve endings leading to erectile dysfunction
- Redness and pain at the treatment site
- Fatigue which may lead to loss of desire

Managing Side Effects

Below are tips for managing the most common side effects related to sexual dysfunction in men.

Erectile Dysfunction

Erectile dysfunction can be either mental or physical. Your doctor can do a test to determine the cause. If the cause is mental, see the suggestions below for managing emotional issues. If the cause is physical, you have several options.

- Prescription medications can treat erectile dysfunction by increasing blood flow to the penis. (If erectile dysfunction is caused by nerve damage, medications such as these will not help.) Common medications include:
 - Sildenafil (Viagra)
 - Tadalafil (Cialis)
 - Vardenafil (Levitra, Staxyn)
- Penile injections are shots delivered before sex into the penis to help cause and sustain an erection. Your doctor may wish to do a practice injection at a healthcare office to make sure they work for you.
- A vacuum constriction device (or pump) is a plastic tube placed over the penis. Air is then pumped out of the device, creating suction. This suction causes more blood to flow to the penis.
- Penile implants are prostheses (artificial devices) surgically placed inside the penis to help create an erection. There are three main types of penile implants:
 - A semirigid penile implant is a flexible rod placed inside the penis that can be bent up or down.
 - A two-piece penile implant is made up of an inflatable cylinder inside the penis and a pump inside the scrotum.
 - A three-piece penile implant is made up of an inflatable cylinder inside the penis, a pump inside the scrotum, and a fluid supply in the abdomen.
- Being overweight may also cause erectile dysfunction. If you have gained weight during treatment, read Nutrition Tips for Managing Weight Gain.

Talk to your healthcare team about which of these options may be best.

Lack of Desire

During and after cancer treatment, many men report a lack of sexual desire. Lack of desire may come from hormonal changes or from other side effects that make sex unenjoyable.

- Rethink what sex and intimacy mean.
 - Do not expect sex after cancer to be exactly the same as sex before cancer. Your body has been through a lot of changes.
 - Depending on your treatment type, orgasms may no longer result in ejaculation, or you may have difficulty reaching orgasm.
 - Be patient. It may take some time to discover what is comfortable and pleasurable for you.
- If you are taking anti-depressants or pain medication, talk to your doctor about adjusting your dosage.
 - Both these medications can cause lack of desire.
- If low testosterone is causing your lack of desire, you may be able to take testosterone supplements. Talk to your healthcare team about your options.
- Other treatment side effects such as nausea, fatigue, and pain may interfere with your sex life.
 - Use the other side effect management sections of this handbook to help manage other side effects.

Self-Esteem and Body Image

How you feel about yourself can affect your sex life. Cancer and cancer treatment can cause significant changes to your body. You may have hair loss, weight loss, weight gain, or scars. With these changes, you may not feel the same way about your body. This is all normal. Do not be critical of yourself. Your body battled cancer.

Below are tips for managing issues related to self-esteem and body image.

Hair Loss

- Hair usually grows back after treatment ends.
- In the meantime, try a hat, bandana, or cap.
- When your hair does begin to grow back, use a gentle or baby shampoo.

Weight Changes

- Talk to your healthcare team about reaching and maintaining a healthy weight.
- Ask your healthcare team if it is safe for you to start an exercise program.
 - The endorphins released during exercise can also make you feel better emotionally.

Surgical Scars

- Most surgeries leave some scars. Try using over-the-counter lotions and gels to help minimize incision scars. Moisturizers made with cocoa butter also minimize scars.

Emotional Support

You have to care for your mental health as well as your physical health. If you are struggling with anxiety or sadness, you probably don't feel like having sex. Some options for emotional support include: peer partnering programs, support groups, and one-on-one counseling. Other patients are often great resources for men experiencing sexual side effects of cancer. It can be difficult to talk about these issues, but having someone who has experienced the same journey can be beneficial.

Talking to Your Partner About Sexual Dysfunction

Being able to talk openly with your partner about sex is very important. What worked for you both before cancer may not work now. You may need to start slowly and try different things to find what works for you both. If it has been a while since you've been intimate, start slowly with simple kissing and touching. Here are some basic guidelines for talking to your partner:

- Be honest.
- Always tell your partner if something hurts or is uncomfortable.
- If something feels good, let your partner know.
- Be patient with yourself and your partner.
- Set the scene by going on a romantic date or watching a movie together at home.

- Since cancer treatment can compromise your immune system, be sure to always use condoms to protect against STDs.

Talking to Your Healthcare Team About Sexual Dysfunction

Your healthcare team is made up of health professionals. You should feel comfortable telling them anything. There is nothing embarrassing about sexual dysfunction, as it can happen following cancer and its treatment. After fighting cancer, you deserve to have a healthy sex life.

You may wish to talk to healthcare professionals who specialize in areas related to sexual dysfunction including:

- Urologist
- Endocrinologist
- Sex therapist
- Psychologist or counselor

Talking about sexual dysfunction can be difficult. Here are some sample questions to begin your conversation with your doctor:

- How will treatment affect my sex life?
- What can I do to manage sexual side effects?
- Will I have difficulty having an erection? What can I do to manage this?
- I no longer feel any desire to have sex. What can I do to feel like myself again?
- Could you recommend a specialist?
- Will treatment affect my fertility?

Sore Mouth, Throat, and Tongue

Some cancer treatments can cause mouth sores, ulcers, and tender gums, leading to dehydration, poor eating, and weight loss. Follow these tips to manage sore throat, mouth, and tongue.

- Choose soft, bland foods.
 - Softer foods will be easier to chew and swallow.
 - Soups and stews are good options, as long as meats are soft and tender.
 - Try breakfast foods like instant oatmeal, grits, pancakes, waffles, and cold cereal that has been softened in milk.
 - Pick side dishes like cottage or ricotta cheese, macaroni and cheese, mashed white or sweet potatoes, and rice or risotto.
 - Try desserts like custard, tapioca pudding, ice cream, milkshakes, and sherbet.
 - Choose snacks like applesauce, gelatin, smoothies, and yogurt.
- Prepare foods in ways that make them easier to eat.

- Cut foods into small pieces. You may consider using a blender or food processor to puree foods.
 - Cook foods until they are soft and tender.
 - Serve foods with gravy, broths, or sauces.
 - Choose soft or canned fruits or applesauce instead of raw fruits with tough skins.
- Avoid foods and drinks that make mouth sores worse.
 - Avoid citrus fruits and juices, salty or spicy foods, and acidic foods like tomatoes.
 - Do not drink carbonated or caffeinated drinks.
 - Refrain from having beer, wine, liquor, or any other type of alcohol.
- Avoid very hot foods.
 - Hot foods can cause mouth and throat discomfort.
 - Choose room temperature or cold foods that are soothing.
 - Allow soups and hot foods to cool to room temperature before serving.
 - Try freezing fruits, and suck on frozen fruit pops, fruit ices, or ice chips.
- Choose foods that are good sources of protein to combat weight loss.
 - Aim to have a good source of protein with meals and snacks.
 - Ground meats, eggs, cottage cheese, yogurt, custard, beans, lentils, and smoothies are good soft food choices that also provide protein.
 - Eat small, frequent meals. You may find it easier to eat smaller amounts at a time.
- Drink at least 8-10 eight-ounce glasses of water each day.
 - Drink liquids with your meals as this will make it easier to swallow foods.
 - Sip cool drinks in between your meals.
 - Drink with a straw. This can help push the foods past the painful sores in your mouth.
 - Avoid caffeinated or/and carbonated beverages.
 - Avoid alcohol. Alcohol can irritate the mouth.
- Use good mouth care.
 - Rinse your mouth several times a day. Mix ¼ tsp. of baking soda and 1/8 tsp. salt with 1 cup warm water to make a rinse that removes food and promotes healing.
 - Do not use a mouthwash that has alcohol. Alcohol makes a sore mouth worse.
 - Use a toothbrush with soft bristles.
 - Remove dentures (except during eating) if your gums are sore. Keep dentures clean.
 - Avoid cigarettes, cigars, and tobacco products.
 - Ask your doctor about special mouthwashes and sprays that can numb the mouth and throat.
 - Tell your doctor if your gums are bleeding or if you have white patches in your mouth. Both can be signs of infection.

Weight Gain

Weight gain is common among cancer patients. This can be for a variety of reasons. The following tips help maintain a healthy weight before, during, and after cancer treatment.

- Know the factors that can cause weight gain.
 - Medication, hormone therapy, or chemotherapy can lead to weight gain.
 - Fatigue and other side effects can cause decreased physical activity.
 - Stress, fear, or depression can lead to changes in eating habits.
 - Fluid retention causes swelling.
- Eat a variety of fruits, vegetables, whole grains, and beans.
 - All of these foods are high in fiber and low in calories.
 - Fiber helps you feel fuller longer.
- Choose whole grain foods.
 - Whole grains also contain fiber and are a lasting energy source.
 - Whole grain foods include whole grain breads, cereals, pasta, crackers, and brown rice.
- Choose lean proteins.
 - Protein foods also help you feel fuller longer.
 - Lean proteins include eggs, fish, skinless chicken, turkey, lean beef, lean pork, beans, and soy products.
- Choose low-fat or fat-free dairy products.
 - Low-fat and fat-free dairy products contain the same amount of protein as regular dairy products.
 - Low-fat and fat-free dairy products include 1% or skim milk, low-fat yogurt and reduced-fat cheese and cottage cheese.
- Limit foods high in fat and calories.
 - High-fat foods like regular butter, creamy dressing and sauces, sour cream, mayonnaise, fried foods, and dessert contain more calories and can contribute to weight gain.
 - Limit frequency and portions of high-fat foods and choose reduced-fat items when possible.
 - Avoid high-fat cooking methods, such as pan or deep frying. Broiling, steaming, grilling, and roasting are recommended.
- Avoid high-calorie beverages.
 - Avoid drinking large amounts of sugar-sweetened beverages such as sodas, sports drinks, sweetened teas, lemonade, and sweetened fruit juice.
 - Choose low-calorie, low-sugar beverage options such as water and unsweetened tea.
 - Limit or reduce alcohol consumption. If alcohol is consumed at all, it is best to limit to no more than one drink per day for women and two drinks for men.

- Avoid eating when you are not physically hungry.
 - Listen to your body. Don't confuse boredom or stress for hunger.
 - Try making a list of alternate activities you can do when you have the urge to eat when not hungry.
- Watch your portion sizes.
 - Try measuring out your portions so you know exactly how much you are eating.
 - Check the nutrition label to determine serving sizes.
 - Choose to eat all meals and snacks off of a plate rather than out of the package so you can keep track of how much you are eating.
- Limit dining out.
 - Restaurants often serve large portions of higher calorie and higher fat foods.
 - Limit eating out so you are not tempted with large portions of these foods as often.
- Write down your intake.
 - Studies show that those who record all of their food and drink intake eat less calories than those who do not.
 - Keeping a food journal could help keep you mindful about appropriate portion sizes and urges to eat when not hungry.
- Try exercise.
 - Aim for 30 minutes of exercise every day if able.
 - Always discuss any changes in exercise with your physician.
- Always discuss weight gain with your physician.
 - A physician can help determine the cause of weight gain and can give recommendations for how to appropriately manage weight gain.
 - Do not go on a diet to lose weight without discussing with your physician first.

