

GO2 FOR LUNG CANCER

PATIENT SUPPORT

Navigating Non-Small Cell Lung Cancer: 360° of HOPE



6TH EDITION 2024

go2.org



**“The most comprehensive
and accessible resource available
for lung cancer patients.”**

— Arlene

Information presented in “Navigating Non-Small Cell Lung Cancer: 360° of Hope” is not intended as a substitute for the advice given by your healthcare team. We recommend you follow the instructions provided to you by your healthcare team and contact them with any questions or concerns.

*This handbook
is dedicated
to all those at risk for
and affected by
lung cancer.*

New versions of this handbook will be released electronically to ensure it includes the most updated information. Please visit go2.org for the most current edition.

GO2 Patient Support Services

Support for Everyone Impacted by Lung Cancer

Confronting lung cancer starts here. GO2 for Lung Cancer puts people living with and at risk for lung cancer at the center of everything we do. From finding care to staying informed and building your resources, we are your community. As your friends, your guides, your advocates, your support system, GO2 is your go-to.



Contact our HelpLine: 1-800-298-2436
email: support@go2.org
go2.org

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Acknowledgments

G02 for Lung Cancer is proud to publish the 6th Edition of "Navigating Non-Small Cell Lung Cancer: 360° of Hope" – with the most recent advancements and updates to help people today.

It is only through the generosity of our supporters that we are able to publish and republish this handbook and offer it free of charge to the lung cancer community. For this 6th edition, special thanks go to our generous sponsors.

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Dear Friends,

I was diagnosed with lung cancer at the age of 56. I was a wife, a mother, a grandmother, business woman, and one of the millions of Americans diagnosed with lung cancer. Faced with a 16% survival rate and following a 14-hour surgery, radiation and chemotherapy treatments that invaded my formerly predictable world, I survived lung cancer with a new purpose in life.

Despite losing three family members to lung cancer, when the doctor said, “You have lung cancer,” I realized I knew very little about the disease. So I searched for information. I was surprised by how difficult it was to find credible information on lung cancer, treatment options, and how to live with cancer. Everyone kept saying that “cancer is a journey” but no one could provide me with a roadmap. I was lost and I was only just diagnosed.

The 6th Edition of this handbook is the culmination of years of research, conversations with lung cancer experts and those diagnosed with the disease, my personal experience, and the experience of many others affected by lung cancer. It is designed to be a resource, whether you are newly diagnosed, facing a relapse, or a loved one of someone living with lung cancer. You will find questions

to pose to your doctor, detailed explanations of complex treatment options, and access to additional resources in the cancer community.

Lung cancer research is advancing rapidly. In recent years, we have seen new drugs brought to market, many clinical trials started across the nation, the advancement of biomarker testing, and even better side effect management. All of which is needed to improve lung cancer survivability. To this end, we are committed to keeping this handbook updated with the latest information available.

It is my greatest hope that this handbook is helpful to you throughout your cancer experience and that we have a positive impact on your life. If I can leave you with one message, it is that you are not alone. Visit our website, join one of our support groups, or simply call us—we are here to help you.

With love,

Bonnie J. Addario

Lung Cancer Survivor
GO2 for Lung Cancer
Co-founder and Board Member

“You are not alone.”
— Bonnie



Dear Friends,

You are not alone.

For over 25 years people from all backgrounds and in every stage of their cancer experience have turned to G02 for one-on-one assistance, supportive connections, treatment information, and finding the best care close to home. This is what inspired the development of this handbook – to provide comprehensive, understandable, real-time information as you navigate through this unknown called “lung cancer.”

Because we were founded by people who have received a lung cancer diagnosis, our work is – and will always be – dedicated to you. Our “north star” is to improve the lives of those at risk and diagnosed with this disease. We are dedicated to confronting lung cancer on every front, every day and for everyone.

I also hope you know that we are your voice for change as we advocate for greater resources and push for breakthroughs by advancing patient-centered studies, research, and clinical trials.

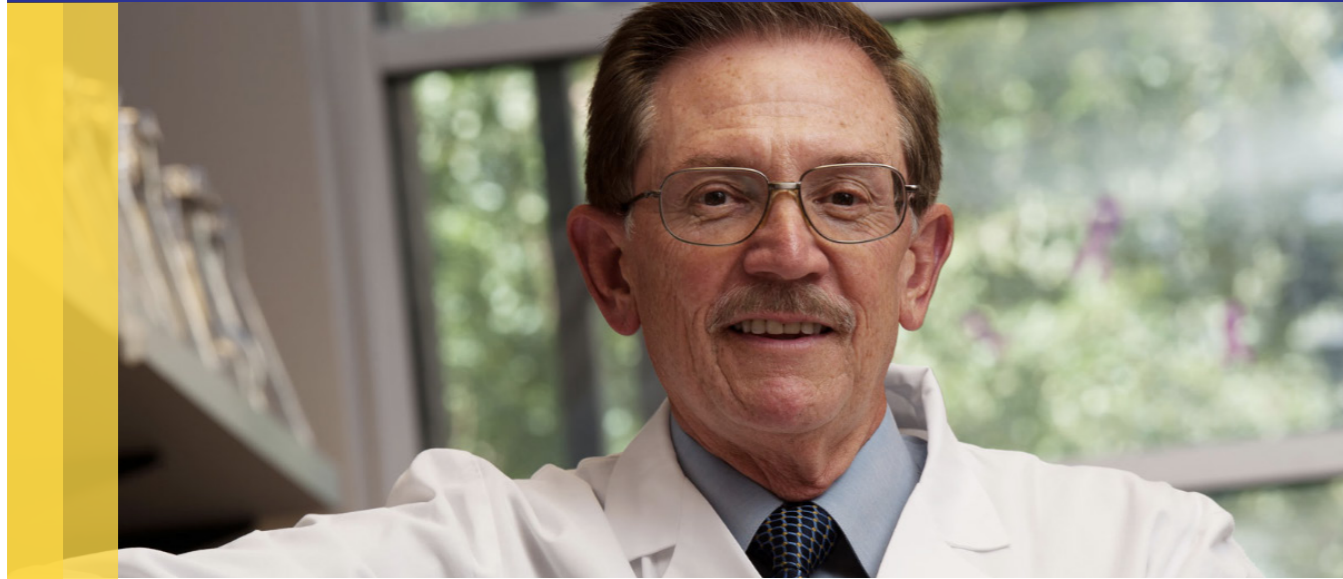
Please consider us your friends, your guides, your teachers, your advocates, and your support system. We are here for you. G02 is your go-to.

Sincerely,

A handwritten signature in black ink that reads "Laurie Fenton Ambrose". The signature is fluid and cursive.

Laurie Fenton Ambrose
President and CEO
G02 for Lung Cancer

“We are dedicated to confronting lung cancer on every front, every day and for everyone.”
— Laurie



Dear Patients,

I am part of a team of leaders in lung cancer who support this organization and its patients. GO2 is a lifeline for many of my own patients, and we are all here to help you and your family in every possible way.

If you are holding this handbook or reading it online, you've taken the best first step to connecting yourself with the most experienced clinicians worldwide and with an organization that provides the information you need on your cancer journey.

It's important to know that there are many, many kinds of lung cancer. It's complex. The way we approach lung cancer today, as opposed to 11 years ago, is through personalized medicine and individualized care because everyone is different.

The pace of advancement and learning new things in lung cancer has never been faster than it is today. More and more, lung cancer is a "poster child" for all the other cancers meaning we can take the information from the laboratory and

translate it into patient care. All of us need to have our running shoes on if we're going to keep up. Today, when something is found in the laboratory it takes less than a year to make its way to the clinic and right to the patient.

From the start, getting information must be part of your lung cancer journey. Most of my patients are informed before they come to see me. Sometimes they pick up bad information, but by and large they know a lot. Having knowledgeable patients making decisions together with their doctors, as a partnership, is a very positive approach for both patients and physicians. It is important for you to know that often, there are options, not always right or wrong answers.

You are a patient who now holds in your hands a resource that is your best first step toward understanding and living with lung cancer. This book will help you become educated, informed and, most importantly, you will find answers, directions, options, and HOPE.

What we want all our patients to do is live their lives every day to the fullest.

Warmly,

A handwritten signature in black ink that reads "David R. Gandara". The signature is fluid and cursive.

David R. Gandara, MD

Professor of Medicine at the University of California, Davis School of Medicine and Associate Director of Clinical Research, and Director of Thoracic Oncology UC Davis Comprehensive Cancer Center

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PATIENT SUPPORT

Connecting the Community

Helping the lung cancer community to develop **Connections**, gain **Awareness**, learn about the latest **Research**, easily access **Education** materials, and find personalized **Support** options.

Contact the GO2 HelpLine at 1-800-298-2436 or email support@go2.org.

- To connect with caring and highly trained staff who listen, answer your questions, and provide support
- To receive education for your specific cancer type – small cell lung cancer and non-small cell lung cancer
- To learn about or get started with any of our trusted services and programs

Phone Buddy Program

Be matched with a peer who's been there for support and information.

Gathering Hope Community Social

Connect with others and find hope, friendship, and support in this popular monthly virtual group event.

HealthUnlocked

Learn from others, find support, and stay up to date on events in this online message group.

Support Group Network

Find lung cancer support groups across the nation or learn how to start your own.

Events

Join a community-building event that raises awareness and much-needed resources to confront lung cancer.

LungMATCH Program

Talk one-on-one with our expert navigators to learn about lung cancer treatments and clinical trial options.

The Lung Cancer Living Room Expert Speaker Series

Learn from leaders in lung cancer care who share their knowledge and answer questions in this monthly event.

Free Education Materials

Receive information you can trust, that is easy to understand, and is focused on your lung cancer type.

"Your Community" Newsletter

Gain hope from survivors, learn from others, and find tips and tools for living better with lung cancer.

Visit go2.org/resources-and-support or contact the HelpLine to learn more.



Introduction

“I belong to GO2 for Lung Cancer. I host a run every year in Gainesville, Florida, because I want to help all patients have a fighting chance to be warriors in this battle.”

— Caren

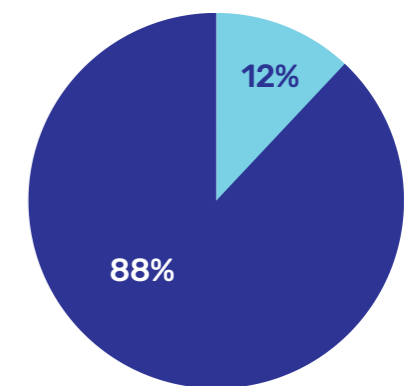


Introduction

According to the National Institute of Health, about 12 out of every 100 cancers diagnosed in the US are lung cancer.¹ It's most often diagnosed in people older than 65 years of age and both men and women have a similar risk of developing lung cancer.²

Over the past 5 years, the number of new cases has dropped and the number of people who survive the disease has increased. There have been many new treatments approved for lung cancer. Between 2018 and December 2022, the Food and Drug Administration (FDA) approved 41 new lung cancer therapies. That's huge progress!

More new treatments are being introduced all of the time that offer greater hope for those diagnosed with lung cancer. Ask your healthcare team about new treatments being studied or recently approved. One may be right for you!