Weight Loss

During cancer treatment, the body needs more calories and protein, especially when side effects can make it difficult to eat. Follow these tips to increase intake.

- Eat small, frequent meals (5-6 a day) instead of 3 large meals.
 - Eat every 2 to 3 hours even if you do not feel hungry.
 - Set a timer to remind you it is time to eat. Eat the most when you feel hungriest.
 - Eat protein foods like chicken, fish, meat, eggs, nuts, and beans first.
- Use smoothies and shakes to get in calories and protein.
 - Liquids can be easier to consume than solid foods.
 - Smoothies or shakes can serve as a small meal replacement.

- Add ingredients such as whole milk, powdered milk, protein powder, peanut butter, ice cream, or yogurt to smoothies or shakes to add calories and protein.
 - Premade liquid nutrition supplements are available at grocery and drug stores. Ask a registered dietitian which type is best for you.
 - Ingredients such as whole milk, peanut butter, ice cream, yogurt, or fruit can be added to liquid nutrition supplements.
- Add more fats to foods to increase the calories.
 - Fat has more calories per gram than carbohydrates or protein.
 - Use butter, oils, mayonnaise, sour cream, and salad dressings liberally.
 - When cooking, use oil or butter instead of a nonstick spray.
 - Add mayonnaise to sandwiches and tuna or chicken salad.
 - Add peanut butter or cream cheese to toast or crackers.
- Drink most liquids between meals instead of with meals.
 - Liquids such as water, juice, or soda while you eat can make you feel full faster.
 - Drink only small amounts with meals.
 - Drink higher calorie liquids like juice and milk between meals.
 - Drink smoothies, shakes, and nutrition supplements with or in place of a meal.
- Snack regularly throughout the day.
 - Keep quick and easy snacks with you.
 - Try granola bars, trail mix, peanut butter crackers, nuts, and dried fruit.
 - Keep your favorite snacks around so you will eat more.
 - Eat a bedtime snack. It will not affect your appetite at your next meal.
 - Peanut butter crackers, half a sandwich, yogurt, and cereal are good bedtime snacks.
- Discuss weight loss with your oncologist. There are prescription medications that can assist with increasing appetite.

Nutrition

When you are faced with a cancer diagnosis, nutrition can be an important part of your journey. Eating a well-balanced diet before, during, and after cancer treatment can help you feel better, maintain your strength, and speed your recovery. Use these tips about nutrition written by registered dietitians.

I Have Cancer. What Should I Eat?

How do I make the best food choices throughout cancer treatment?

When you are faced with a lung cancer diagnosis, nutrition can be an important part of your journey. Eating a well-balanced diet before, during, and after cancer treatment can help you feel better, maintain your strength, and speed your recovery.

- **Maintain a healthy weight.** Unintentional weight loss is common during lung cancer. This can be due to lung cancer treatments or the cancer itself. Monitor your weight closely. If you are losing more than 1-2 pounds per week consistently, discuss with your healthcare team how you can increase your calorie intake.
- **Eat small, frequent meals throughout the day.** Eating frequent small meals will ensure your body is getting enough calories, protein, and nutrients to tolerate treatment. Smaller meals may also help to reduce treatment-related side effects such as nausea. Try eating 5-6 small meals or “mini” meals about every three hours.
- **Choose protein-rich foods.** Protein helps the body to repair cells and tissues. It also helps your immune system recover from illness. Include a source of lean protein at all meals and snacks. Good sources of lean protein include:
 - Lean meats such as chicken, fish, or turkey
 - Eggs
 - Low fat dairy products such as milk, yogurt, and cheese or dairy substitutes
 - Nuts and nut butters
 - Beans
 - Soy foods
- **Include whole grain foods.** Whole grain foods provide a good source of carbohydrate and fiber, which help keep your energy levels up. Good sources of whole grain foods include:
 - Oatmeal
 - Whole wheat breads
 - Brown rice
 - Whole grain pastas

- **Eat a variety of fruits and vegetables every day.** Fruits and vegetables offer the body antioxidants, which can help fight against cancer. Choose a variety of colorful fruits and vegetables to get the greatest benefit. Try to eat a minimum of 5 servings of whole fruits and vegetables daily.
- **Choose sources of healthy fat.** Avoid fried, greasy, and fatty foods, Choose baked, broiled, or grilled foods instead. Healthy fats include:
 - Olive oil
 - Avocados
 - Nuts
 - Seeds
- **Limit sweets and added sugars.** Foods high in added sugars like desserts and sweets provide little nutritional benefit and often take the place of other foods that are better for you.
- **Stay hydrated.** Drinking enough fluids during cancer treatment is important for preventing dehydration. Aim to drink 64 ounces of fluid daily. Avoid drinking large amounts of caffeinated beverages. Too much caffeine can lead to dehydration.
- **Use good mouth care.** Chemotherapy and radiation to the head or chest can irritate the lining of the mouth, throat, and esophagus. This irritation can make eating and swallowing difficult. Good mouth care is very important if you have mouth soreness. Brush teeth with gentle toothpaste after eating and floss daily.
- **Practice good food safety.** Wash your hands often while preparing food. Use different knives and cutting boards for raw meat and raw vegetables. Be sure to cook all foods to their proper temperature and refrigerate leftovers right away.
- **Talk to your healthcare team before taking any vitamins or supplements.** Some medications and cancer treatments may interact with vitamins and supplements. Choose food first as the main source for nutrients.
- **Drink alcohol in moderation, if at all.** Alcohol may contribute to dehydration, can lower the abilities of your immune system, and provides no beneficial nutrients.
- **Most importantly, know that your cancer journey is unique to you and your treatment.** You may experience side effects that affect your ability to follow these suggestions. If you are struggling with any side effects, such as loss of appetite, nausea, diarrhea, vomiting, or any other nutrition concerns, your needs may be different. A registered dietitian can suggest nutrition guidelines that will be appropriate for your cancer journey.

High-Calorie Sample Menus

Cancer and its treatment can cause your body to use energy very quickly. When your body uses large amounts of energy, you may lose weight or have difficulty gaining weight. Your oncologist or registered dietitian may suggest that you follow a high-calorie diet to help keep you at a healthy weight.

If you are struggling with eating enough calories due to the side effects of your cancer or treatment, the following tips can help you increase your calorie intake:

- Try consuming several small meals throughout the day, spaced 2-3 hours apart.
- Eat more when your appetite is best.
- Use condiments to add calories to your food, such as adding extra butter, sour cream, oils, cheese, whole milk, whipped cream, mayonnaise, salad dressing, jelly, jam, syrup, and honey.
- Avoid drinking beverages with meals. These take up room in your stomach, making you feel full faster. Save them for in-between meals.
- Avoid foods labelled “lite” or “diet”.

The sample menu below provides 3,000 calories a day. Check with your healthcare team or registered dietitian to see how many calories you need in a day.

High-Calorie Sample Menu: Day 1

| Meal | Suggested Items | Notes |
|--------------------------------------|---|--|
| Breakfast <i>Calories 750</i> | 1 large scrambled egg 1 medium biscuit 2 Tbsp. butter 2 Tbsp. jelly 1 cup grape juice 1 cup 2% or whole milk | Biscuits, butter, whole milk, and juice are high in calories. |
| Morning Snack <i>Calories 253</i> | 1 cup celery stalks 2 Tbsp. peanut butter 2 Tbsp. raisins | For variety, try almond, hazelnut, or soy nut butters. Dried fruits are high in calories. |
| Lunch <i>Calories 788</i> | grilled chicken sandwich with 4 oz. chicken 1 leaf lettuce 1 slice tomato 1 oz. cheese | Double the cheese or mayonnaise for even more calories at lunch. |

| | | |
|--|---|--|
| | 1 Tbsp. mayonnaise 1 cup applesauce 1 oz. pretzels | |
| Afternoon Snack <i>Calories 294</i> | Orange Pineapple Smoothie* | |
| Dinner <i>Calories 779</i> | 1 cup spaghetti with ¾ cup tomato sauce and 3 oz. cooked ground beef 1 medium breadstick 1 Tbsp. butter | Large serving of spaghetti noodles and butter help to increase calories. |
| Bedtime Snack <i>Calories 144</i> | ½ cup chocolate ice cream | |

High-Calorie Sample Menu: Day 2

| Meal | Suggested Items | Notes |
|--|---|--|
| Breakfast <i>Calories 721</i> | 1 cup Cheerios with 1 cup 2% or whole milk and ½ cup dried blueberries 1 English muffin with 2 Tbsp. peanut butter | Dried fruits and nuts are calorie boosters. |
| Morning Snack <i>Calories 279</i> | 6 oz. fruit yogurt 6 vanilla wafers | Use regular yogurt and skip the light or low-fat yogurt. |
| Lunch <i>Calories 702</i> | 1.5 cups Turkey Pot Pie with Cornbread Crust* 1 cup green beans with 1 Tbsp. butter and 1 oz. almonds 1 cup cranberry juice | Large servings of casseroles and combination dishes like pot pies help to add calories. Add a handful of nuts or dried fruits as dessert. |
| Afternoon Snack <i>Calories 360</i> | High-calorie liquid nutrition supplement | Look for the words “plus” or “high-calorie” on the liquid nutrition drinks. |
| Dinner | 3 oz. pork loin ¾ cup glazed carrots | Stir in extra butter, whole milk, cheese, and sour cream to increase calories in |

| | | |
|---------------------------------------|--|---|
| Calories 782 | ¾ cup mashed potatoes made with milk and butter 1 medium dinner roll 2 Tbsp. butter | mashed potatoes. |
| Bedtime Snack Calories 164 | 1 serving Pear Crisp* | Baked desserts can add calories even in small servings. |

High-Calorie Sample Menu: Day 3

| Meal | Suggested Items | Notes |
|---|--|--|
| Breakfast Calories 750 | 2 medium waffles 1 Tbsp. butter ¼ cup maple syrup ½ cup vanilla yogurt 1 cup grapes | Large servings of butter, syrup, and waffles help to add calories. |
| Morning Snack Calories 240 | 4 squares graham crackers 1 cup 2% milk | Swap the 2% milk with whole milk or a milkshake to add calories. |
| Lunch Calories 780 | Curried Chicken Salad Sandwich* 2 slices white bread 1 cup carrot sticks with 2 Tbsp. ranch dressing 1 cup canned pears | Extra salad dressing and fruit servings help to increase calories. |
| Afternoon Snack Calories 240 | 6 cheese crackers | |
| Dinner Calories 757 | 4 oz baked salmon ¾ cup rice with 1 Tbsp. butter ¾ cup steamed broccoli with 1 oz. melted cheese 1 medium dinner roll with 1 Tbsp. butter | Sprinkle cheese and butter on rice and broccoli to boost calories. |
| Bedtime Snack Calories 272 | 3 medium gingersnap cookies 1 cup 2% or whole milk | |

*Denotes My PearlPoint recipe. You can find these recipes at mypearlpoint.org.

Food Safety

The immune system is weakened during all types of cancer treatment. Unfortunately, chemotherapy medications are not able to tell the difference between healthy cells and cancer cells. For this reason, perfectly healthy red and white blood cells are damaged or killed during treatment and shortly thereafter. The result of this is that body is not as good at fighting illness and infection. A common term used to refer to a very low neutrophil (white blood cell) count is **neutropenia**. Paying special attention to food safety during cancer treatment to reduce the risk of exposure to food borne illness may also be referred to a **neutropenic diet**. The following are some simple tips to reduce exposure and avoid unnecessary infection and/or illness during the time the immune system is compromised.

Keep EVERYTHING Clean

- Wash hands often and thoroughly especially before handling any food as well as after. Be sure to wash hands with warm water and soap for at least 20 seconds. Pay special attention to finger nails and the backs of the hands.
- Keep raw and cooked foods separate. Do not reuse any utensils, cutting boards, plates, dishes, etc. once they have been touched by raw meat or eggs. Utensils, cutting boards, plates, dishes, etc. that have been used for preparing raw meats or eggs should be washed in hot, soapy water. It is best to keep a separate cutting board for meat and fruits/vegetables. Have an extra clean cutting board available for additional preparation as well.
- When shopping for and storing raw meats, keep them away from other foods and cover the packages with extra plastic wrap or use plastic bags. This will prevent any liquids from leaking onto other foods or surfaces. Store meats and eggs toward the bottom of the refrigerator to prevent any dripping on other foods below.

Cook Food Thoroughly

- Avoid raw meat such as sushi, undercooked eggs (make sure eggs are at least “over easy” and not “sunny side up”), and other meats that have not been cooked to a proper internal temperature.
- Cook all eggs until both the white and the yolk are firm.
- Use a meat thermometer to make sure that all meats are cooked to the proper internal temperature prior to eating. Here is a chart for reference:

| Meat | Internal Minimum Temperature |
|---------------------------------------|-------------------------------------|
| Ground Beef | 165° F |
| Turkey | 165° F |
| Chicken | 165° F |
| Steak or other cuts of beef | 160° F |
| Whole chicken, turkey, duck, or goose | 180° F |

| | |
|--------------------|--------|
| Pork | 170° F |
| Egg dishes | 160° F |
| Casseroles | 165° F |
| Reheated leftovers | 165° F |

Foods To Avoid

- Raw or undercooked meats
- Unpasteurized milk and juices
- Soft cheeses made with unpasteurized milk such as feta, blue cheese, Roquefort, Stilton, brie, or Farmer's cheese
- Processed meats such as luncheon meats as well as anything else from a deli counter
- Refrigerated meat spreads or paté
- Smoked fish or precooked shrimp or crab meat
- Sprouts such as bean sprouts, alfalfa sprouts, or broccoli sprouts
- Pre-cut fresh fruit and vegetables. Buy them whole, wash, and cut them yourself using proper sanitary techniques as outlined above.
- Unwashed fresh fruits and vegetables
- Unroasted or raw nuts and seeds
- Raw tofu or tempeh
- Food from salad bars of buffets
- "Fresh" salad dressings, salsas, sauces, etc. sold in the refrigerated section of the grocery store.
- Raw apple cider
- Raw honey
- Unrefrigerated cream filled pastries

The guidelines above were created with those who have severely weakened immune systems in mind. Consult your physician or health care team for regular updates on your blood counts and the status of your immune system.

Must Have Grocery List

It's always important to have good, healthy foods on hand, especially if you are fighting cancer or are a cancer survivor. Eating well during cancer treatment can help to improve your overall health, improve your response to treatment, and maintain good health during treatment and recovery. Having a well-stocked pantry can assure that you are getting the calories and nutrition your body needs. Below are some suggested items that are healthy kitchen staples.

Pantry

Grains

- Whole grain breads, English muffins, pita bread, flour or corn tortillas
- Crackers: saltines, club crackers, whole wheat crackers, graham crackers
- Whole grain brown rice or white rice
- Whole wheat and refined pastas such as, penne, bowtie, macaroni, egg noodles, etc.
- Quick cooking oats and steel cut oatmeal
- Couscous, bulgur, or quinoa
- Cream of wheat
- Grits
- Dry cereal
- Natural popcorn
- Flour, cornmeal, breadcrumbs

Fruit/ Vegetables

- Canned fruit
- Dried fruit
- Individual fruit cups
- Applesauce, no sugar added
- Potatoes and sweet potatoes
- Onions
- Garlic
- Canned tomatoes (diced, whole), tomato sauce, marinara sauce
- Canned no salt added vegetables
- Instant mashed potatoes

Dairy

- Nonfat dry milk powder or whey protein powder
- Evaporated Milk

Proteins

- Canned tuna, salmon, or chicken (Choose those packed in water, not oil)
- Natural peanut and almond butter
- Unsalted nuts and seeds
- Canned or dried beans, vegetarian refried beans, lentils.
- Protein bars

Fats and Oils

- Oil, olive, canola, cooking spray

Other

- Canned low sodium soups
- Low sodium chicken, beef, or vegetable stock
- Dried herbs and spices
- Vinegars such as red wine and balsamic
- Decaffeinated teas
- Flavored drink mixes, lemonade
- Pudding or gelatin mixes
- Individual pudding or gelatin cups
- Honey, sugar, stevia

Refrigerator:

Fruits/Vegetables

- Fresh and jarred fruits and vegetables
- Packaged salad mixes such as spinach, romaine and arugula

Dairy

- Low-fat milk,
- Low-fat plain or Greek yogurt
- Cheese slices, cheese sticks, shredded or crumbled cheese
- Reduced fat cottage or ricotta cheese
- Fortified soy, almond, or rice milk

Proteins

- Eggs
- Skinless chicken breasts or ground chicken breast
- Lean pork

- Lean cuts or lean ground beef
- Ground turkey or turkey breast
- Nitrate and nitrite-free deli meats
- Hummus

Fats and Oils

- Mayonnaise
- Salad Dressings
- Reduced

Other

- Beverages- 100% juices, tea, sports drinks, liquid nutrition supplements
- Fat-free sour cream
- Lemon juice, lime juice
- Sauces and condiments like low sodium soy sauce

Freezer:

Grains

- Frozen whole grain waffles
- Whole grain breads, rolls, English muffins, bagels, etc.

Fruits/ Vegetables

- Frozen vegetables and fruits
- Frozen juice concentrate (100% juice)

Dairy

- Frozen desserts: sherbet, frozen yogurt, ice cream

Proteins

- Chicken breasts
- Fish such as tilapia, salmon, flounder
- Shrimp

Other

- Popsicles

Practical Concerns

A cancer diagnosis brings with it practical concerns such as financial, emotional, and legal issues. If possible, it is best to address these concerns before you begin treatment because you may not want to deal with issues when you are not feeling well. It may help to discuss these issues with your nurse navigator and to involve your caregiver. In the next few sections, you will find information on the following:

- *Preparing financially for cancer*
- *Legal considerations*
- *Hospice and palliative care*
- *Finding emotional support*

Financial Concerns and Cancer

A cancer diagnosis can cause financial concerns. Even if you have insurance, there are things you need to think about. Here are the questions you need to ask before you start treatment:

Am I insured? Is my insurance going to cover the cost of treatment?

- Before you begin treatment, take a look at your insurance plan to see what starting treatment will cost you.
- A portion of costs will be “out of pocket” with any insurance plan.
 - See if you can get this cost automatically taken out of your bank account or pay check or paid with a credit card.
- You have to meet your deductible before your insurance company will pay for care.
- As soon as possible, determine what your co-payment will be for each appointment and treatment.
 - Use this to make a budget for future treatments and doctor appointments
- Most insurance plans have the option for cancer patient to be assigned a case manager.
 - Be sure to ask for this service.
 - This person will be able to answer all your questions.
 - If your insurance company does not have a case manager service, ask to speak to the same representative each time you call.
 - If your insurance is through your employer, someone in HR will be able to answer questions about your coverage.
- You may need to find a supplemental program to cover fees that your primary insurance does not.

What if I don't have insurance?

- State Medicaid: www.cms.gov
- Medicare: www.medicare.gov and www.cms.gov
- Affordable Care Act: www.healthcare.gov/law/
- Hill Burton: <http://www.hrsa.gov/gethealthcare/affordable/hillburton/>
- Your Local Health Department and Local Free Clinics: <http://freeclinics.us/clinics/search>
- Discuss possible grant money for lung cancer patients with your nurse navigator.

Can I afford treatment? What other expenses can I expect?

- Before you begin treatment, ask the billing department for the expected cost.
 - When you begin, your doctor will give you a treatment plan.
 - For example, you will do a certain number of rounds of chemotherapy or a certain number of weeks of radiation.
 - Take this plan to the billing department to get an estimate of the cost of your prescribed treatment plan.
 - The more information you get the better you can prepare.
- Ask the billing department if there are any ways you might be able to save money.
 - Many providers will give you a discount if you pay in full.
 - Ask if you can set up a payment plan where you pay a certain amount each month towards your bill.
- You will need to change your current budget to include costs related to your cancer diagnosis and care.

Are there options for treatment that are less expensive? Are these options just as effective? Am I eligible for a clinical trial?

- Ask your doctor and healthcare team these questions.
- Be sure to discuss all your treatment options with your healthcare team.
- Clinical trials are not more or less expensive than other treatments. Many insurance plans cover clinical trial treatments. Ask your doctor and healthcare team for more information

Does my hospital or treatment center have options for financial assistance? Is there assistance I can apply for? Does my hospital have a reduced cost program? If so, what are the eligibility requirements?

- Many hospitals have options for financial assistance.
- Ask if there is someone you can talk to about your options.

What other costs should I expect?

- Additional expenses you need to consider include:
 - Transportation
 - Child care
 - Nutritional supplements

- Additional prescriptions
- Prostheses (artificial body parts) or wigs
- Household chore services (cleaning, grocery shopping, etc.)

10 Financial Assistance Tips for Cancer Survivors

Whatever your financial situation, a diagnosis of cancer can complicate your budget. Review these tips for greater financial peace of mind.

1. Understand your current and upcoming financial situation.

- Use the budgeting worksheets in this handbook to help you understand your regular income and expenses. Doing so can ensure that you are not blindsided by the impact of any extra expenses.
- Learn about the costs of your treatment plan. Before you begin treatment, your doctor will prescribe a certain treatment plan; for example, a certain number of weeks of chemotherapy. The billing department of your doctor's office or treatment facility may be able to give you an estimate.

2. Ask your doctor if there are more affordable options for treatment.

- Start with these questions: Are there less expensive treatment options? Would these options be as effective?

3. If you do not already have a system for handling your finances, now is the time to develop one.

- Decide how you will keep track of your finances moving forward. Will you keep handwritten records? Will you use a computer program? Set aside a day and a time every month to pay your bills (or weekly if needed).
- Ask a financial planner for help; your bank may have a customer service agent who is helpful.

4. Keep accurate records of all medical bills, insurance claims, payments, and receipts, as well as any mail regarding those items.

- Get a notebook or special folder to keep track of everything in one place.

5. When looking for financial assistance, always start with your doctor's office.

- Practices often have financial assistance and options for uninsured and underinsured patients. Your doctor's office may also have a social worker or patient representative who can help you identify resources.
- Be sure to request any applications or possible services offered.

6. When contacting the billing department, ask to speak with the same representative each time.

7. When asking for assistance, see if the billing department is willing to set up a payment plan for you. You may get a discount if you are able to pay your bill in full at the time of service.

8. Working with your insurance company and understanding your coverage will help you know all your options.

- Many insurance companies offer case managers for diagnoses like cancer.