- All other cancer types
- Lung cancer

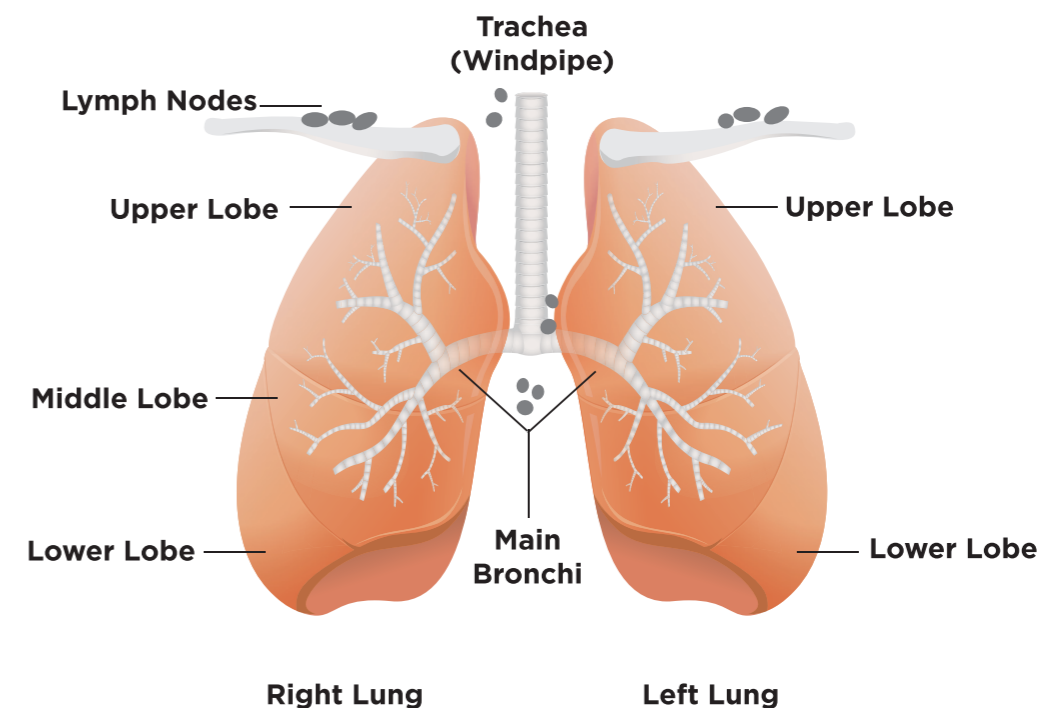
“Looking at the entire journey is overwhelming, but if you can move through one thing at a time, you’ll get through it. My mantra is, ‘Do not give up. Keep going.’”

— Tim



Lung Cancer Basics

Lung Cancer Basics



“My cancer center gave me this handbook as soon as I was diagnosed. I got hope after meeting several stage 4 lung cancer survivors and speaking with Bonnie at the World Conference.”

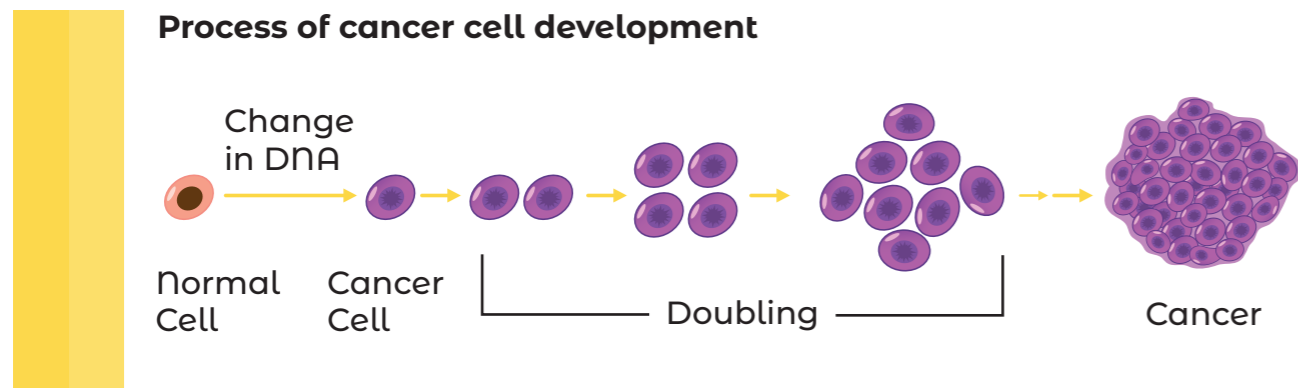
— Lisa

Learning about your body and about lung cancer, and understanding how it is diagnosed and what your treatment options are, empowers you to talk to your healthcare team. The human body is very complex. Just knowing the parts of your lungs and the basics of how they work can help you better understand lung cancer and treatments. This allows you to be more involved in making decisions about your care.

Your lungs are 2 sponge-like organs in your chest. The right lung has 3 sections, and the left lung has 2 sections. These sections are called lobes. When you breathe in, air comes in through your mouth and nose and travels to your lungs through the **trachea** (windpipe). The trachea divides into tubes called the **bronchi**, which enter the lungs and divide into smaller branches called **bronchioles**. At the end of the bronchioles are tiny air sacs known as **alveoli**. When the air you breathe travels down into these air sacs, oxygen crosses into the bloodstream and is carried through the rest of your body.³

How Cancer Develops

Cells are the basic building blocks of your body. Healthy cells grow, mature, die, and are then replaced by other healthy cells. Each cell has a map that controls how it grows and functions. This map is your **DNA (deoxyribonucleic acid)**. Sometimes, when your body makes new cells, mistakes happen and the DNA is damaged. When cells with damaged DNA divide or double, they make more damaged cells. Sometimes, these damaged cells stick together and form tumors. Tumors can be **benign** (not cancer) or **malignant** (cancer). The kind of cancer a person has is based on where the damaged cells begin to grow. If the damaged cells start to grow in the lung, it is called lung cancer.⁴



As your body sees cells that are unhealthy or damaged, it will usually try to destroy them. This protects you from germs and diseases. Cancer cells are hard for the body to find and destroy because they are seen as a part of your body. This allows cancer cells to double and grow. As cancer grows, the normal healthy cells in the lung are replaced by cancer cells.

Risk Factors

A **risk factor**⁵ is something that increases the chance of a disease occurring. Cancer risk factors increase the chance that your body will make a mistake when making new cells and create unhealthy, damaged cells. Some risk factors for lung cancer are things we can control, and others are not. A **carcinogen** is a general name for something that causes cancer.

Risk factors include:

- Smoking cigarettes now or in the past.
- Being exposed to radon gas. Radon is a gas that has no smell, taste, or color that occurs naturally in soil and rocks and seeps into the air through groundwater.
 - According to the National Cancer Institute (NCI),⁶ radon gas occurs in very low levels outdoors and is only a risk when breathing the gas in high levels in a closed space such as a building or home. One out of every 15 homes has radon levels that are too high. To learn how to get your home tested, call 1-800-55-RADON (1-800-557-2366) or send an email to Radon@ksu.edu.
- Having other lung illnesses such as emphysema, chronic obstructive pulmonary disease (COPD) or tuberculosis.
- Being exposed to chemicals such as arsenic, asbestos, beryllium uranium, and Agent Orange.
- Being exposed to secondhand smoke.
- Having a family history of lung cancer.

If you smoke, quitting is one of the most important things you can do to improve your health.

Even if you have lung cancer, quitting or cutting back on how much you smoke can improve how you respond to treatment. If you want to quit, your healthcare team can help you.

“Find out where to get the best treatment, who is the best person to see, and how to get a second opinion. You find peace of mind when you have the right care.”
— Heidi



Screening for Lung Cancer

Screening for Lung Cancer

Cancer screening is a test to check for disease in someone without any symptoms. The goal of screening is to find cancer early when it is easier to treat. Lung cancer screening results might also show if you have other conditions or diseases that need to be treated.

The US Preventive Service Task Force (USPSTF)⁷ states that adults ages 50–80 years who have a 20-pack-year smoking history and currently smoke or have quit within the past 15 years should have a lung cancer screening done every year. A 20 pack-year smoking history means smoking at least a pack a day for 20 years or 2 packs a day for 10 years, and so on.

Low-dose CT (LDCT) scans are the only proven method to screen for lung cancer. Chest x-rays should not be used for screening.

Lung Nodules

Lung cancer screening⁸ may find spots on the lung called nodules. Lung nodules are abnormal spots that may show up on your lung cancer screening scan or other imaging tests. Nodules can also be called lesions, coin lesions, growths, or solitary pulmonary nodules. Many people have lung nodules by age 50.

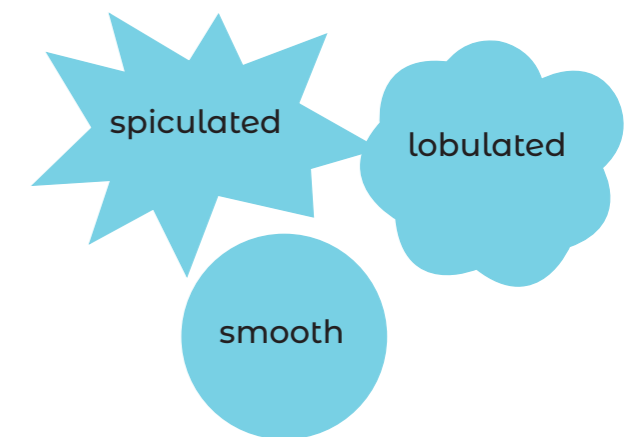
When a nodule is found, your healthcare team will look at it very closely. The way it looks tells your team how likely it is that the nodule could be cancer and guides them on the best way to manage it. Most lung nodules are not cancer,⁹ but lung

nodules that are large, look unusual, or change over time will need more testing. Your healthcare team can help you choose your best next step.

Lung nodules are described by the following:

- Margin
- Density
- Size
- Consistency

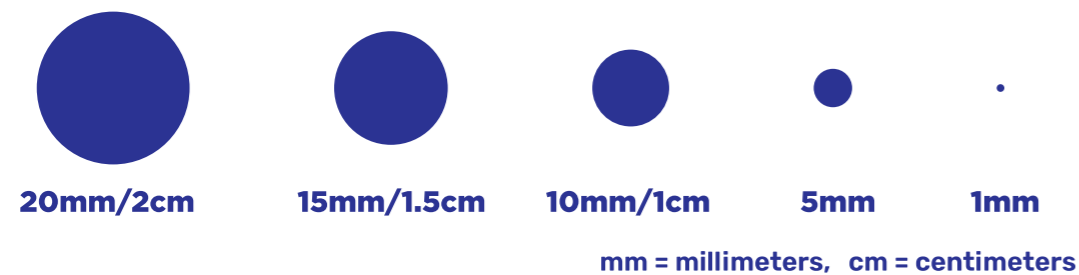
The **margin** is where the edges of the nodule touch normal lung tissue. The margins of many cancers are uneven, look spiky, and are sometimes called spiculated. Most nodules that are not cancer have smooth or rounded margins or look like many round nodules together – also called lobulated.



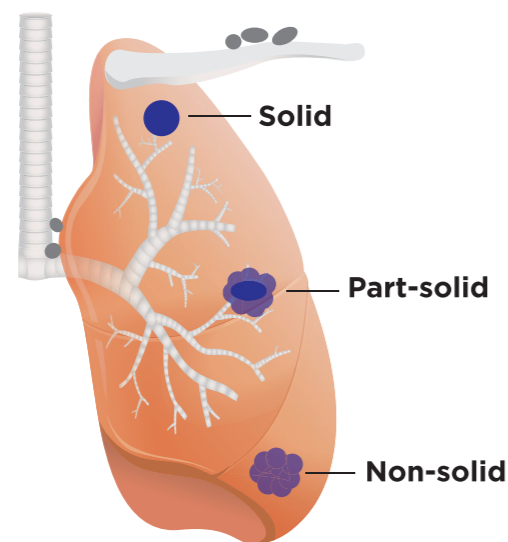
Density describes how compact or thick something is. A nodule is more dense than normal lung tissue and looks gray on a CT scan. Some nodules have pieces of calcium inside of them that look white, like bone. These are called calcified nodules and are less likely to be cancer.