9. Look to nonprofit organizations for help.

- Many national organizations have local branches that may be able to help with specific costs. The assistance might not be much, but every little bit can help.
- Examples of organizations include: churches, American Cancer Society, CancerCare, Salvation Army, and the United Way.
 - American Cancer Society: (800) 227-2345
 - CancerCare: (800) 813-HOPE (4673)
 - United Way: Dial 211 or visit www.211.org or www.unitedway.org.

10. If you realize you are going to be late making a payment, be sure to call your creditors as soon as you can and let them know of your situation.

- Some companies like your credit card or mortgage company might temporarily change your payment requirements or interest rate.

Managing My Health Insurance

Even with insurance, the cost of cancer is high and often requires lots of visits with primary care doctors and specialists for labs, tests, and treatment. Your insurance may not cover the cost of everything. You will also have out-of-pocket costs such as co-pays and deductibles that may build up. To stay on top of these, make sure you know what to expect ahead of time. Here are some tips for navigating your health insurance and the cost of cancer care:

Be familiar with your health insurance policy.

Learning about your health insurance can be a very daunting task. The best place to find out about your policy is through your health insurance company.

- If possible, see if your provider will assign to you a case manager. If not, ask to speak with the same representative each time you call. This will make communication easier for both you and the representative.
- If your insurance is through your employer, you can also contact your Human Resources representative with any questions.

Know what you are expected to pay.

Before you start treatment, take a look at your insurance plan and see what is covered and what additional costs you will need to pay.

- A portion of the costs will be out-of-pocket regardless of your insurance plan.

- See if there is an option to get this cost automatically taken out of your bank account or pay by check or with a credit card.
- Most health insurance companies have a deductible. A deductible is the certain amount that you will have to pay before the insurance plan will start paying. Even with the deductible met, you may have to make co-payments.
- Always look in advance into what your co-payment will be for each appointment and treatment.

Make a budget.

Use coverage, co-pay, and deductible information to make a budget for future treatments and doctor's appointments. This is also a good way to plan your new budget and not be surprised by the additional costs.

- Use the budgeting worksheets provided at the end of this handbook.

Submit everything to your insurance company.

Submit all of your medical expenses, regardless if you think your insurance company will cover it or not. The only way to get an expense covered is to submit it. It is better to ask and be turned down than spend unnecessary money out-of-pocket.

Look for financial assistance.

If you are still having trouble managing costs, look to financial assistance programs. Forms of assistance include co-pay as well as premium assistance and prescription assistance programs. All financial assistance is usually dependent on income and cancer type.

Patient advocate foundation may be able to assist with co-pays. Call 1-800-532-5274 for more information.

The Basics of Medicare

Medicare is an insurance program run by the United States government. Medicare is for people who

- Are 65 years and older and are eligible for Social Security benefits
- Are receiving Social Security Disability Insurance and have completed a 2-year waiting period for Medicare
- Have Railroad Retirement/Disability benefits
- Have end-stage renal disease or Amyotrophic Lateral Sclerosis

Medicare has 4 types of possible coverage.

Part A (Hospital Insurance): Part A covers inpatient care. It is free for most Medicare recipients. The services covered by Part A include hospital care, skilled nursing facility care, nursing home care, hospice, and home health services.

Part B (Medical Insurance): Part B covers medically necessary services, meaning services or supplies that are needed to diagnose or treat your medical condition and meet accepted standards of medical practice. Part B also covers preventive services such as healthcare to prevent illness or detect it at an early stage when treatment is most likely to work best. These services include clinical research, ambulance services, durable medical equipment, mental health, second opinion, and limited outpatient prescription drugs. Part B of Medicare does come at a cost. In most cases, participants pay a premium of about \$105 a month.

Note: Part A and B usually cover 80% of costs for individuals, leaving 20% left for the individual to pay. (For example, if your bill is \$4,000, Medicare would pay \$3,200 and you would pay \$800.) With this type of Medicare, there are Medigap programs to cover the additional 20%. These programs have a limited enrollment period; if that period is missed, you may lose access.

Part C (Medicare Advantage Plans): Part C plans are offered through private companies approved by Medicare. These plans cover all the services provided by Medicare Part A and Part B. These plans vary depending on location and have their own set premiums, deductibles, and co-pays.

Part D (Prescription Drugs): Part D may be covered by your premium if your income is below a certain amount. Otherwise, you will pay according to your income (no more than \$69.30 a month).

If the cost of Medicare is too much, look to Medicare.gov for options to help pay your costs. Medicare.gov is also a great resource to look up what is specifically covered by Medicare.

I Am Uninsured. What Are My Options?

If you are uninsured or underinsured and have been diagnosed with cancer, you should know your options for health insurance and reduced-cost medical care.

Medicaid:

Medicaid is an insurance program for those who are low income and meet the eligibility requirements. Medicare is funded by state and federal government.

- Eligibility depends on what state you live in because each state individually runs its own program.

- Visit your local government website or Department of Human Services for more information.
- Medicaid programs have strict rules about who can qualify. If someone in your household is able to work, you may not be able to receive Medicaid.
- Medicaid programs often include:
 - Children
 - Pregnant women
 - Social Security insurance recipients
 - People diagnosed with some cancer types
- Even if you are in one of the above categories, you will still need to qualify based on your income.
- Under the Affordable Care Act, many states expanded their Medicaid programs to include almost all adults with an income below 138% of the federal poverty limit. For example, if two people live in your household and have a combined income of less than \$21,707, you may qualify.
- For the most up-to-date information on these expansions, visit healthcare.gov and the Kaiser Family Foundation at kff.org.

COBRA:

The Consolidated Omnibus Budget Reconciliation Act (COBRA) was created to allow some people to temporarily keep insurance coverage if there are changes in their employment. The program allows you to keep your former job's insurance by paying the full price of the insurance to your employer (not the reduced rate you paid as an employee).

- Examples of employment changes include the following:
 - Being fired or laid off from your job
 - Voluntarily leaving your job
 - Having your hours reduced, making you ineligible for insurance
 - Having health insurance through a spouse's job, and he or she died, or you are now divorced or separated
- COBRA is a very expensive option and may seem unaffordable, but COBRA can buy you some time. If you have cancer, your medical bills from being uninsured could be more than COBRA.
- If you are eligible but have not signed up for COBRA, you may be able to pay past premiums and obtain COBRA coverage.

Affordable Care Act:

The Affordable Care Act (ACA) was signed into law in 2010. The ACA changed a lot of the laws of the U.S. healthcare system. The goal of the ACA was to increase the quality and affordability of healthcare in the U.S. As part of the ACA, people can sign up for health

insurance through the government-run healthcare marketplace if they do not have insurance through their employers or another source.

- Now that the March 31, 2014, enrollment deadline has passed, the only way to apply for coverage through the ACA marketplace is to see if you qualify for a special enrollment period.
- The enrollment period for 2015 will begin on November 15, 2014. In the meantime, you can look to healthcare.gov to see if you might qualify for a subsidy and what your deductible and premiums might be.
- Now that insurance companies can no longer disqualify individuals based on pre-existing conditions, the marketplace has multiple options that are great for those with a cancer diagnosis.
- If you are under 26 years old, you can still be on your parent's health insurance plan.
- Your options through the marketplace depend on where you live. It is best to check the marketplace directly to see your individual options. Visit healthcare.gov for more information.

Local Health Department and Local Free Clinics:

- Look to local free clinics to get your medical treatment.
- You can also do a search of free clinics in your area at The National Association of Free & Charitable Clinics at www.nafcclinics.org/clinics/search.
- In addition to free clinics, there are approximately 170 healthcare facilities that still provide free or reduced cost services under the Hill Burton free and reduced cost healthcare law.
- You must apply at the admissions office of the participating hospital to determine if you meet eligibility requirements.
- For more information, visit the US Department of Health and Human Services at www.hrsa.gov.

Finding Transportation

Transportation to and from treatment can be difficult to find and maintain. Some first steps to finding reliable transportation include the following:

- Always begin by asking your healthcare team if your treatment center provides transportation assistance.
- Try calling your insurance provider. Some insurance plans also provide help with transportation to and from treatment.

If neither of these options is helpful, try some of these resources:

The American Cancer Society's Road to Recovery

The American Cancer Society offers a volunteer-run service called Road to Recovery. This service provides transportation to and from treatment for people who have cancer and do not have a ride or are unable to drive themselves. Because this service is run by volunteers who donate their time and use their own cars, the drivers cannot usually drive long distances. Call (800) 227-2345 to learn how to schedule a ride in your area.

Public Transportation

Bus systems and local public transportation are good options. Most public transportation systems have door-to-door service options for medically needy and handicapped individuals. Note, however, that your healthcare team may advise you not to use public transportation if you have a weakened immune system.

Financial Assistance to Cover Gas Costs

If you are able to drive and have to travel a long distance, you may be able to find financial assistance to cover the gas costs of transporting yourself. There are multiple resources for this assistance including the American Cancer Society, CancerCare, and Grind for Life. These resources can provide a limited amount of financial assistance for the cost of gas or other costs of travelling, such as bus passes or the cost of medical transport. Also check with your treatment center. Sometimes local organizations provide gas cards directly to treatment centers to distribute.

You can contact the organizations listed above using the following information:

- American Cancer Society: (800) 227-2345 or cancer.org.
- CancerCare: (800) 813-HOPE (4673) or www.cancercare.org.
- Grind for Life: (561) 252-3839 or www.grindforlife.org.

Free or Reduced-Cost Flights

Sometimes getting to treatment also includes having to fly for treatment. Angel Flight is an organization that provides free air transportation for medically necessary trips. They are a group of pilots and volunteers. You can contact Angel Flight by calling (918) 749-8992 or visiting www.angelflight.com.

Finding Lodging

A cancer diagnosis may require you to travel for doctor appointments and treatment. Some forms of treatment require you to visit a treatment center for multiple days in a row for weeks at a time. There are a couple of options to consider when having to make these kinds of extensive trips.

Checking with Your Treatment Center

If you need assistance finding or paying for lodging, tell your healthcare team as soon as possible. Some treatment centers have lodging coordinators especially if the center treats a lot of patients from out of town. Treatment centers may also have their own lodging such as a hospitality house. Ask your healthcare team if your treatment center has resources to help with lodging.

American Cancer Society's Hope Lodge

The American Cancer Society (ACS) sponsors Hope Lodges in most major cities throughout the country. It is free to stay at all the Hope Lodge locations. If you have an ACS Hope Lodge in your area, your oncology nurse or social worker should be able to help with the application process. This resource is not for those who are homeless. ACS will check to make sure you have somewhere to stay once you have checked out. To contact the American Cancer Society, call **(800) 227-2345** or visit www.cancer.org.

Hotels with Medical Rates

For discount lodging, hotels with medical rates are a great option. Most major hotel chains offer medical rates for those who are travelling for medical treatment. Make sure you book your rooms in advance. The hotel may require proof from your doctor that you are traveling for medical reasons.

Joe's House

The nonprofit Joe's House provides an online nationwide database of places that offer lodging for cancer patients. Check out their website to determine options in your area. You can search by state, city, and even treatment center. The search results include nonprofit lodging as well as hotels that provide medical discounts. Visit Joe's House at www.joeshouse.org.

What Do I Need To Know About Social Security Disability Benefits and Cancer?

Do you have a cancer diagnosis? Are you no longer able to work? You may qualify for Social Security Disability benefits.

The Social Security Administration (SSA) offers financial assistance in the form of Social Security Disability benefits. **A cancer diagnosis does not automatically make you eligible for SSA benefits.** You have to apply. Here is what you need to know about Social Security Disability benefits and cancer:

- Social Security Administration (SSA) and Social Security Disability benefits
 - To qualify, you must meet the SSA's definition of disability.
 - A cancer diagnosis does not automatically meet the SSA's definition of disability.
 - The SSA processes cancer disability claims on a case by case basis.
 - You must prove you cannot work for at least one year because of your diagnosis.
 - You need proof from your doctor that you cannot work.
 - People who have stem cell or bone marrow transplants automatically meet the definition.
 - In cases of advanced stage cancer, you may qualify for "Compassionate Allowance."
 - This allows applicants to qualify for benefits in as little as ten days.
 - Visit <http://www.disability-benefits-help.org/compassionate-allowances> for more info.
 - Apply as soon as possible. The SSA denies most disability claims at first. You can appeal the decision.
 - You can fill out the forms online at <http://www.ssa.gov/> or at your local Social Security Office.

The SSA offers two types of disability programs.

1. Social Security Disability Insurance (SSDI)
 - You must have worked jobs in which you paid Social Security taxes.
 - You must meet the SSA's definition of disability.
 - People approved for SSDI are eligible for Medicare after a two year waiting period.
 - SSDI is not health insurance.
2. Supplemental Security Income (SSI)
 - SSI is a needs-based program. You must prove your income and assets are below the limit.
 - You do not need work credits to qualify.
 - You must meet the SSA's definition of disability.
 - SSI is also available for individuals over 65 without a disability who meet the financial need requirement.
 - People approved for SSI automatically qualify for Medicaid.
 - In some cases, you may qualify for both SSDI and SSI.
 - SSI is not health insurance.

To check your eligibility for all SSA programs, use the Benefit Eligibility Screening Tool (BEST) at <http://www.benefits.gov/ssa>. Based on your answers, this tool lists benefits you may be eligible to receive. This tool does not guarantee approval.

For more information you can also call the Social Security Administration at (800) 772-1213.

Advanced Directives

Advanced directives or an advance care plan are legal papers. These papers tell your family and healthcare team your medical wishes. They are used in case you cannot make a medical decision. For example, if you are unconscious, your healthcare team and family will follow your advanced directives.

Advanced directives may differ by state. Your hospital or treatment center can give you the forms. Be sure to give your family members and healthcare team a copy of your advanced directives. If you change your mind about the kind of treatment you prefer, you can change your advanced directives.

Advanced directives may include living wills, medical power of attorney, or DNR orders. Here is a list of things to consider for your advance care plan:

- Life support or use of equipment such as dialysis machines, ventilators, and respirators
- DNR (Do Not Resuscitate)
 - DNR orders tell your healthcare team not to do CPR if your heart or breathing stops.
 - CPR (cardiopulmonary resuscitation)
 - First aid used when your heart or breathing stops. CPR can include chest compressions, electric shock, or medication.
- DNI (Do Not Intubate) orders
 - DNI orders tell your healthcare team not to put a tube through your nose or mouth to help you breathe.
- Artificial nutrition and hydration
 - If you are unable to eat or drink, your healthcare team will provide you with nutrition and fluids through an IV or feeding tube.
- Treatment of new conditions
- Organ and tissue donation
- Medical Power of Attorney
 - Medical power of attorney lets you name another person, such as a family member or close friend, who can make decisions about your medical care if you cannot.
 - This may also be called a healthcare proxy, appointment of healthcare agent, or durable power of attorney.
 - Most states will not allow anyone on your healthcare team to be your medical power of attorney.

A cancer diagnosis can be a stressful time. It may be scary to consider these issues before you are very sick. However, it is important to think about these issues early. You will not want to deal with them when you are feeling very ill.

Palliative and Hospice Care

At some point in your cancer journey, you may need to consider palliative care or hospice. Palliative care is a treatment that helps relieve pain and symptoms but does not provide a cure. Palliative care can be used along with your prescribed cancer treatment. Hospice is a type of palliative care. Specifically, hospice is end-of-life care. Both palliative care and hospice

aim to improve quality of life. Talk with your healthcare team about what is best for you. Below you will find more information about hospice and palliative care. Use the questions at the end to guide talks with your healthcare team.

- **Palliative care**

- Palliative care helps relieve pain and symptoms but does not provide a cure.
- You may use palliative care at any point during your cancer journey. A patient does not have to be terminal to receive palliative care.
- Palliative care can be combined with other forms of treatment.
- You may use palliative care to manage side effects from treatment.
- Some forms of palliative care may be covered by Medicare, Medicaid, or other insurance plans. Often, costs for palliative care fall on the individual.

- **Hospice**

- Hospice is a type of palliative care.
- Hospice is end-of-life care. Terminal patients with a life expectancy of six months or less often use hospice.
- Hospice care is not usually given at the same time as other curative treatments. Hospice is given after treatment options have been exhausted.
- Medicare pays for all hospice costs. In most states, Medicaid pays for hospice costs. Most other insurance plans have hospice benefits.

- **Questions to Ask Your Healthcare Team**

- Should I consider palliative care now or in the near future?
- Will my insurance cover my palliative care?
- How long can I get palliative care?
- Where will I get my palliative care?
- Can I still do treatment for my illness while doing palliative care?
- Should I consider hospice care now or in the near future?
- Will insurance cover my hospice care?
- If my life expectancy is longer than six months, can I still get hospice care?
- Can I get hospice care in my home?
- Who will be caring for me? Will they be doctors, nurses, social workers, or home health aides?
- What legal issues such as advanced directives, living wills, or medical power of attorney should I think about?

Emotional Support Programs

A cancer diagnosis can make you feel anxious and depressed. This is normal. It may help to talk to someone. It can be especially helpful to connect with other survivors and patients. You are not alone in your fight. You may find it helpful and inspirational to hear others' stories. You may also be able to help someone else by sharing your story. Here is some information about available emotional support:

- **Support groups**
 - Connects you with a group of people in a similar situation
 - Support groups meet on a regular basis.
 - Support groups meet online, over the phone, or face-to-face.
 - Ask your healthcare team about local support groups.
 - Licensed social workers or other medical professionals facilitate most support groups.
 - Support groups can be for current cancer patients, survivors, or family members.
 - Some groups are defined by diagnosis, age, or sex.
 - A support group is meant to help you through your cancer journey. The first support group you go to may not be the right fit for you. If you do not enjoy the first group, try another.
 - Where can you find support groups?
 - Your hospital or treatment center
 - Your local American Cancer Society chapter
 - Visit cancer.org or call (800) 227-2345.
 - Cancer Support Community
 - This includes The Wellness Community and Gilda's Club.
 - Visit cancersupportcommunity.org or call (888) 793-9355.
 - CancerCare
 - Visit cancercare.org or call (800) 813- HOPE (4673).
- **Connect with a Fellow Survivor**
 - One-on-one partnering programs will match you with a fellow cancer survivor. This person may have a similar diagnosis and may be finished with treatment.
 - These allow for a more personal connection.
 - Most programs are for family members as well as patients.
 - Usually these programs are run through phone or email.
 - How can you connect with a fellow survivor?
 - Imerman Angels
 - Visit imermanangels.org or call (877) 274-5529.
 - Cancer Hope Network
 - Visit cancerhopenetwork.org or call (800) 552-4366.
- **Individual Counseling from a Medical Professional**
 - If you find it difficult to function in your daily life because of anxiety or depression, you may need individual counseling from a medical professional.
 - Ask your healthcare team for a recommendation.
 - Visit CancerCare for more information.

Survivorship

Even after treatment ends, your cancer journey continues. Many cancer survivors refer to the time after treatment ends as the “new normal.” It may take you a while to readjust to life after treatment. You may wish to make changes in your nutrition and lifestyle to help prevent recurrence. Use these sections to help you navigate your “new normal” and to promote wellness during survivorship.

Follow-Up Care

Follow-up care after completing lung cancer treatment is very important. Your healthcare team will help you manage long term side effects and watch for any changes such as the cancer spreading or coming back. Here are some things to remember about follow-up care:

- Always go to your follow-up appointments.
 - You will probably have follow up exams every 3-6 months following treatment depending on the stage of your cancer.
 - After some time goes by without a recurrence, your healthcare team will probably recommend checkups only once or twice a year.
 - Be sure to tell your healthcare team if you notice any changes in your health.
- Follow your recommended screening schedule.
 - Your screening schedule will depend on the type and stage of your cancer and other aspects of your medical history.
 - Typically a few months after treatment your doctor will order a computerized tomography (CT) scan to take pictures of your lungs to set a new baseline.
 - Your doctor will use this image to compare with future scans to check for recurrence.
 - Your doctor will probably recommend a CT scan every 6 to 12 months in addition to regular checkup appointments.
 - At most appointments with your oncologist you will have a lab visit first to do blood tests. Your oncologist uses these blood tests to check for tumor markers, protein levels, blood cell counts, and general health.
- If you change your primary care physician, make sure your new doctor has all your medical records and history.
- Tell your doctor about any side effects.
 - Some side effects occur after treatment ends. Let your healthcare team know of any and all changes so they can help you manage them effectively.
- Keep your health insurance if at all possible.
 - Follow-up care, especially imaging, can be very expensive if you do not have health insurance.

Smoking Cessation

Why is smoking bad?

Smoking increases your risk for heart disease, stroke, and emphysema. Smoking also increases your risk for a number of cancers, including:

- Lung
- Oral
- Nasal and Paranasal
- Throat
- Esophageal
- Bladder
- Kidney
- Pancreatic
- Ovarian
- Cervical
- Colorectal
- Stomach

If you already have a cancer diagnosis, smoking can increase your risk of recurrence.

Why should I quit?

Quitting smoking has almost immediate benefits. Here are some of the benefits of quitting smoking:

| Time Since Quitting | Benefit |
|---------------------|---|
| 20 minutes | Blood pressure and heart rate drop |
| 12 hours | CO ₂ levels in blood stream return to normal* |
| 3 months – 9 months | Circulation and lung function improve |
| 1 year | Risk of heart disease cut in half |
| 5 years | Risk of mouth, throat, esophageal, and bladder cancer cut in half |
| 10 years | One-half as likely to die from lung cancer, and risk of laryngeal and pancreatic cancer decreases |
| 15 years | Risk of heart disease is the same as a non-smoker's |

Source: smokefree.gov

*If the CO₂ (carbon dioxide) levels in your bloodstream are high, your lungs have to work harder to return these levels to normal. When you exhale, CO₂ leaves your body.

How can I quit?

The first step is to talk to your healthcare team about the best quitting strategies for you.