Screening for Lung Cancer

Most nodules that are small in **size** are not cancer. If you have a nodule and you are at high risk for lung cancer, you may be asked to come back in a year or sooner for another screening test just to make sure the nodule hasn't changed. Smaller nodules are usually managed in this way, while larger nodules may need more testing. Nodule size may be listed as centimeters or millimeters, as shown below.



The **consistency** of a nodule can be solid or it may have a solid part or a hazy part around it. This is called a part-solid or semi-solid nodule. A nodule that is hazy with no solid parts is called a non-solid or a ground glass nodule (GGN) because it looks like ground glass.



Always contact your healthcare team if you have questions or concerns about the plan to manage a nodule that is found during screening.



Signs and Symptoms of Lung Cancer

Signs and Symptoms of Lung Cancer

It is important to know the signs and symptoms of lung cancer. A **sign** is something that can be seen by someone else; for example, a rash is a sign. A **symptom** is something that cannot be seen by someone else but must be described by the person; for example, a headache is a symptom. Early lung cancer may not have any signs or symptoms. As lung cancer progresses, signs and symptoms may develop.

Possible signs and symptoms of lung cancer may include:¹⁰

- A cough that doesn't go away
- Shortness of breath that is not caused by activity
- Wheezing that is not caused by an illness
- Coughing up blood
- Pain in the chest
- A hoarse voice or other change in the voice
- Feeling tired all the time
- Weight loss with no known cause
- Headaches
- Painful lumps in the neck, armpits, or groin

These signs and symptoms can be caused by other diseases and conditions and may not be lung cancer. However, you should visit your healthcare team right away if you have any of these signs and symptoms.



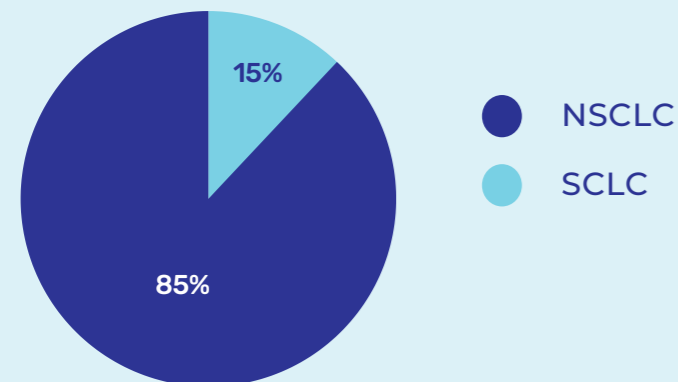
Types of Lung Cancer

Types of Lung Cancer

There are 2 main types of lung cancer:

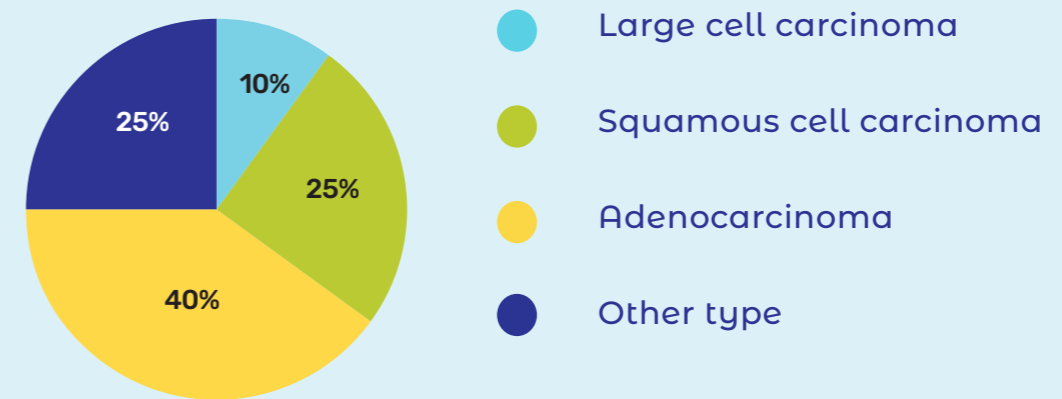
- Non-small cell lung cancer (NSCLC)
- Small cell lung cancer (SCLC)¹¹

For every 100 people diagnosed with lung cancer, about 85 will have NSCLC and 15 will have SCLC.



Non-Small Cell Lung Cancer

For every 100 people diagnosed with NSCLC, about 10 will have large cell carcinoma, 25 will have squamous cell carcinoma, 40 will have adenocarcinoma, and another 25 will have other less common types of NSCLC.¹²



There are 3 common sub-types of NSCLC.¹³ These include:

- **Adenocarcinoma** is the most common subtype of NSCLC. It begins in the tissue that lines the outside of the lungs.
- **Squamous Cell Carcinoma** is the 2nd most common sub-type of NSCLC. It begins inside the lungs in the thin, flat cells that line the breathing tubes.
- **Large Cell Carcinoma** is the 3rd most common sub-type of NSCLC. It often begins in the outer regions of the lungs.

There are also other types of NSCLC that are less common.

If you've been diagnosed with a type of lung cancer that is not mentioned here and would like more information, contact our HelpLine at 1-800-298-2436 or email support@go2.org.

Small Cell Lung Cancer

Small cell lung cancer (SCLC) is a less common¹⁴ type of lung cancer that affects a small number of people. Only about 15 out of every 100 lung cancers are found to be SCLC.

SCLC is named for the small, oval-shaped cancer cells seen under a microscope. It often starts in the breathing tubes known as bronchi in the center of the chest and spreads rather quickly – sometimes before any symptoms are noticed. This type of lung cancer is most often diagnosed when it is in its later stages.

If you would like more information on small cell lung cancer, contact our HelpLine at 1-800-298-2436 or email support@go2.org.

Other Types of Cancer

There are also cancers that are not lung cancer but they can affect the lungs. These include:

- **Mesothelioma** is caused by being exposed to asbestos. It begins in the lining that covers the lungs or the stomach.¹⁵ It can affect the lining of the lungs, heart, and stomach. For more information on this disease, visit the National Cancer Institute Malignant Mesothelioma page at cancer.gov.¹⁶
- **Carcinoid** tumors begin in endocrine cells and often grow slowly. These cells put out hormones and line organs like the small intestines and lungs. Carcinoid tumors are often called endocrine tumors. For more information on carcinoid tumors, visit the Carcinoid Cancer Foundation.¹⁷
- **Sarcoma** begins in tissues all over the body, so it can also be found in the lungs. For more information on sarcoma, visit the Sarcoma Foundation of America at curesarcoma.org.¹⁸

“My approach to the cancer treatment included extensive research with each step during the entire process, while relying on my spiritual grounding to work through the side effects.”

— Patrick



Diagnosing Non-Small Cell Lung Cancer

Diagnosing Non-Small Cell Lung Cancer

When lung cancer is suspected, tests are done to gather more information. This allows your healthcare team to create the best plan for you.

These tests may include:¹⁹

- **Scans** give a detailed view of the body to see the areas affected by cancer.
- A **biopsy** confirms whether cancer is present, and if so, what type.
- **Biomarker testing** looks inside cancer cells to find the exact type of cell changes that occurred.

Scans

During the diagnosis process, you will have different types of scans. These tests give your healthcare team more information about the size of the suspected cancer and where it is in your body. They are used to help make treatment decisions. There are several types of scans, and each has its own purpose. You may have one or more of the following types of scans.

Computed Tomography (CT) Scan

A CT scan²⁰ uses a special type of x-ray that gives a very detailed picture of the inside of your body. It is more detailed than a chest x-ray and is safe and painless. CT scans can find very small tumors in the lung and can show whether cancer has spread to other parts of the body. This scan will help your healthcare team know the exact size of the tumor and its exact location.

Magnetic Resonance Imaging (MRI)

An MRI²¹ uses large magnets, magnetic fields and radio waves to create clear images of the body. It's safe and painless and is sometimes used instead of a CT scan because it can give a more detailed picture of certain parts of your body like the brain. As the scan is working, you will hear knocking or clicking noises as it is taking pictures.

Positron Emission Tomography (PET) Scan

A PET scan²² uses a machine that rotates around your body. Before the scan, a member of your healthcare team will inject a small amount of sugar water with radioactive isotopes into your vein. **Radioactive isotopes** are used because they put out a very small amount of radiation. This small amount of radiation is very safe, and it is useful because it makes cancer cells show up brightly in the scan. This allows your healthcare team to easily see cancer and measure how active it is.

Often, a PET scan is combined with a CT scan using a special machine. This allows your healthcare team to compare the bright images on the PET scan with the detailed images on the CT scan.

Bone Scan

A bone scan is a very specific test that shows whether cancer has spread to the bones. Before the scan, a member of your healthcare team will inject a small amount of sugar water with radioactive isotopes into your vein. This mixture gathers in areas of abnormal bone growth. The level of radioactivity gives a clear picture of areas that might have cancer growth.

Biopsy Methods

During a **biopsy**, a sample of tissue or fluid is taken from your body and examined. Your healthcare team can learn detailed information about cancer and make the best treatment plan for you based on the results of your biopsy. There are a few ways a biopsy may be done. Your healthcare team can talk to you about which method is best for you, why that method was chosen, and how they will keep you comfortable during the process.

Fine Needle and Core Biopsy

A needle biopsy may be done using **fine needle aspiration (FNA)** or a **core biopsy**. Both FNA and a core biopsy use a needle to remove cells from the tumor or area where cancer may be located. This may include your lung, lymph nodes or other areas of your body. One difference between these methods is that a core biopsy can collect a larger piece of tissue than FNA.^{23, 24}

Before the needle is inserted, the skin will be numbed, so the process should not hurt. Sometimes, FNA is done with the help of a CT scan or an MRI to guide the needle to the exact location needed.

Thoracentesis

During **thoracentesis**^{25, 26} a thin needle is used to remove fluid that may have gathered in the chest, outside of the lungs. The fluid is then closely studied for cancer cells. Like an FNA, the skin will be numbed so the procedure will not hurt. If a larger amount of fluid has gathered in the chest, removing the fluid through thoracentesis can help you breathe easier and feel more comfortable.

Bronchoscopy

During a **bronchoscopy**,²⁷ a flexible tube, called a bronchoscope or scope, is passed through the nose or mouth and into the large tubes of the lungs. The scope allows your doctor to see the lungs through a small camera and take a tissue sample for biopsy at the same time. The throat is numbed, and medicine is used to relax you or put you to sleep.

There are a few ways a bronchoscopy can be done. These include:

- Robotic bronchoscopy
- Electromagnetic navigation bronchoscopy procedure
- Autofluorescence bronchoscopy
- Endobronchial ultrasound

A **robotic bronchoscopy**²⁸ may be used if a tumor is in the small tubes of the lungs. Since these small tubes have curves, using a robotic controller, like in a video game, makes it easy to guide the scope into these hard-to-reach areas. A computer-assisted camera is also used, which allows your doctor to see 3-D views of your lungs and take a tissue sample for biopsy.

An **electromagnetic navigation bronchoscopy procedure (ENB)**²⁹ uses electromagnetic energy to steer the bronchoscope. Tiny instruments are guided through the scope to the inside of the lung. Computers are used to find tumors and take tissue samples for biopsy. ENB can also place markers on the tumor. This makes it easier to find the tumor again later and can help target radiation to the tumor.

An **autofluorescence bronchoscopy**³⁰ uses a special light that makes cancer or pre-cancer tissue appear in a different color than other tissue. This method gives more information than a simple bronchoscopy. Tissue samples can also be removed for biopsy testing.

An **endobronchial ultrasound (EBUS)**^{31, 32, 33} uses high-frequency sound waves along with a bronchoscope. This allows a better view of the areas in the center of the chest to see if cancer has spread outside of the lung. Tissue samples can also be removed for biopsy testing.