With smoking, your body builds up a dependency on nicotine, a chemical found in tobacco. As you quit smoking, your body will go through withdrawals from nicotine. Some common symptoms and side effects of withdrawal include:

- Cravings
- Feelings of sadness
- Stress and anxiety
- Difficulty sleeping
- Restlessness
- Weight gain

Here are some tips to help you manage the side effects of withdrawal:

- With your doctor's permission, you may wish to use nicotine replacement therapies (NRT).
 - NRTs give you a small, decreasing dose of nicotine without smoking to help you wean yourself off nicotine and minimize withdrawal symptoms.
 - NRTs come in many forms such as gum, lozenges, inhalers, and patches.
 - Some NRTs are available without a prescription, but always talk to your healthcare team first.
 - Other prescription medications are available to help you quit. Check with your doctor to see if these may be right for you.
- Tell your friends and family that you are trying to quit.
 - They can support you and hold you accountable.
 - Ask a friend or family member you trust to be your "sponsor." If you feel the urge to smoke, you can call them to talk until the craving passes.
 - If your friends or family members smoke, ask them not to smoke around you and not to offer you cigarettes. This will only make achieving your goal harder.
- Join a support group or online support group to connect with other people trying to quit.
- Change your routine.
 - For example, if you always have a cigarette with your coffee, find a new morning routine. Try watching the news with your coffee, or replace your cigarette with a healthy snack.
- Know your triggers and have a plan.
 - What triggers your cravings—stress, food, other people smoking?
 - Avoid triggers if at all possible.
 - If you encounter a trigger, have a plan to keep yourself from smoking such as chewing gum, counting to 10, or calling a friend.

- If you have a setback, don't be too hard on yourself. Get back on track as soon as possible. However, do not use a slip as an excuse to start smoking regularly again.
- Do not use other tobacco products or e-cigarettes as a replacement for smoking.
 - Other tobacco products can also increase your risk for cancer and diseases.
 - E-cigarettes have not been studied enough to know their safety. The chemicals inhaled with e-cigarette use may have their own risks.

Resources for Quitting

[Smokefree.gov](#)

Call **(800) Quit-Now** to connect with your state's helpline.

Survivorship Nutrition

Once cancer treatment is complete it is time to restore and rejuvenate the body by feeding it with the best foods for optimal nutrition. Nutrition status, physical activity, and body weight all play a role in preventing cancer recurrence. Here are some guidelines to follow while adopting a new lifestyle now that cancer treatment is over.

Eat a wide variety of colors of fruits and vegetables every day.

- Fruits and vegetables contain phytochemicals that fight against cancer. Each color contains a different phytochemical. A wide variety of colors introduces more types of these cancer fighting chemicals into the body.
- Choose organic varieties when available to limit exposure to chemicals and pesticides. Wash all fruits and vegetables very well.
- Frozen fruits and vegetables are a great alternative to fresh and are easy to have available when time for shopping is limited.

Choose complex carbohydrates for increased energy.

- Select complex carbohydrates like whole grains (oats, wheat, brown rice, whole grain pasta) and whole fruits and vegetables.
- Complex carbohydrates are digested slowly due to their high fiber content, providing sustained energy.
- Choose grain products that have whole wheat or a whole grain flour listed as one of the first 3 ingredients.
- Avoid highly processed and refined grains (white enriched flour, baked goods, snack foods, sweets).
- A serving of whole grain is one slice of bread, $\frac{1}{2}$ cup of cooked rice or pasta, and $\frac{1}{2}$ cup of whole grain cold cereals and oatmeal.

Choose lean protein most of the time.

- Choose lean proteins that include beans, eggs, white meat chicken and turkey, and fresh fish (not farm raised). When available, select organic and locally farmed. Other good sources of protein are nuts, and tofu.
- Limit red meat to less than 18 ounces per week. Red meat includes beef, pork, and lamb. For reference, one ounce of meat contains 7 grams of protein. To make sure that you are getting enough protein, aim to eat a source of protein at every meal.

Incorporate good fats into meals and snacks.

- Eliminate fried foods and eat foods that are high in omega-3 fatty acids such as avocados, fish, and nuts.
- Avoid trans fats and avoid foods containing partially hydrogenated oils.

Limit sweets and simple sugars. Avoid artificial sweeteners.

- Choose fruit to satisfy cravings for sweets. Sweets provide our body with empty calories and no nutritional value.
- Stevia is a plant-based natural sweetener that is an acceptable alternative to sugar, or artificial sweeteners like aspartame sucralose, and saccharin.

Drink plenty of water.

- Staying hydrated is essential to rejuvenating the body. Too much caffeine may lead to dehydration.
- Green tea and white tea are also good beverage options for staying hydrated.
- Aim for 64 ounces of caffeine free fluids per day. If you are not drinking any water, start slowly and gradually increase water intake.

Eat consistently throughout the day to avoid overeating.

- Five to six small meals per day eaten every 2-3 hours help to keep blood sugar levels more stable.
- Smaller, more frequent meals help with weight management by encouraging metabolic rate to increase.
- Smaller, more frequent meals allow for better absorption of nutrients.

Achieve and maintain a healthy body weight for your height.

- Eat healthy by following the guidelines on this handout.
- Consult with a registered dietitian to determine individual energy needs and a realistic goal weight.
- Monitor food intake and measure portion sizes.
- Begin to track food intake in a journal.

Exercise

- If not currently exercising, gradually work toward 45-60 minutes daily. This can be split up into 10 or more minute increments to make it more possible when time is a factor.
- Be realistic and start slowly. A regular exercise program may help to minimize stress and depression.
- Choose an enjoyable activity. Enlist a friend or relative as an accountability partner.

Nutrition Supplements

- Choose food first as the primary source for vitamin and minerals. Ask a registered dietitian for guidance on vitamins, minerals, and other nutrition supplements.
- Do not rely on supplements for cancer prevention.

Drink alcohol in moderation, if at all.

- Alcohol is a contributing factor to many types of cancer.
- Alcohol provides the body with calories but not any nutrients.

Fear of Recurrence

Many believe that once treatment ends, the cancer journey is over, but that's not the case. Many cancer survivors struggle with the fear of recurrence. What if my cancer comes back? What if my cancer spreads? For some, these fears can become overwhelming even years into remission. These fears are completely normal, but there are things you can do to try to manage them.

Take charge of what you can.

You may feel afraid because of the lack of control you have over the situation. To take back some control in your life, try making positive changes.

- Talk to a registered dietitian about developing a survivorship nutrition plan. Good nutrition can reduce your chance of recurrence and make you healthier all around.
- Start an exercise program. Exercising is not only good for your body; it is also good for your mind. Exercising releases endorphins, natural chemicals that make you feel happier. Many people also say exercising helps clear their minds and lower stress. Always talk to your doctor before starting any exercise program.
- Stay on top of your screenings and checkups. At the end of your treatment, work out a screening and checkup plan with your oncologist. What kind of scans or tests do you need? How often do you need them?

Take a deep breath.

If you feel yourself starting to get worked up, close your eyes, take a deep breath, and count to ten. This may seem like silly or old advice, but taking a second to gather your thoughts can make you feel a lot better.

Try meditation or visualization. Find a quiet, comfortable spot in your home. Take a few moments to yourself to breathe deeply and reflect on the positive things in your life. Think about some of your goals, even simple ones, and imagine yourself reaching them. In the rush of everyday activities, we sometimes forget to just breathe.

Find a hobby.

Hobbies can be a great source of entertainment and can also take your mind off of negative things. Try one of the hobbies listed below or make up one of your own. Find something that you enjoy and are passionate about.

- Knitting
- Cooking
- Painting
- Hiking
- Photography
- Writing
- Yoga

Volunteer.

Volunteering can be a worthwhile way to pass your free time and make a difference in your community. Is there a cause you are passionate about? Education, the environment, animals. To find a variety of volunteer opportunities in your neighborhood, visit VolunteerMatch.org or Volunteer.gov.

A quick word of caution: For some, volunteering for a cancer support organization may hit too close to home. Consider how it may affect you to be in this environment with constant reminders of your experience. You need to do what is best for you. If you are unsure how it may affect you, volunteer once before committing more time.

Talk about it.

You may find it helpful to talk to someone. It can be especially comforting to connect with other survivors. Hearing other survivors' stories can show you what you are feeling is normal, and you are not alone. You may also be able to help someone else by sharing your story. Here are some options for connecting with other survivors:

- Support Groups
 - Cancer Support Community hosts support groups around the country.
 - Visit cancersupportcommunity.org or call (888) 793-9355.
- Ask your healthcare team about other groups in your area or at your hospital.
- One-on-One Partnering Organizations
 - These organizations connect you with a fellow survivor. Usually the connections happen via phone.

- Imerman Angels
 - Visit imermanangels.org or call (877) 274-5529.
- Cancer Hope Network
 - Visit cancerhopenetwork.org or call (800) 552-4366.
- Survivor Retreats
 - Epic Experience offers outdoor adventure retreats to adults with a past cancer diagnosis. Activities are based on the season.
 - Visit epicexperience.org or call (855) 650-9907.
- First Descents hosts retreats for young adults (18-39) to learn to rock climb, kayak, or surf.
 - Visit firstdescents.org or call (303) 945-2490.

Educate yourself.

Knowledge is power. Talk to your oncologist about your fear of recurrence. Here are some questions to ask:

- What are my chances of recurrence?
- What can I do to lower my risk?
- What signs do I need to look for to know if my cancer has returned?

Armed with the answers to these questions you can better understand your situation and minimize fear of the unknown.

If you do face a recurrence, remember that every survivor's situation is different. With clinical trials and new medications, there may be many treatment options available. Not all recurrences are equal.

Know what triggers your emotions, and avoid it.

Do movies or TV shows that address cancer upset you? Don't watch them. Does the sight of the sweatshirt you wore on treatment days bother you? Throw it out or donate to a clothing bank. Do you get especially anxious around scan days? Ask a friend to go to lunch with you.

If you can identify the objects or activities that trigger negative feelings, you can make a special effort to avoid them.

Don't dismiss your fear.

It is normal and understandable to fear recurrence. A cancer diagnosis is a scary thing. If you've already been through treatment, you know how difficult it can be. Don't be too hard on yourself. It is okay to be scared. It is okay to be upset. Admitting your feelings can be an important first step to managing your emotions.

Remember what works for other people may not work for you. Try a few different things. Once you find an activity that makes you feel at ease, be sure to include it in your schedule. Take time for yourself.

If your fear of recurrence becomes overwhelming or interferes with your day-to-day activity, talk to your doctor. You may need individual counseling from a medical professional. Your doctor can make a recommendation for you.

Immunizations for Cancer Survivors

What are immunizations?

Immunizations help your body build a resistance to specific diseases. Most immunizations work by introducing a small, safe amount of the disease to your immune system. This way if you are ever exposed to the disease, your body's immune system already knows how to fight it. Most immunizations are vaccines given as a shot or series of shots.

Many people receive one-time immunizations when they are children for diseases such as chickenpox. Some immunizations, such as tetanus shots, need boosters to keep them effective. Other immunizations, such as flu vaccines, need to be received annually.

What are the risks of vaccines?

As with any treatment or medication, vaccines can cause side effects. Each vaccine carries risk for different side effects. Most side effects are minor such as pain where you receive the shot and mild fever. There are risks for serious side effects, but vaccines are carefully tested for safety. In most cases, the great benefits of vaccines outweigh the minor risks. To learn more, visit the Centers for Disease Control and Prevention (CDC) at www.cdc.gov. Talk to your healthcare team about the risks and benefits of vaccines to determine what is best for you.

I'm a cancer survivor; what immunizations do I need?

For cancer survivors, immunizations are especially important because cancer treatments weaken the body's immune system. Below is the immunizations schedule recommended by the CDC for people with weakened immune systems, such as cancer survivors.

| Vaccine | Schedule |
|--|--|
| Influenza (flu) | Annually |
| Tetanus, diphtheria, pertussis (Td/Tdap) | One Tdap vaccine with Td booster every 10 years. |
| Varicella (chickenpox)* | Should NOT get vaccine** |
| HPV vaccine (women and men)* | 3 doses through age 26 |
| Zoster (shingles) | Should NOT get vaccine** |
| Measles, mumps, rubella (MMR)* | Should NOT get vaccine** |
| Pneumococcal (PCV13) | 1 dose |
| Pneumococcal (PPSV23) | 1 or 2 doses |
| Meningococcal | 1 or more doses |

| | |
|--------------|---------|
| Hepatitis A* | 2 doses |
| Hepatitis B* | 3 doses |

Source: Center for Disease Control

* These vaccines are only for adults who did not get them as children.

** If you received these vaccines before your cancer diagnosis, there is no harm done. In fact, it is good that you are protected from these diseases. If you have not received these vaccines, it is not safe to receive them with a weakened immune system.

If you are planning to travel outside of the United States, check the recommended vaccines for where you are going. You may need additional immunizations.

Always consult with your oncologist before receiving any vaccine.

What else do cancer survivors need to know about immunizations?

Influenza (Flu)

If you are a cancer survivor, the CDC recommends getting the annual flu vaccine. However, only get the flu shot; do NOT get the nasal spray version. The nasal spray version contains live viruses so it is not safe for people with a compromised immune system.

Caregivers or anyone living with a cancer survivor should also receive the flu vaccine to lower the risk of infection.

Pneumococcal

There are two pneumococcal vaccines: PVV13 and PPSV23. For cancer survivors, doses of each may be needed. Ask your healthcare team about the best pneumococcal schedule for you.

Meningococcal, Hepatitis A and B

These vaccines are recommended for adults with certain jobs, lifestyles, or other health factors that increase their risk of these diseases. Your healthcare team can tell you if you are at a higher risk.

Varicella, Zoster, and MMR

As shown in the chart above, people with a compromised immune system, such as cancer survivors currently or recently out of treatment, should NOT receive these vaccines.

Worksheets

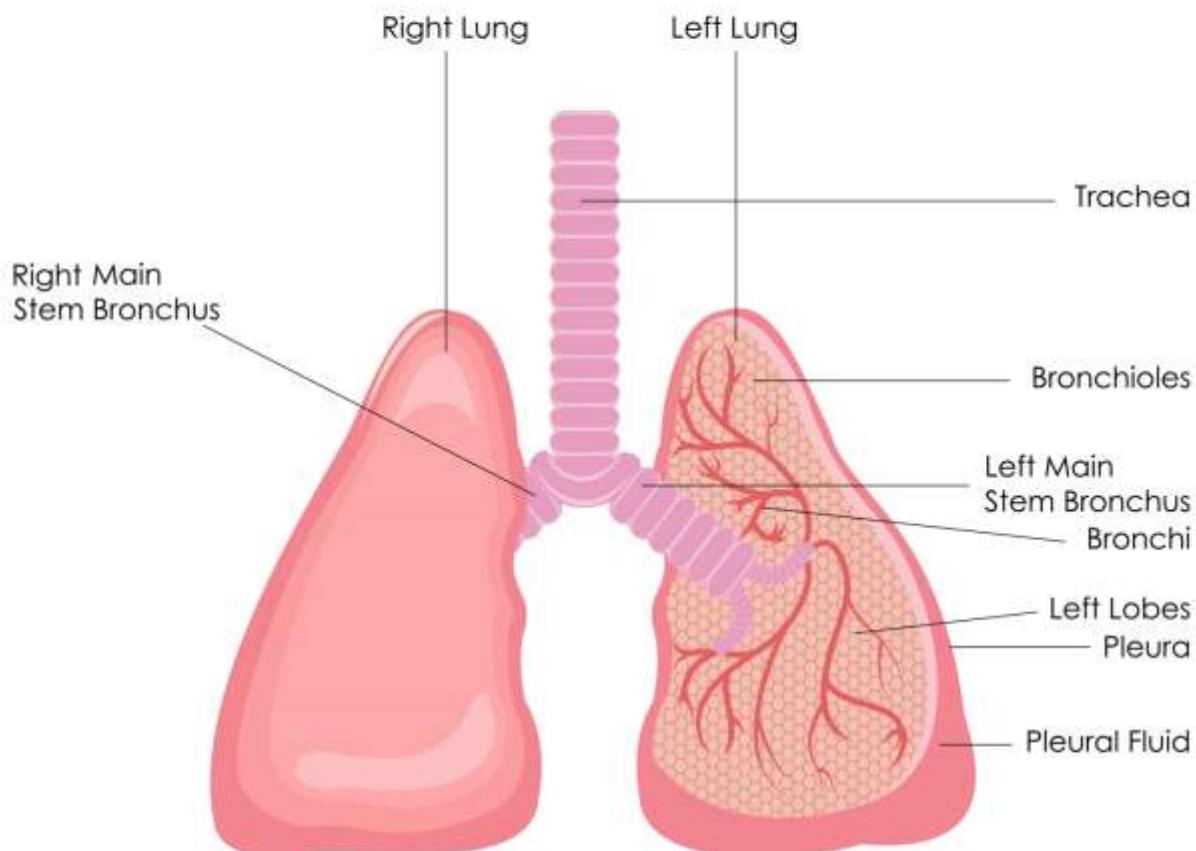
The following worksheets can help you organize your life and keep track of all your information during your cancer journey. If you visit, My PearlPoint at my.pearlpoint.org and sign up for a personalized dashboard, you can print as many worksheets as you need.

- My Diagnosis
- Questions for Your Healthcare Team
- My Medical History
- Immunizations Records
- Appointment Notes
- My Healthcare Team Contact List
- Treatments and Side Effects Logs
- Laboratory Flow Sheet
- Budgeting Worksheets
- Calendars

My Diagnosis

Your healthcare team will give you details about your cancer. Ask your healthcare team to fill out this form. *Note: Some questions to not apply to some cancers.*

Tumor location (ask your healthcare team to draw the location of your tumor):



Lungs

Tumor size and characteristics:

Stage:

Grade:

Genetic considerations:

| Mutation | Positive or Negative |
|----------|----------------------|
| EGFR | |
| ALK | |
| ROS1 | |
| KRAS | |
| Other | |

Metastasis:

Other information:

Questions for Your Healthcare Team

When you are diagnosed with cancer, you may feel overwhelmed with information. Ask your oncologist the following questions to make sure you have the answers you need.

What is my diagnosis?

What stage is my cancer? What is my prognosis?

What are my treatment options? What would you recommend?

Am I eligible for a clinical trial?

What are the long-term and short-term side effects of treatment? How will these affect my normal activities?

How can I manage these side effects?

How can I keep myself as healthy as possible during treatment?

Will I be able to have children? What are my options to preserve fertility?

Where can I find help with financial concerns?

Where can I find help with lodging or transportation?

What will my follow-up care plan include?

My Medical History

Your healthcare team will need to know your medical history so they can determine the care that is best for you. They may have specific forms for you, but this form will help you collect basic information you will need before your appointments.

Basic Information

Name:

Birthdate:

Phone Number(s):

Address:

Social Security Number:

Employer:

Spouse's Name:

Spouse's Phone Number:

Emergency Contact:

Emergency Contact's Phone Number(s):

Primary Care Physician

Primary Care Physician:

Practice:

Phone Number:

Address:

My Medical History (continued)

Past Medical History

In the past, have you been diagnosed with any of the following?

Circle all that apply.

Anemia Arthritis Asthma Blood Clots Cancer Colitis Concussions Depression
Diabetes Heart Disease Hepatitis High Blood Pressure High Cholesterol HIV/AIDS
Impaired Mobility Irritable Bowel Syndrome Kidney Disease Liver Disease
Lung Disease Migraines Other STDs Urinary Tract Infections Other _____

List any past surgeries, imaging, hospitalizations, or other major procedures you've had in the past.

| Procedure | Description | Date |
|-----------|-------------|------|
| | | |
| | | |
| | | |
| | | |
| | | |
| | | |

My Medical History (continued)

Family Medical History

Has anyone in your family experienced any of the following? If so, who?

| | Relation |
|---------------------------|----------|
| Asthma | |
| Blood Clots | |
| Cancer (List Cancer Type) | |
| Depression | |
| Diabetes | |
| Heart Disease | |
| High Blood Pressure | |
| High Cholesterol | |
| Blood Clots | |
| Low Blood Pressure | |
| Kidney Disease | |
| Lung Disease | |
| Irritable Bowel Syndrome | |
| Liver Disease | |
| Colitis | |
| AIDS/HIV | |
| Other | |
| Other | |

Do you know any other pertinent family medical history?

My Medical History (continued)

Current Medications and Allergies

Please list all current medications, including any vitamins, supplements, or over-the-counter medications.

List all allergies.

My Medical History (continued)

Current Issues

Are you experiencing any of the following? Circle all that apply.

Bloating Constipation Diarrhea Dry Mouth Fatigue Gas High Blood Sugar Nausea
Pain Unable to Sleep Vomiting Weight Gain Weight Loss Other_____

Please describe any problems you are having.

Are you able to go about daily activities normally? Yes or No

Do you feel like your normal self? Yes or No

What questions do you have for the doctor?

My Medical History (continued)

Insurance Information

Be sure to take all insurance and prescription cards with you to your appointment.

Insurance Provider:

Policy/ Group #:

Policy Holder's Name:

Patient's Relation to Insured:

Secondary Insurance Provider:

Account Number:

Policy Holder's Name:

Patient's Relation to Insured:

My Immunization Record

For cancer patients, immunizations are especially important because cancer treatments weaken the body's immune system. Immunizations help your body build a resistance to specific diseases. Most immunizations work by introducing a small, safe amount of the disease to your immune system. This way if you are ever exposed to the disease, your body's immune system already knows how to fight it. Ask your healthcare team which immunizations you need. Use this chart to keep track of your immunization record.

| Vaccine | Date Given | Next Date Due | Comments/Reactions |
|---------------------------|------------|---------------|--------------------|
| Tetanus | | | |
| Diphtheria | | | |
| Pneumococcal Influenza | | | |
| MMR | | | |
| Hepatitis B | | | |
| Hepatitis A | | | |
| Influenza (Flu) | | | |
| Other | | | |
| Other | | | |

Appointment Notes

Take notes on all the new information your healthcare team provides at appointments. Write down any new instructions, medications, treatment plans, etc., so you can reference them later.

Date: _____ Doctor: _____

Questions: _____

Notes: _____

Plan: _____

List lab work, imaging, or other tests.

| Test & Date | Purpose | Results |
|-------------|---------|---------|
| Test: | | |
| Date: | | |
| Test: | | |
| Date: | | |
| Test: | | |
| Date: | | |

Next Appointment: _____

My Healthcare Team Contact List

Your healthcare team may include many different doctors, nurses, and specialists. Keep all your important contact information in one easy-to-find place.

| | Name | Contact Info |
|----------------------|------|---|
| Caregiver | | Phone: Phone: Fax: Email: Address: |
| Primary Care Doctor | | Phone: Phone: Fax: Email: Address: |
| Medical Oncologist | | Phone: Phone: Fax: Email: Address: |
| Radiation Oncologist | | Phone: Phone: Fax: Email: Address: |

My Healthcare Team Contact List (continued)

| | Name | Contact Info |
|------------------------|------|---|
| Surgeon | | Phone: Phone: Fax: Email: Address: |
| Nurse Navigator | | Phone: Phone: Fax: Email: Address: |
| Hospital | | Phone: Phone: Fax: Email: Address: |
| Pharmacy | | Phone: Phone: Fax: Email: Address: |

My Healthcare Team Contact List (continued)

| Name | Contact Info |
|--------------------|---|
| Home Health | Phone: Phone: Fax: Email: Address: |
| Physical Therapist | Phone: Phone: Fax: Email: Address: |
| | Phone: Phone: Fax: Email: Address: |
| | Phone: Phone: Fax: Email: Address: |

Treatments and Side Effects Log

Keeping track of your treatments, medications, side effects, and overall well-being is very important during your cancer journey. How your nutrition, activities, and medications affect the way you feel can provide insight for you and your healthcare team.