Endoscopic Esophageal Ultrasound

Endoscopic esophageal ultrasound^{34, 35, 36} uses a thin flexible tube like a bronchoscopy, except the tube is passed through the mouth and into the esophagus (food pipe). This can show nearby lymph nodes and allow your healthcare team to take a sample for biopsy.

Lymph Node Biopsy

After a diagnosis of cancer is confirmed, a **lymph node biopsy** is usually done to see if cancer has spread to the lymph nodes (structures that help filter fluid and waste from the body). A lymph node biopsy may be done by placing a needle into the lymph node and removing tissue, removing the lymph node itself, or by taking a tissue sample during a bronchoscopy. The area will be numbed, and medicine can be used to relax you or put you to sleep.

Mediastinoscopy

A **mediastinoscopy**^{37, 38} uses a tube with a camera, called a mediastinoscope, to see inside the chest and around the outside of the lungs. This provides a close look at tissues near the lungs. If needed, a tissue sample can be taken for biopsy.

Video-Assisted Thoracoscopic Surgery (VATS)

A thoracic surgeon (lung surgeon) performs **video-assisted thoracoscopic surgery (VATS)**^{39, 40} using a thoracoscope that is placed into the chest through a small incision (opening) in the chest wall. A thoracoscope is a flexible tube with a camera on the end to see the surface of the lung and the chest wall. During this time, 1 or more tumors may be removed. Healing and getting back to your routine is faster with a small incision.

Thoracotomy

A thoracic surgeon (lung surgeon) will make an incision (opening) in the chest to see the lungs directly. In a **thoracotomy**, a tumor, lung tissue, or lymph nodes may be removed. Recovery time is longer, and sometimes a 3–5 day hospital stay is needed. Healing and getting back to your routine takes longer with a larger incision.

Biopsy Results

After a biopsy, your liquid or tissue samples are sent to a lab to be studied by a pathologist. A **pathologist** is a doctor who looks closely at tissue or body fluids to diagnose a disease. The doctor will look at fluid and take very thin slices of tissue, stain them, and look at them under a microscope. Each type of cell looks very different under a microscope, so the doctor can see which cells are cancer and which are not.

Biopsy results include a lot of information that helps your healthcare team make the best decisions about your care. Biopsy results can include the tumor grade, the exact type of lung cancer, and the stage of cancer.

Tumor Grade

If the tissue sample is large enough and shows cancer, the doctor may be able to grade the tumor. When the doctor grades the tumor,⁴¹ cancer cells are compared to normal cells. The tumor grade tells how much the cancer cells from your biopsy look like normal cells.

- **Low-grade cancer:** The cancer cells look a lot like normal cells and tend to grow and spread slower.
- **High-grade cancer:** The cancer cells look a lot different than normal cells and tend to grow and spread faster.

Stages of Non-Small Cell Lung Cancer

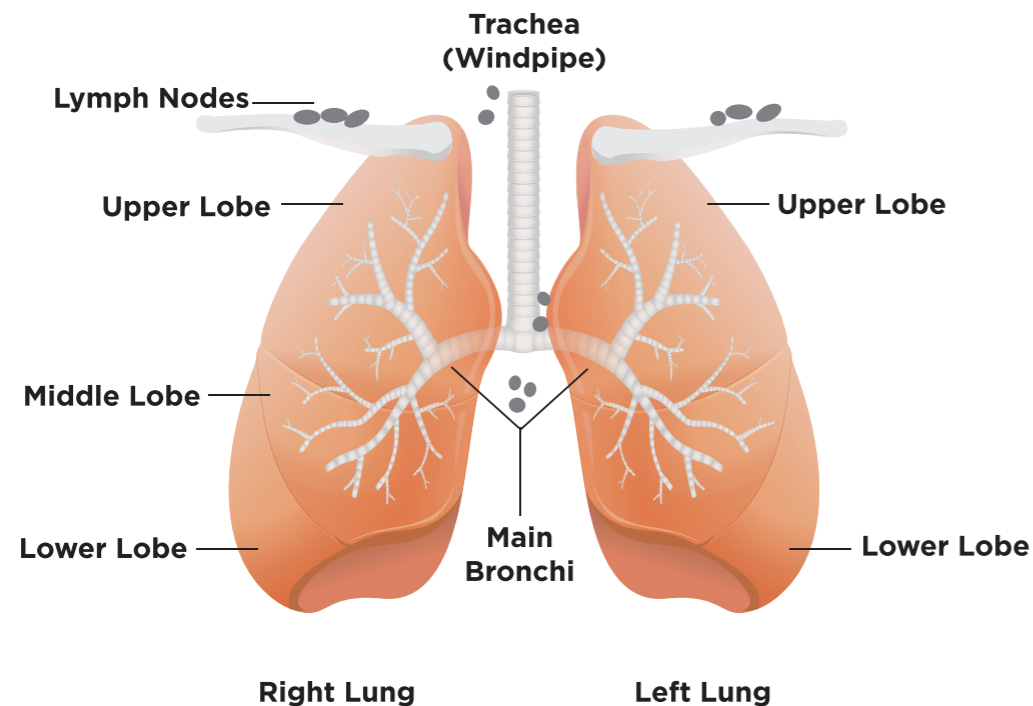
The stage of lung cancer is determined by the information found in your scans and biopsy results. The information includes:

- The size of the primary tumor (the first tumor)
- The number of lymph nodes with cancer cells inside of them
- Whether cancer has spread to other organs

Size of the primary tumor: The size of the primary tumor is measured in centimeters. One centimeter (cm) is about the length of one staple.



The number of lymph nodes with cancer cells inside of them: The lymph system has groups of small pea-sized **lymph nodes** that clean the waste out of the fluid that passes through them. These groups are found in many different parts of your body, like the armpits, neck and groin. When waste collects in a node, it can swell, and it may feel sore. A large group of lymph nodes in the chest drains fluid from the lungs. Cancer cells can break off from a tumor and travel to other parts of your body through the blood or lymph system. Sometimes cancer cells can become trapped in the lymph nodes and start to grow there. If cancer is found in the lymph nodes, that information is used to stage cancer.



Spread to other organs: When cancer spreads to other organs through the lymph or blood vessels, it is called **metastasis or mets**. Early-stage cancers have not spread to other organs or have not spread very far. Late-stage cancer shows spread to organs that are far away from the lungs.

NSCLC Stages

Information about the size of the primary (first) tumor, the number of lymph nodes affected, and how far cancer has spread is used to stage cancer.^{42a} Staging cancer means it is given a number, or a number and a letter, that describes it. You may have heard of cancer staging numbers 0, I, II, III, IV or 0, 1, 2, 3, 4. In this type of staging, a higher number means the cancer is more advanced. The boxes below show how cancer is defined at each stage.

NSCLC Stage 0 = Cells are found in the lining of the airways that are not normal. They are not cancer but are at risk for becoming cancer.

NSCLC Stage 1 = Cancer is found early and is in one lung and has not spread to lymph nodes. Stage 1 is divided into **stages 1A and 1B** based on the size of the tumor and how far it has spread inside one lung.

NSCLC Stage 2 = Cancer is found early but has spread inside or just outside of one lung and may have spread to nearby lymph nodes on the same side of the body. Stage 2 is divided into **stages 2A and 2B** based on the size of the tumor and whether it has spread to certain nearby lymph nodes and other lung structures.

NSCLC Stage 3 = Cancer is in one lung and has spread to the chest and to lymph nodes further away from the lungs. Stage 3 is divided into **stages 3A, 3B, and 3C** based on the size and number of tumors, the location and types of lymph nodes found to have cancer, and exactly where the cancer has spread in the chest area.

NSCLC Stage 4 = Cancer is advanced and has spread to the lining or fluid around the heart or lungs or has spread to distant parts of the body. Having tumors in both lungs, no matter the size of the tumors, is stage 4. Stage 4 is divided into **stages 4A and 4B** based on the number of tumors, and exactly where the cancer has spread.

Other Types of Cancer Staging

Your healthcare team may also use the **TNM system** to stage lung cancer. This staging system was developed by the American Joint Committee on Cancer (AJCC) and the International Union Against Cancer (IUAC).^{42b} Since its development, it has become one of the most used staging systems for cancer.

T = Tumor This describes the size of the tumor, where it is located, and whether it has spread.

N = Lymph Node This describes whether cancer has spread to the lymph nodes in and around the lungs.

M = Metastasis This describes whether cancer has spread to areas outside the lymph nodes.

After information about the Tumor (T), Lymph Nodes (N), and Metastasis (M) are known, cancer then is staged using numbers, 0, 1, 2, 3,4 or 0, I, II, III, IV.

The complete TNM staging system is complex. To help you better understand the staging process, please visit the National Cancer Institute website for pictures of each stage of the disease.

To see a complete chart of this staging system, please see the Appendix B, located in the back of this handbook.

National Cancer Institute website:
<http://www.cancer.gov/cancertopics/pdq/treatment/non-small-cell-lung/Patient/page2>.

Questions to ask your healthcare team during the diagnosis process:

- What type of lung cancer do I have?
- What is my stage of lung cancer and what does that mean for me?
- Has cancer spread to other parts of my body? Which parts?
- Will I need more tests before deciding what treatments are best for me?

Biomarkers

When a pathologist confirms a diagnosis of NSCLC, comprehensive biomarker testing should always be done because there are treatments that work through NSCLC biomarkers to treat cancer. **Biomarkers** are changes or mutations inside cancer cells that make them different from healthy cells.^{43, 44} They are what drive cancer cells to grow and spread.

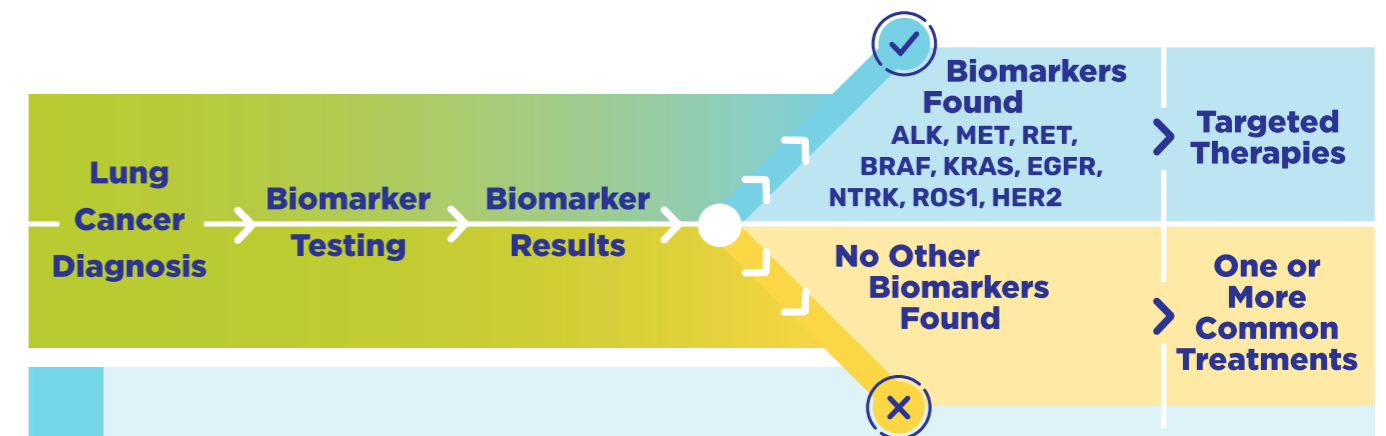
Biomarker testing tests biopsy tissue or a blood sample (liquid biopsy) for mutations or changes in cancer cells.⁴⁵ Your results will guide your team to the best treatment for you. Biomarker testing may also be called molecular testing, assays, or profiles.

A **comprehensive biomarker** test should be done to look for many biomarkers at one time rather than only a few.⁴⁶ This will use less biopsy tissue and will make sure you know all your possible treatment choices.