Date(s)/Week: _____

Treatments or procedures:

Include specific dates, descriptions, and medications given.

Foods Eaten:

| Breakfast | Lunch | Dinner | Snacks |
|-----------|-------|--------|--------|
| | | | |
| | | | |
| | | | |
| | | | |
| | | | |
| | | | |
| | | | |

Activity or Exercise:

| Activity | Duration |
|----------|----------|
| | |
| | |
| | |
| | |
| | |
| | |
| | |

Treatments and Side Effects Log (continued)

Medications/ Vitamins/ Supplements:

Current Weight: _____ Physical Well-Being*: _____ Emotional Well-Being*: _____

*On a scale of 1-10. 10 = feeling your best. 1= feeling your worst.

Treatments and Side Effects Log (continued)

Side Effects:

Record all side effects experienced by checking mild, moderate, or severe. If none, leave blank.

| Side Effect | Mild | Moderate | Severe |
|--|------|----------|--------|
| Change in taste and smell | | | |
| Constipation | | | |
| Diarrhea | | | |
| Difficulty swallowing | | | |
| Dry mouth | | | |
| Fatigue | | | |
| Feeling full quickly | | | |
| Gas and bloating | | | |
| Hair loss | | | |
| Lactose intolerance | | | |
| Loss of appetite | | | |
| Lymphedema | | | |
| Nausea | | | |
| Neuropathy | | | |
| Pain | | | |
| Skin changes (blisters, rashes, itchy, etc.) | | | |
| Sore mouth, throat, or tongue | | | |
| Weight loss | | | |
| Weight gain | | | |

For help managing side effects, download PearlPoint's new Cancer Side Effects Helper app to your smart phone.

Notes:

To keep track of this information online, visit *My PearlPoint* (my.pearlpoint.org) to create a personalized dashboard. On your dashboard, you can virtually track your well-being and save notes on your progress.

Laboratory Flow Sheet

Your healthcare team monitors the effects and toxicity of chemotherapy treatments by watching your Complete Blood Count and Differential (CBC) results. These ranges are listed on the report your doctor receives after routine blood work. Use this report or ask your healthcare team to help you fill out the sheet below so you can monitor your CBC.

If you notice a change in levels, ask your healthcare team for an explanation. Lab work will be ordered for your needs. Lab work may vary slightly between males and females and between different labs.

| | Lab Values | | | | | | | |
|--------------|------------|--|--|--|--|--|--|--|
| Date | | | | | | | | |
| Weight | | | | | | | | |
| CBC | | | | | | | | |
| WBC | | | | | | | | |
| ANC | | | | | | | | |
| HGB | | | | | | | | |
| HCT | | | | | | | | |
| PLT | | | | | | | | |
| RBC | | | | | | | | |
| MPV | | | | | | | | |
| MCV | | | | | | | | |
| MCH | | | | | | | | |
| MCHC | | | | | | | | |
| RDW | | | | | | | | |
| Differential | | | | | | | | |
| Other | | | | | | | | |
| | | | | | | | | |
| | | | | | | | | |
| | | | | | | | | |
| | | | | | | | | |
| | | | | | | | | |
| | | | | | | | | |

Lab Reports and Terminology

Complete Blood Count and Differential

Your WBC, RBC, HGB, HCT, PLT, and MVP will be monitored throughout the course of your treatment. These lab results give important information about how your body is affected by the chemotherapy.

WBC: white blood cells or leukocytes. White blood cells help the body to fight infections. There are several different types of white cells that have different functions. The WBC is the total of all the white cells counted.

RBC: red blood cells. These are also called erythrocytes or corpuscles. Immature red blood cells are called reticulocytes. RBCs carry oxygen from the lungs to the tissues of the body.

HGB: hemoglobin. Hemoglobin is the pigment of the red blood cells that actually carries the oxygen.

HCT: hematocrit. This is the percentage of RBCs in the volume of the whole blood in your body. This is also called packed cell volume or PCV.

PLT: platelets or thrombocytes. These cells help the blood to form a clot when your body has had a trauma or is bleeding.

MCH, MCHC, MCV, RBC, HCT, HGB all give us information in the diagnosis of anemia. Anemia is defined as a lack of the proper amount of red blood cells.

MVP: mean platelet volume. This is the average volume of platelets. A high MPC means there is the presence of larger platelets. A low MPV indicates the platelets are smaller than normal.

MCV: mean corpuscular volume. This is the calculation of the average volume of the RBC and is determined by the hematocrit count divided by the RBC count.

MCH: mean corpuscular hemoglobin. This is the calculation of the average weight of Hgb of each RBC. This is determined by the hemoglobin divided by the RBC.

MCHC: mean corpuscular hemoglobin concentration. This number tells us the concentration of hemoglobin in an average RBC. It is calculated by dividing hemoglobin by hematocrit.

RDW: red cell distribution width. This is the numerical expression of the degree of variation in the volume of the population of red blood cells. Normally, as new normal sized cells are produced, the RDW increases.

Differential: a differential count calculates the total white blood cells and categorizes their different types. The differential is reported as a percentage and an absolute number by type of cell.

Other Terminology

Granulocyte: white blood cells with a grainy appearance under a microscope. Neutrophils, eosinophils, and basophils are all granulocytes. Neutrophils are further classified as either bands or segs. This defines the level of maturity of these cells. These cells fight infection.

Polymorphonuclear leukocytes: also called PMNs or Polys. These refer to granulocytes which are neutrophils, eosinophils, and basophils. The name means “possessing a nucleus (or center) consisting of many parts or lobes.” This is another descriptive name for white blood cells.

Blast, myelocyte, metamyelocyte, progranulocyte: these are immature WBCs that are not normally in the peripheral blood circulation.

ANC: absolute neutrophil count. Neutrophils are white blood cells that help the body fight infection. This number is used to monitor neutropenia and the effects of chemotherapy and colony stimulating factors.

Budgeting Worksheets

| Sources of Income: | Expected: | Actual: |
|---|-----------|---------|
| Salary | | |
| SSI/SSDI | | |
| Employment Benefits: Short-Term Disability | | |
| Investments | | |
| Total: | | |

Have you had stop working due to your diagnosis? Have you considered applying for Social Security Disability Insurance?

| Monthly Expenses: | Expected: | Actual: |
|---|-----------|---------|
| Mortgage/Rent | | |
| Energy Bill/ Gas Bill | | |
| Water Bill | | |
| Groceries | | |
| Credit Cards | | |
| Car Payment | | |
| Gasoline | | |
| Loans | | |
| Home/Cell Phone | | |
| Cable | | |
| Housecleaning/Landscaping | | |
| Child Care | | |
| Insurance Premiums (health, life, home, etc.) | | |
| Clothing | | |
| School | | |
| Other Fees | | |
| Total: | | |

To reduce these costs, have you considered:

- Are you eligible for Food Stamps?
- Are you able to get assistance with your electric bill from Low Income Heating Energy Assistance Program (LIHEAP)?
- Is there a local free cleaning service in your area?
- Do you qualify for government assistance for housing, child care, or cell phone?

Budgeting Worksheets (continued)

| Medical Expenses: | Expected: | Actual: |
|--|-----------|---------|
| Insurance Deductible | | |
| Co-Payments | | |
| Prescriptions | | |
| Transportation (parking fees, flights, etc.) | | |
| Medical Supplies | | |
| Caregiving/Home Care | | |
| Supplements | | |
| Mental Health Care | | |
| Legal Services | | |
| Travel | | |
| Assistance Received: | | |

Possible sources of assistance:

- Have you considered a prescription assistance resource like NeedyMeds to reduce costs of prescriptions? Call **(800) 530-6987** or visit www.needymeds.org.
- Are you eligible for co-pay assistance based on cancer type?
- Can you reduce transportation and gas costs through resources like Road to Recovery or CancerCare?
 - o For Read to Recovery call the American Cancer society at **(800) 227-2345** or visit www.cancer.org.
 - o Call CancerCare at **(800) 813-HOPE (4673)** or visit www.cancercare.org.
- Is there a sliding scale resource in your area for mental health services?

| | Expected: | Actual: |
|--|-----------|---------|
| Total Income: | | |
| Total Expenses (Monthly/Medical): | | |
| After Expenses: (Total Income – Total Expenses = After Expenses) | | |

Budgeting Worksheets (continued)

Financial Assistance

When applying for financial assistance, keep track of your applications (as outlined in the chart below) to make sure you submit everything and hear back from the programs in a timely manner. You may have to follow up with some programs. If a program provides reoccurring support, you will want to make note of that in the frequency column.

Calendars

Month: _____

| Sunday | Monday | Tuesday | Wednesday | Thursday | Friday | Saturday |
|--------|--------|---------|-----------|----------|--------|----------|
| | | | | | | |
| | | | | | | |
| | | | | | | |
| | | | | | | |
| | | | | | | |
| | | | | | | |

Notes:

Calendars (continued)

Week: _____

| | |
|-----------------|--|
| Monday | |
| Tuesday | |
| Wednesday | |
| Thursday | |
| Friday | |
| Saturday/Sunday | |

Notes:

Appointment Details

Use this sheet to plan the details of your appointments in advance.

Date:

Time:

Location:

Provider:

Reason:

- Office visit
- Imaging
- Lab work
- Surgery
- Treatment
- Other _____

Transportation:

Lodging:

Notes:

Additional Resources

Additional Resources

My PearlPoint

At *My PearlPoint*, a website for adults impacted by cancer, you can find more educational, nutritional, and practical information to help you through your cancer journey. You can also find recipes, videos, survivor stories, and more. Create a personalized dashboard to save all the resources you find in one convenient location.

mypearlpoint.org

(877) 467-1936 X 101

guidance@pearlpoint.org

American Cancer Society

For more than 100 years, the American Cancer Society (ACS) has worked relentlessly to save lives and create a world with less cancer and more birthdays. Together with millions of our supporters worldwide, we help people stay well, help people get well, find cures, and fight back against cancer.

www.cancer.org

(800) 227-2345

National Cancer Institute

A collection of information run by the National Institutes of Health.

www.cancer.org

(800) 4-CANCER

Lungcancer.org

Lungcancer.org is a service of CancerCare®, a non-profit organization providing free, professional support—including counseling, support groups, financial assistance, educational workshops and publications—to anyone coping with lung cancer.

www.lungcancer.org

(800) 813-HOPE (4673)

Lung Cancer Alliance

Lung Cancer Alliance offers personalized support, information, and referral series at no cost to help patients, their loved ones, and those at risk.

www.lungcanceralliance.org

(800) 298-2436