Liquid biopsy uses a blood sample and is a newer way to do biomarker testing. Since small amounts of cancer⁴⁷ DNA can be found in blood or other fluids; sometimes biomarker information can be found using this method instead of needing tissue. A liquid biopsy can be used for biomarker testing but cannot be used for diagnosing cancer.

Liquid biopsy works best when cancer is more advanced and has spread outside of the lung. It may be a good choice if there is not enough tumor tissue to do biomarker testing from the original biopsy. If your liquid biopsy does not show biomarkers, you will need a tissue biopsy to confirm whether biomarkers are present.

Biomarkers are named after the exact changes or mutations that occurred inside the cell. Since these names can be complex and very long, they are called by their symbols (letters that stand for their longer names). Biomarker results will include a list of biomarkers found in your tissue or blood sample.



Biomarkers are changes or mutations inside cancer cells that make them different from healthy cells.⁴⁸ They are what drive cancer cells to grow and spread.

Biomarker testing tests biopsy tissue or a blood sample (liquid biopsy) for mutations or changes in cancer cells.⁴⁹ It may also be called molecular testing, assays or profiles. Biomarker testing should always be done for people with NSCLC because there are treatments that work through NSCLC biomarkers to treat cancer. This type of treatment is called targeted therapy.

Contact our HelpLine at 1-800-298-2436 or email support@go2.org to learn more about biomarkers or biomarker testing.

Diagnosing Non-Small Cell Lung Cancer

Biomarker testing results can sometimes take up to 3 weeks. This may feel like a very long wait, but it's important to ensure you are getting the right treatment for your cancer type.

See Appendix A at the back of this handbook for a list of known biomarkers and their full names.

If you have NSCLC, you should have comprehensive biomarker testing. If lung cancer spreads, or goes away and then comes back, it can have a different biomarker. New biomarker testing can offer new treatment choices for you.

If you would like help understanding your biomarker results, contact our HelpLine at 1-800-298-2436 or email support@go2.org.



Lung Cancer Treatment Basics

Lung Cancer Treatment Basics

Starting treatment for lung cancer comes with many decisions. Thinking about making some of these decisions can feel overwhelming. Your healthcare team, your loved ones, your beliefs, your goals and even where you live can all impact decisions on where you receive treatment and what types of treatment you choose.

Depending on where you live, you may receive treatment in a community cancer center, a hospital, or an academic medical center. No matter where you receive treatment, being prepared for visits with your healthcare team and knowing who is on your team can help you feel better about starting the treatment process.

Cancer Treatment Centers

There are 3 main types of places where you can receive your cancer care.

- A **community cancer center** is one that stands on its own and is not part of a hospital or university. They often have all cancer services under one roof.
- Some **hospitals** have cancer centers and offer services within their network. These cancer centers may have one building or many buildings.
- An **academic medical center** is a partner to a medical school or other healthcare schools, and they are sometimes known as teaching hospitals. They are large centers that often have access to new treatments, advanced technology and ongoing research studies.

Most cancer centers have support programs, social services, financial assistance, and palliative care services to address more than just your cancer treatment needs. Ask your healthcare team about the programs and services your center has to offer.

It is important to find the type of cancer care that meets your needs. Where you receive your treatment is just as important as the team providing your care.

If you need help finding a cancer center near you, please call our HelpLine at 1-800-298-2436 or email support@go2.org.

The National Cancer Institute (NCI) has a list of cancer centers across the country that meet high standards in cancer care. They are called NCI-Designated Cancer Centers and there are more than 70 centers across 36 states. It is likely that there is an NCI Cancer Center near you.

Members of Your Healthcare Team

Your healthcare team will include people who have skills in a certain area of cancer care. Having specialists work with you is very important because they bring great knowledge about their area of care.

Cancer treatments can affect your whole body, and each member of your healthcare team should know what the other team members are doing. For this reason, your primary care doctor will remain a part of your care and manage non-cancer-related illness and check-ups. They should always be informed of your health status.

Here are some of the healthcare team members that may work with you.⁵⁰ Some may have different titles than the ones listed here and some may perform a few of the jobs across titles. It's a good idea to write down the names of your healthcare team members, what they do, and how you can reach them. Keeping this information handy is always helpful.

You may have one or more of these **specialty doctors** on your team:

- **Medical oncologist:** A cancer doctor who uses medicine (such as chemotherapy) to treat cancer.
- **Pathologist:** A doctor who studies tissue from a biopsy to diagnose diseases.
- **Pulmonologist:** A doctor who specializes in lung problems.
- **Radiation oncologist:** A cancer doctor who uses radiation (high-energy beams) to treat cancer.
- **Radiologist:** A doctor who uses x-rays, CT, MRI, and PET scans for cancer diagnosis and treatment.
- **Thoracic surgeon:** A doctor who specializes in surgery of the chest.

You may have one or more of the following **specialty nurses** involved in your care:

- **Chemotherapy nurse:** A nurse who specializes in providing chemotherapy and can help with managing side effects.
- **Nurse navigator:** A nurse who offers education, support, and coordination of services from diagnosis through treatment.
- **Research nurse:** A nurse who provides care during a clinical trial.

You may have one or more of the following **specialty professionals** involved in your care:

- **Registered dietitian:** A healthcare team member who helps determine diet needs to maintain health.
- **Occupational therapist:** A healthcare team member who helps people increase independence in daily tasks.
- **Physical therapist:** A healthcare team member who helps the body move and recover after injury or disease.
- **Social worker:** A healthcare team member who provides counseling and helps people find resources to meet their needs.
- **Speech therapist:** A healthcare team member who helps people improve speech and swallowing skills.

Visits with Your Healthcare Team

Prepare for your visits by writing down your questions and concerns. This makes sure you're organized and can get all the information you need to take the best care of yourself. Your team is there to care for you and should take the time to talk to you and answer your questions.

Tips to prepare for your appointment:

- Write down all your questions as you think of them.
- Bring your questions with you to your appointment.
- Ask all of your questions and write down the answers.
- Ask again if you don't understand the answers.
- Take someone with you to your appointments (or have them join by phone or Zoom) who will also listen and ask questions.
- Ask if you can voice record the visit.

At each visit, your healthcare team will assess how you are doing with your treatment. They may take your temperature, blood pressure, collect blood, and discuss side effects or other symptoms you may have. Your team may also discuss any new tests that may be needed or new test results.

The following are examples of tests that are sometimes needed.

Pulmonary Function Test (PFT)

The PFT is a breathing test that shows how well your lungs are working. It measures how much air your lungs can take in, the rate of airflow inside your lungs, how well you are able to empty your lungs when breathing out, and some other lung functions.

Pulse Oximetry (Pulse Ox)

If you are short of breath, your team may use a pulse oximeter to measure how much oxygen is in your blood. The pulse oximeter is a small device placed on your fingertip that reads your oxygen level through your skin. If you have a low level of oxygen in your blood over a period of time, your healthcare team may provide you with oxygen.

High-Altitude Simulation Test (HAST)

The High-Altitude Simulation Test (HAST) is used to see if you will need oxygen when you fly or travel to a city that is at a high altitude. You may also hear HAST called a “hypoxia altitude simulation test.” Since higher altitudes have lower amounts of oxygen, heart or lung problems can occur in some people. During this test, your healthcare team will take your blood pressure, pulse, and respiratory rate while you are breathing a normal air mixture. They may also monitor your heart rhythm. Then you will breathe air that has a lower level of oxygen, and you will be closely watched for 20–30 minutes. If you have trouble breathing during the test, you may be tested again with oxygen to see if your breathing difficulty is preventable.

Blood Tests

Chemotherapy and radiation therapy can affect the cells in the bone marrow that makes blood cells. A **complete blood count** test will be done routinely so your team can manage any changes that may occur and keep you healthy. Blood tests can also show how well other organs are functioning, such as your kidneys and liver.

Second Opinions

Before starting or changing treatment, you may want a second opinion. A second opinion simply means making an appointment with a different cancer specialist to hear what that person recommends as the best treatment for you. This allows you to feel most confident in your treatment plan if both doctors agree. It offers more treatment options if the two opinions are different. Getting a second opinion on treatment options is very common and is a normal part of the process.

There are many ways to find a doctor for a second opinion.

- Ask your current cancer doctor to refer you for a second opinion.
- Ask a social worker at your cancer center to help you get a second opinion.
- Call or look online for a nearby medical school that has a lung cancer specialist.
- Call or look online for a lung cancer support group.
- Contact our HelpLine at 1-800-298-2436 or email support@go2.org for help finding a lung cancer specialist.

Before your visit for a second opinion, ask for copies of your medical records, scans, and pathology reports to be sent so the doctor can review your records before you arrive.

“GO2 recommended I go talk to another lung cancer specialist. They opened up the doors to the right treatment, but they also opened their doors to their heart. That’s the best thing.”

— Hank, Jr.



Non-Small Cell Lung Cancer Treatments

Non-Small Cell Lung Cancer Treatments

Overview

Treatment options for NSCLC are based on your stage of cancer, how well your lungs are working, and many other factors related to your personal health. They may include surgery, targeted therapy, radiation therapy, chemotherapy, immunotherapy, clinical trials, palliative treatments, or a combination of these.

It's a good idea to make a list of your questions as you learn about your treatment options and bring them to your next appointment.

Lung cancer treatments fall into 2 categories:⁵¹

- **Local therapy:** Surgery and radiation therapy are examples of local therapies because they remove or destroy cancer in a select area of the body.
- **Systemic therapy:** Chemotherapy and immunotherapy are examples of systemic therapies because they destroy cancer in the whole body. This type of therapy can be given by mouth as a pill, or it can be given through a vein.

Questions to ask your healthcare team when deciding about your treatment type:

- Is my treatment plan based on my biomarker test results?
- What are all my treatment options?
- Will I need more than one type of treatment?
- What are the pros and cons of each type of treatment?
- Are there any clinical trials that are right for me?
- What is the goal of my treatment (cure, stop cancer from growing, or help ease symptoms)?

Questions to ask your healthcare team about the effects of your treatment:

- How will treatment affect my daily life?
- What are the side effects? How can they be prevented or treated?
- What can I do to best prepare for treatment?
- Will I need to be in the hospital? If so, for how long?
- What is the cost of treatment? Will my insurance cover the cost?

Surgery

When it is a treatment option?

Surgery⁵² to remove lung cancer may be an option in NSCLC stages I, II, III, or 1, 2, 3. In the early stages, surgery can be the only treatment needed. Other times, surgery is one part of a larger treatment plan. Treatments such as chemotherapy, immunotherapy, or radiation can be done before surgery in order to shrink the tumor or after surgery to treat any remaining cancer. The order of treatment depends on the tumor size and how far it has spread.

How is it done?

Your healthcare team will talk to you about whether you need surgery and what type of surgery is best for you. If you need lung cancer surgery, the goal will be to remove all of the tumor with the smallest amount of lung tissue possible. A small part of the lung will be removed when the tumor is small. Larger tumors or those that are close to the middle of the chest will need larger parts of the lung removed. In some cases, only one lobe may need to be removed, while in other cases, the entire lung may need to be removed. Many people are able to live very full lives with only one lung.

Ask your healthcare team for a referral to a thoracic surgeon (lung surgeon) to help you decide about having lung surgery and to perform surgery on your lungs.

Lung cancer surgeries⁵³ are named based on the amount of lung tissue that is being removed.

When a small portion of the lung needs to be removed it is called:

- **Wedge Resection:** A small wedge-shaped piece of the lung is removed.
- **Segmental Resection** or **Segmentectomy:** A slightly larger piece of the lung is removed as compared to a wedge resection.

When a lobe of the lung needs to be removed, it is called:

- **Lobectomy:** An entire lobe of the lung is removed. This surgery is done when the lung cancer tumor is located away from the center of the chest.

When the entire lung needs to be removed, it is called:

- **Pneumonectomy:** The entire lung is removed. This surgery is done when the lung cancer tumor is larger and closer to the middle of the chest.

When lung cancer surgery is needed, sometimes lymph nodes around the tumor also need to be removed to look for cancer cells. This is called a lymph node dissection or lymphadenectomy.

- **Lymph node dissection** or **lymphadenectomy:** Several lymph nodes around your tumor will be removed to see if any cancer cells are inside of them.

After lung cancer surgery, the tissue that is removed from the lung is sent to the pathologist. They will look at the tissue and the edges around the tumor to see if all of the tumor was removed. If there are no tumor cells at the edges, it means the entire tumor was removed. These results will be shared with you and your healthcare team and will be used to guide the next steps after surgery.

What can I expect during and after surgery?

- The surgery will take place in an operating room with medicine to put you to sleep.
- You will stay in the hospital for about one week for recovery.
- You may have an epidural (an injection in your back) for pain control and other drugs to control pain.
- You may have a chest tube to drain fluid that might collect after surgery.
- A respiratory therapist will teach you breathing exercises to help you get stronger quickly after surgery.
- You may have an inhaler filled with medicine to help you if you have trouble breathing.

What are some possible side effects of surgery?

- You may have pain from the surgery or chest tube incision; be sure to ask for pain medicine before your pain is severe. Controlling pain will be a large part of your recovery.
- You may feel numb on the side of your chest where you had surgery.
- If fluid builds up around the lungs, you might develop a condition called a pleural effusion. If this happens, it may be hard to breathe or you may have a rapid heartbeat; you should call your healthcare team.

- You will have a tube placed into your throat during surgery to help you breathe. When the tube is removed after surgery, you may have a mild sore throat or be hoarse.
- For comfort, women may want to avoid wearing a bra for a week or two after surgery.

Your healthcare team will talk to you about other possible aftereffects and the benefits and risks of having surgery.

Questions for your healthcare team about surgery:

- What type of surgery is right for me and why?
- What are the risks of the surgery?
- What are the long-term effects after the surgery?
- How long will I be in the hospital?
- What side effects should I expect?
- Will I feel pain? If so, how will it be controlled?
- When can I get back to my normal activities?



Tips for Recovering from Surgery – Bonnie’s Perspective

After any surgery for lung cancer, you may have side effects because of the surgery. I know because I have been there. Your healthcare team will be able to tell you many things you can do to recover after surgery, but there are some things only someone who has been through it can tell you.

A few things I have learned in my own experience that may help you as you recover from a surgical procedure include:

- Be sure to talk to your team before the surgical procedure, so you know exactly what to expect after the surgery.
- After lung surgery, the incision area may be sore. A cold pack for 20 minutes at a time may help relieve the swelling at the site. Talk to your surgeon to make sure this is okay for you to do.
- It may help if you sleep with your head and shoulders raised. This may help your lungs to expand more fully and allow you to breathe better.

- Unless your surgeon says you should stay in bed, be sure to get up, sit in a chair several times a day, and walk a little more each day. Unless your condition requires that you stay in bed, you will recover faster if you get up and moving as soon as possible after surgery.
- The first day or two after surgery, you should take pain medicine regularly as instructed by your doctor in order to make it easier to move; however, the sooner you stop taking pain medicine, the more energy you will have.
- Eat small meals often. These small meals will allow you to have energy throughout the day without having a full stomach that may interfere with your breathing. As you eat more frequently, but smaller meals, be sure you are drinking lots of fluid.
- Keep all appointments with your healthcare team, and report any symptoms that you think are not normal following your surgery!

Bonnie J. Addario

Lung Cancer Survivor
 GO2 for Lung Cancer
 Co-founder and Board Member

Targeted Therapy

What is it?

Targeted therapies^{54, 55} are drugs that stop cancer by attacking a specific “target” in cancer cells. These targets are called biomarkers, and they are what drive cancer cells to grow and spread. If your biomarker test results show that you have a biomarker with an approved targeted therapy, you will likely be treated with a targeted therapy drug.

How is it given?

There are 2 ways targeted therapy drugs are given. Some targeted therapy treatments come in the form of a pill and others are given through an IV (a small tube inserted in a vein). IV treatments are given at a hospital, cancer center, or infusion center.

There may be one or more targeted therapy drugs for your biomarker. Some targeted therapy drugs are given alone and some are combined with other drugs. Some are only approved to be used after lung cancer has spread or metastasized, while others can be used with early-stage cancer.

Common Targeted Therapy Drugs for Non-Small Cell Lung Cancer

Biomarker names can be very long, so they are shortened and are named by taking a few letters from their longer name. The following is a list of targeted therapy drugs that are approved by the Food and Drug Administration (FDA) and the biomarkers (EGFR, ALK, ROS1, etc.) they are designed to target. Your healthcare team will choose a targeted therapy according to your biomarker.

Biomarker	Brand Name	Generic Name
EGFR	Gilotrif	afatinib
	Iressa	gefitinib
	Tagrisso	osimertinib
	Tarceva	erlotinib
	Tarceva with Cyramza	erlotinib with ramucirumab
	Vizimpro	dacomitinib

Biomarker	Brand Name	Generic Name
EGFR-Exon 20	Rybrevant	amivantamab-vmjw

Biomarker	Brand Name	Generic Name
ALK	Alecensa	alectinib
	Alunbrig	brigatinib
	Lorbrena	lorlatinib
	Xalkori	crizotinib
	Zykadia	ceritinib

Non-Small Cell Lung Cancer Treatments

Biomarker	Brand Name	Generic Name
ROS1	Rozlytrek	entrectinib
	Xalkori	crizotinib
	Augtyro	repotrectinib

Biomarker	Brand Name	Generic Name
BRAF V600E	Mekinist with Tafinlar	trametinib with dabrafenib
	Braftovi with Mektovi	encorafenib with binimetinib

Biomarker	Brand Name	Generic Name
RET	Gavreto	pralsetinib
	Retevmo	selpercatinib

Biomarker	Brand Name	Generic Name
MET Exon 14	Tabrecta	capmatinib
	Tepmetko	tepotinib

Biomarker	Brand Name	Generic Name
NTRK	Rozlytrek	entrectinib
	Vitrakvi	larotrectinib

Non-Small Cell Lung Cancer Treatments

Biomarker	Brand Name	Generic Name
KRAS G12C	Lumakras	sotorasib
	Krazati	adagrasib

Biomarker	Brand Name	Generic Name
HER2	Enhertu	trastuzumab deruxtecan

Biomarker	Brand Name	Generic Name
Other Targeted Therapy Drugs	Avastin	bevacizumab
	Mvasi	bevacizumab-awwb (Other generics are also available)

*Cyramza can be used with chemo in NSCLC that doesn't have an identified biomarker

New approvals for lung cancer treatments are happening often. To be sure you have the most up-to-date information, visit: go2.org/education.

Clinical trials can offer you more treatment options.

A clinical trial is a study done by a team of doctors, nurses, and other healthcare providers to find new ways to treat lung cancer safely. If you have any questions about clinical trials or your treatment options, our LungMATCH team can help. Contact our HelpLine at 1-800-298-2436 or email support@go2.org.

What are some possible side effects of targeted therapy?

Side effects of targeted therapy will vary based on the type of drug and other health factors. This is not a complete list of side effects. To see common side effects for each targeted therapy drug, please ask your healthcare team. The American Cancer Society’s webpage also has a list of side effects at www.cancer.org/cancer/lung-cancer/treating-non-small-cell/targeted-therapies.html.

Targeted therapy side effects may include:

- Rash
- Diarrhea
- Vision problems
- Tiredness
- Nausea
- Heart and lung problems

Call your healthcare team right away if you have:

- A new or worsening side effect from treatment such as trouble breathing, chest pain, fainting, dizziness or confusion
- Diarrhea with bad cramping or pain, blood in the stool or urine, or dark urine
- Fever of 100.5F or higher
- Changes in vision, memory, or thinking skills
- Swelling in any part of the body

Questions to ask your healthcare team about targeted therapy:

- Have I had comprehensive biomarker testing?
- What are my biomarker results?
- Can my biomarker be treated with targeted therapy?
- Will I have targeted therapy as a pill or through an IV (in a vein)?
- How often will I get targeted therapy?

Radiation Therapy

What is it?

Radiation therapy treats cancer by using high-energy x-ray beams to kill tumors. Radiation therapy is a **local therapy** because it is focused directly on the tumor instead of treating the entire body.

Sometimes radiation therapy is given at the same time as chemo (called combined therapy or chemoradiation) and sometimes it is given alone. Combined therapy can cause more side effects, but it can be better at killing cancer.

How is it done?

There are a few types of radiation therapy and each works in its own way.

External beam radiation is the most common type of radiation.⁵⁶ This treatment uses a machine called a linear accelerator to treat lung cancer with high-energy photons or x-rays. The high-energy beams are aimed at the cancer. They kill the DNA of the cancer cell, which stops the cell from being able to function.

External beam radiation treatment is painless. During treatment, you'll be lying on a table, a machine will move around you, and you'll hear some noises from the machine.

Types of external beam radiation include:

- **3-D Conformal Radiation Therapy (3D-CRT)**⁵⁷ is the most used type of external beam radiation. The radiation oncologist first scans the tumor to create a 3-D image of the tumor and the normal tissues around it. These images are then used to aim the beam at the tumor and to protect nearby healthy tissue.

- **Intensity-Modulated Radiation Therapy (IMRT)**⁵⁸ is an advanced form of 3D-CRT that focuses small "beamlets"⁵⁹ of radiation on the tumor. These small beamlets limit how intense the radiation is and can protect the healthy tissue around the tumor. This allows the radiation oncologist to treat tumors that are close to healthy organs. There are fewer side effects as compared to traditional radiation, but treatment times can be longer.
- **Image Guidance Radiation Therapy (IGRT)**⁶⁰ uses a CT, MRI, or PET scan during the treatment process. This helps to direct the beam in a precise way, and the use of the scan helps to monitor the progress of treatment.
- **Particle Beam (Proton) Therapy**⁶¹ is a type of radiation treatment that uses protons instead of x-ray radiation. At high energy, protons can kill cancer cells with much less damage to the healthy tissue near the tumor, which results in fewer side effects.

Radiosurgery or stereotactic radiotherapy^{62, 63} uses pinpoint radiation beams that focus on one small area and treat it with a very high dose of radiation. When it is used on the body (outside of the brain) it is sometimes called **stereotactic body radiation therapy (SBRT)**. It can sometimes be used instead of surgery in early-stage lung cancer.⁶⁴

To make sure the radiation is aimed at the exact location of the tumor, markers are placed inside the body, either in or near the tumor. A marker is a small gold seed or platinum coil. One to 5 radiosurgery treatments may be needed, with each treatment lasting several hours.

What are some possible side effects of radiation therapy?

The side effects of radiation therapy depend on the area of the body that gets the radiation.

Radiation side effects may include:

- Mild or moderate fatigue that may last a few weeks after radiation has ended.
- Irritation to skin or loss of hair in the area where radiation is given.
- Sore throat or trouble swallowing if radiation was given near the throat.
- Diarrhea if radiation is aimed near the lower stomach.
- Radiation aimed at the brain may cause short-term memory loss, but newer methods can reduce this risk.

Other types of side effects may include:

Radiation pneumonitis⁶⁵ is a rare form of pneumonia that can be caused by radiation 2–6 months after treatment is finished. Contact your healthcare team if you have shortness of breath, chest pain when you breathe, a cough, or a low fever after finishing radiation.

Radiation pneumonitis is diagnosed by a chest x-ray and treated with steroid medicine. With treatment, there are usually no lasting problems.

Radiation fibrosis⁶⁶ is scarring of the lungs caused by radiation therapy. The amount of scarring depends on how much of your lung was treated and the dose of radiation to that lung. It can sometimes cause shortness of breath and coughing. Your healthcare team may offer you oxygen if scarring develops.

Call your healthcare team right away if you have any of these symptoms:

- Trouble breathing, chest pain, fainting, dizziness, or confusion
- Diarrhea with bad cramping or pain, blood in the stool or urine, or dark urine
- Fever of 100.5F or higher
- Changes in vision, memory, or thinking skills
- Swelling in any part of your body

Questions to ask your healthcare team about radiation therapy:

- How will the radiation therapy be given?
- How many treatments will I have per week and for how long?
- What side effects should I expect and how do I manage them?
- Will I also need other treatments, such as chemotherapy or surgery? If so, when will I receive them and in what order?
- Will I need a special diet during or after my radiation treatment?
- Can I drive myself to and from the treatment facility?
- Will I be able to continue my normal activities during treatment?
- After my treatment is complete, how often will I need to return for checkups?

Chemotherapy

What is it?

Chemotherapy (chemo) is a treatment that kills fast-growing and dividing cells and can be used to treat NSCLC at any stage.

Chemo is a systemic therapy because it works to kill cancer all over the body. Your team will talk with you about the dose and the schedule for chemo.

How is it done?

Chemo⁶⁷ is usually given in a vein either through an IV (a small tube inserted in a vein) through a port (a permanent IV placed under the skin near the collarbone), or in the form of a pill.

A **port** allows easy access to the bloodstream and protects the veins in your arms. Chemo that is given through IV or port is given in cycles followed by a rest period to allow your body time to recover. These types of chemo treatments are given at a hospital, cancer center, or infusion center.

Chemo that is given in the form of a pill is less common and can be taken at home.

A **chemo regimen**⁶⁸ is when more than one chemo drug is used at the same time. This is a very common way chemo is used. Your first chemo regimen is called your first-line treatment. If different treatments are needed after this, they are called second-line treatments. The Food and Drug Administration (FDA) labels chemo regimens as first-line or second-line treatments. This means each chemo drug has been found to work best as a first-line or second-line treatment.

The first-line chemo regimen for NSCLC includes a platinum-based drug plus one other type of chemo drug. If you need additional therapies, different chemo drugs may be used.

There are many chemo drugs for NSCLC that are approved by the Food and Drug Administration (FDA). The National Comprehensive Cancer Network provides guidelines for cancer treatments that include chemo drugs. Your healthcare team will select chemo drug(s) based on your health needs.

Common NSCLC drugs are:

Brand Name	Generic Name
Abraxane	nab-paclitaxel
Alimta	pemetrexed disodium
Gemzar	gemcitabine hydrochloride
Navelbine	vinorelbine
Paraplat, Paraplatin	carboplatin
Platinol, Platinol AQ	cisplatin
Taxol	paclitaxel
Taxotere	docetaxel
Toposar, VePesid	etoposide

If both surgery and chemo are needed⁶⁹, chemo can be used before or after surgery. When it is used before surgery, it is called **neoadjuvant therapy**. The purpose of using chemo before surgery is to shrink cancer that may be in lymph nodes and the chest to ensure the best surgical outcome. When chemo is used after surgery, it is called **adjuvant therapy**. The purpose of using chemo after surgery is to kill cancer cells that may not have been removed with surgery.

What are some possible side effects of chemotherapy?

Side effects⁷⁰ will depend on the type and length of your treatment and your body's own reaction to chemo drugs. Many side effects can be reduced or prevented with help from your healthcare team. Always tell your team about your side effects.

Chemo side effects may include:

- Nausea/vomiting
- Loss or change in appetite/taste
- Hair loss
- Feeling tired
- Nerve pain
- Shortness of breath
- Coughing
- Mouth sores
- Brittle bones
- Hearing loss

Possible long-term effects from chemo:

- Menopause
- Infertility
- Changes to heart and lungs
- Weak or brittle bones

If you are of childbearing age, talk to your healthcare team about options.

Brittle bones

Chemotherapy and the effects of lung cancer can sometimes make bones brittle. This is called osteoporosis. There are drugs that can help to prevent this. Ask your healthcare team if one of these drugs might be right for you.

Note: Since your teeth are bones, drugs for brittle bones can also affect your teeth. Talk to your healthcare team and dentist about having dental work before starting any of the drugs for brittle bones.

Call your healthcare team right away if you have:

- A new or worsening side effect from treatment such as trouble breathing, chest pain, fainting, dizziness, or confusion
- Diarrhea with bad cramping or pain, blood in the stool or urine, or dark urine
- Fever of 100.5F or higher
- Changes in vision, memory, or thinking skills
- Swelling in any part of the body

Questions to ask your healthcare team about chemotherapy:

- Will I have one drug or a combination of drugs?
- What is my chemo schedule?
- Can I drive myself to/from treatment?
- How will we know if the treatment is working?
- What side effects should I tell you about?
- Can I prevent or treat any of the side effects?
- Will I have side effects after the treatment is completed?
- Can I take vitamins while I am on chemo?
- Do I have to eat certain foods or avoid certain foods?

Immunotherapy

What is it?

Immunotherapy⁷¹ is a type of cancer treatment that helps the body's own immune system find and attack cancer cells. This extra help is important because cancer cells can disguise themselves as healthy cells. Your healthcare team may refer to immune therapy as systemic therapy because it works on cancer cells all over your body.

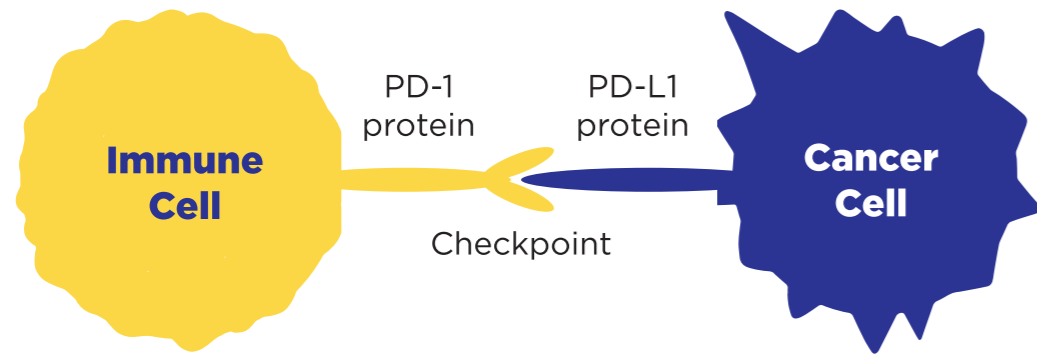
How does it work?

To understand how immunotherapy works, first you need to know a little bit about the immune system. Your immune system protects your body against germs and diseases that can make you sick. Most of the time, it knows which cells in the body are normal and healthy and which cells are not healthy. This allows it to attack disease and germ cells without attacking healthy cells.

When your immune system finds cancer cells, it goes to work to destroy them. Sometimes it has trouble finding cancer cells because they can hide and appear like healthy cells. Cancer cells hide from the immune system by attaching themselves to immune cells. Staying attached to immune cells slows down or stops the ability of the immune cell to attack the cancer cell.

The place on the cells⁷² where the cancer cell and the immune cell attach to each other is called a checkpoint. There are proteins on the surface of each cell that attach the immune cell and the cancer cell together.

- The protein on the immune cell is called PD-1 or CTLA-4.
- The protein on the cancer cell is called PD-L1.

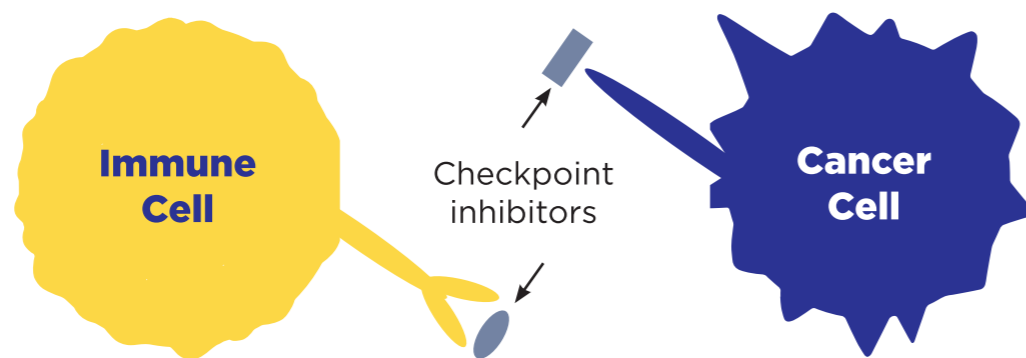


Without immunotherapy: PD-1/PD-L1 are attached at the checkpoint. The cancer cell is hidden and protected from attack.

Immunotherapy works by blocking cancer cells from attaching to immune cells. This leaves cancer cells exposed and allows the immune system to attack them.

A **checkpoint inhibitor**⁷³ is a type of immunotherapy. It works by blocking the checkpoint proteins from attaching to each other

With immunotherapy: PD-1/PD-L1 checkpoint is blocked by a checkpoint inhibitor. Cancer cells can be found and attacked.



Immunotherapy Drugs

Your healthcare team will determine whether immunotherapy is right for you based on your stage of cancer and the timing of other treatments you may need.

Common Immunotherapy Drugs for NSCLC:⁷⁴

Immunotherapy drugs that block the PD-1 protein on the immune cell	
Brand Name	Generic Name
Keytruda	pembrolizumab
Libtayo	cemiplimab-rwlc
Opdivo	nivolumab
Jemperli	dostarlimab

Immunotherapy drugs that block the PD-L1 protein on the cancer cell	
Brand Name	Generic Name
Imfinzi	durvalumab
Tecentriq	atezolizumab

Immunotherapy drugs that block the CTLA-4 protein on the immune cell

Brand Name	Generic Name
Imjudo	tremelimumab-actl
Yervoy	ipilimumab

What are some possible side effects from immunotherapy?

Side effects will depend on the type and length of your treatment and your body's own reaction to immunotherapy drugs. Many side effects can be reduced or prevented with help from your healthcare team. Always tell your team about your side effects.

Immunotherapy side effects may include:

- Aching joints and muscles
- Constipation and/or diarrhea
- Coughing
- Trouble sleeping and/or feeling tired
- Loss of appetite
- Mouth sores
- Skin reactions
- Throat soreness

Since immunotherapy increases the activity in the immune system, healthy cells are sometimes attacked. Some of the more serious side effects are caused by organ inflammation.

Call your healthcare team right away if you have:

- Trouble breathing, chest pain, fainting, dizziness, or confusion
- Diarrhea with bad cramping or pain, blood in the stool or urine, or dark urine
- Fever of 100.5F or higher
- Changes in vision, memory, or thinking skills
- Swelling in any part of your body

Questions to ask your healthcare team about immunotherapy:

- Is immunotherapy right for me?
- Which immunotherapy drug do you recommend for me and why?
- What are the benefits and risks of taking immunotherapy?
- What should I do if I have a severe reaction to immunotherapy?
- What is the treatment for a severe reaction if I were to have one?

Other Types of Treatments

Your healthcare team may offer you other types of treatment to help shrink or destroy tumors in areas that cause discomfort or affect your airway.

Radiofrequency ablation⁷⁵ uses high-energy radio waves to heat the tumor and destroy cancer cells. It is sometimes used when surgery is not an option.

Laser therapy⁷⁶ can sometimes be used to treat small tumors in the lining of the airway or to open up a blocked airway. A laser on the end of a flexible tube is passed through the mouth and into the airway. The tumor is then burned away by the laser.

Argon plasma coagulation (APC)⁷⁷ destroys tumors by using an argon gas jet to apply heat to specific areas without having to make direct contact with the area. This lets your pulmonologist treat a larger area, which will often shorten the procedure time. This procedure may be used to improve breathing if cancer is in or near your airway.

Cryotherapy or cryoablation^{78, 79} destroys tumors by freezing the tissue. A super-cooled probe is used over the entire surface of the tumor. The tissue is then allowed to thaw, and will then be refrozen and thawed several times. Cryotherapy is sometimes used when surgery is not an option.

High-dose rate (HDR) brachytherapy, also called image-guided brachytherapy (IGBT)⁸⁰ sends high-dose radiation directly into tumors that are in the main airway through a very small tube. This protects lung tissue near the tumor and sends high-dose radiation through a very small tube directly into tumors that are in the main airway..

Airway stenting⁸¹ places a small hollow tube in the airway to open areas that are blocked or narrowed due to the lung tumor or scar tissue. The airway stent can stay in place long term if needed.

Balloon bronchoplasty⁸² uses a balloon to open a narrow airway. This is very useful when an airway is narrowed due to scarring. Depending on the location of the scar tissue, the widening of the airway can be done using a flexible or rigid bronchoscope. It can also be done before an airway stent is placed.

Photodynamic therapy (PDT)⁸³ can be used to treat tumors in the outer layers of the windpipe or to open airways that are blocked by tumors. PDT uses a drug called a photosensitizer and a special light to kill cancer cells. After the drug is given through a vein, a bronchoscope is used to shine a special light on the tumor and activate the drug. PDT is usually only used on small tumors since the light that is used cannot pass through bigger tumors.

NSCLC Treatment Options by Disease Stage^{84, 85}

	Stage 1A	Stage 1B	Stage 2A Stage 2B	Stage 3A Stage 3B Stage 3C	Stage 4A Stage 4B
Surgery	✓	✓	✓	✓	Rare
Radiation Therapy	✓	✓	✓	✓	✓
Immunotherapy		✓	✓	✓	✓
Chemotherapy		✓	✓	✓	✓
Targeted Therapy		✓	✓	✓	✓
Palliative Care	✓	✓	✓	✓	✓
Clinical Trials			✓	✓	✓

“Enjoy every sandwich.”
— Mike



Managing Treatment Side Effects

Managing Treatment Side Effects

The side effects of cancer treatment will depend on the type of treatment you receive, how long you receive it, and your body's response. You may not have any side effects, or you may have just a few. It is always important to talk to your healthcare team about ways to manage side effects before you have them. They can often be prevented, treated, or eased with healthy practices or medicines. Cancer treatments have improved over time and so has the management of side effects!

Palliative Care

What is it?

Palliative care is designed to prevent and/or relieve the side effects of cancer and cancer treatment.⁸⁶ The effects might be physical, mental, or emotional. The goal of palliative care is always to improve your quality of life.

Some people aren't sure what the difference is between palliative care and hospice. Palliative care can begin as soon as you are diagnosed and lasts as long as you need it. Hospice care can begin when treatment to cure cancer is no longer being used, and it includes palliative care. Hospice care is received in your home or at a hospice facility, but palliative care may be received anywhere.

Studies show that starting palliative care at diagnosis improves your quality of life, reduces depression, and increases survival.

What does the palliative care team do?

Chemotherapy, targeted therapy, immunotherapy, and radiation can cause side effects like fatigue, anxiety, nausea, and trouble eating. Lung cancer surgery and other treatments may also result in pain. Your palliative care team is trained to help you prevent, decrease, and manage all of the side effects that you might have.

When you meet with your palliative care team, they will check your pain level and ask you about other symptoms and side effects that you may be having. They will explore your goals and match their services to your goals. Most insurance plans, including Medicare, will cover palliative care as part of your lung cancer treatment.

Ask your healthcare team about palliative care. They may be able to contact the palliative care team for you and set up your first visit.

Questions to ask your healthcare team about palliative care:

- Does my cancer center have a palliative care team?
- How can I make an appointment for palliative care?
- Is palliative care covered by my insurance?
- What kind of treatments can I expect with palliative care?

Side Effects at a Glance

Use this chart to see which side effects go with each treatment type. Remember, you may have none or only a few of the side effects listed below.

NOTE: There are different types of targeted therapy drugs, each with its own side effects. The list below provides general side effects for targeted therapy, and not all side effects are listed. If you have side effects that are not listed here, contact your healthcare team for more information.

Side Effect	Chemo-therapy	Immuno-therapy	Targeted Therapy	Radiation Therapy
Aching Joints and Muscles	✓	✓	✓	
Constipation	✓	✓	✓	
Coughing	✓	✓	✓	Only if chest is treated
Diarrhea	✓	✓	✓	Only if pelvis is treated
Fatigue	✓	✓	✓	✓
Hair Loss	✓			Only the radiated area
Loss of Appetite	✓	✓	✓	✓
Low Blood Cell Count	✓		✓	

Side Effect	Chemo-therapy	Immuno-therapy	Targeted Therapy	Radiation Therapy
Memory/Thinking Changes	✓	✓	✓	Only if brain is treated
Mouth Sores	✓	✓	✓	
Nausea/Vomiting	✓		✓	
Nerve Pain/ Numbness	✓			
Shortness of Breath		✓	✓	✓
Skin Changes		✓	✓	✓
Throat Soreness		✓		✓
Trouble Sleeping	✓	✓		

Tips to Manage Treatment Side Effects

You may find it helpful to keep track of which tips you use and what works best for you. Remember to always call your healthcare team with questions or concerns.

Important Things to Know About Side Effects:

- The side effects from cancer treatment are not a measure of how well it is working. It can work very well even if you don't have any side effects.
- This handbook offers some ways to manage side effects, but you may also find other ways that help.
- Most side effects only happen while you are in treatment and go away after treatment is over, but some side effects last longer than others or never fully go away.
- Each person manages cancer treatment side effects in their own way. Even if you are on the same medication as someone else, their side effects may not be the same as yours. The way someone's body works is unique to that person.
- The longer you receive treatment, the more likely you are to have a side effect. Working with your healthcare team and a palliative care team can help.

Aching Joints and/or Muscles

Aching joints and muscles are common side effects of cancer treatment. They may be mild or severe and last a short time or a long time. Sometimes medicines in your chemotherapy "cocktail" can cause your muscles and joints to ache.

Helpful tips to prevent and manage aching joints and/or muscles:

- Gentle stretching and exercise, such as yoga, walking, or swimming, may

help with aching joints and muscles. Exercising makes your muscles stronger and improves joint movement.

- Use a gentle heating pad.
- Take a warm bath or shower.
- Meditation may help with relaxation and ease pain.

Common medications:

- Pain medicines
- Steroids
- Certain anticonvulsants and antidepressants may block pain

Acupuncture, massage, and occupational therapy or physical therapy may also help ease aching joints and/or muscles. Talk to your healthcare team about which option(s) might be right for you.

Constipation

Constipation is a common problem. It happens when you have bowel movements less often, or they are hard and not easy to pass. You may feel bloated (full of gas) or have some cramping or pain in your stomach. You may also not feel like eating.

Helpful tips to prevent and manage constipation:

- If you are taking or start taking opioid pain medication, ask for help from your healthcare team to prevent constipation.
- Drink at least 8 glasses of water daily.
- Eat high-fiber foods such as whole grain cereals, fruits (like prunes, figs, and dates), vegetables, nuts, peanut butter, and popcorn.
- Try to avoid dairy products and fried foods.
- Exercise if you can, even if it is only walking around your house.
- Have a warm drink 30 minutes to an hour before the time you normally have a bowel movement.

Common medications:

- Over-the-counter stool softeners, like Senokot, Colace, or Miralax
- Over-the-counter laxatives, like Dulcolax

Your healthcare team may also prescribe additional medications if needed.

Coughing

Coughing is normal and helps to keep your airway clear. A cough can be caused by a cold, allergies, your cancer and/or treatment. How your healthcare team decides to treat your cough will be based on the cause and whether the cough is dry or wet.

Helpful tips to prevent and manage coughing:

- Use a humidifier to keep your throat and nose from being too dry.
- Drink plenty of water to thin mucous.
- If you suffer from heartburn, stay away from foods that make your heartburn worse because they can also make your cough worse.
- Stay away from smoky places. If you smoke, try to cut back. Your healthcare team can help.
- Stay away from sprays, like hairspray and perfumes, that may bother your throat.

Common medications:

- Over-the-counter cough or allergy medicines
- Cough drops
- Hycodan (hydrocodone bitartrate and homatropine methylbromide)

Tell your healthcare team right away if you cough and see blood and/or colored mucous or if your cough interferes with your sleep or it doesn't go away or gets worse.

Diarrhea

Diarrhea is, in very basic terms, loose stool. It can happen as a side effect of cancer treatment and may also be an unintended result of medications meant to ease constipation.

Helpful tips to prevent and manage diarrhea:

- Avoid milk, dairy products, and spicy/greasy foods.
- Avoid alcohol, caffeine, and carbonated drinks.
- Stay away from gassy foods.
- Drink a lot of clear liquids, like broth and fruit juices, in addition to water to replace lost salt and electrolytes.
- Eat bland foods like bananas, rice, applesauce, and toast.

Common medications:

- Bulking agents, like Citrucel
- Lomotil
- Imodium

Tell your healthcare team right away if you have diarrhea with bad cramping or pain, fever, dizziness, blood in your stool or dark urine. If your diarrhea lasts more than 3 days, tell your healthcare team in order to prevent dehydration (not enough water in the body).

Fatigue – Feeling Very Tired

Fatigue is an extreme tired feeling that may not be relieved by getting extra sleep or rest. Fatigue may lead to trouble completing everyday tasks. Even self-care tasks, such as bathing and eating, may feel hard to start or complete.

Helpful tips to prevent and manage fatigue:

- Exercise if you can. It really does have the power to increase your energy level.
- Seek treatment for depression, pain, trouble sleeping, or other health problems that may be adding to your fatigue.
- Make sure you are eating enough food (and protein) and drinking a lot of liquids.
- Try sitting rather than standing when doing tasks like grooming, prepping a meal, or showering.
- Pace yourself, even on days when you are feeling your best.
- Save your energy by planning, spacing tasks out over time, and organizing all needed items for the task.
- Get plenty of rest, but don't nap during the day for more than 1 hour at a time. A short nap or rest is best.
- Ask for help with tasks when you need it.

Loss of Appetite – Not Feeling Like Eating

Many people with cancer say that foods don't taste and smell the same as they did before treatment. These changes may make you feel like not eating. Some common taste and smell changes are:

- A metallic, medicine, or sweet taste
- Dry mouth
- A need to add salt or sugar to food

- A new dislike for foods you used to enjoy
- Upset stomach from the smell of some foods

Helpful tips to prevent and manage loss of appetite:

- Eat food that tastes good to you. Try to aim for healthy foods that are high in calories, protein, and other nutrients.
- Let other people fix your meals. This will save you energy and keep you away from cooking odors.
- Try to eat 6–8 small meals and snacks every day.
- Try shakes, such as Ensure and Boost. They can help you get nutrition when it is hard to eat.
- If you have dry mouth, suck on ice cubes and candies, or chew gum.

Hair Loss

Hair loss from cancer treatment happens because chemotherapy drugs don't just affect cancer cells. They also affect other cells that divide quickly in the body, like hair cells. Some chemotherapy drugs cause hair loss and some do not. Radiation may also cause hair loss to the areas being treated.

When hair loss happens, it may be lost over time or all at once. Some or all hair may be lost, including eyebrows and eyelashes.

Helpful tips to manage hair loss:

- If your hair is long, it may make it easier to cut it short before hair loss starts.
 - Use mild shampoos, soft hairbrushes, and low heat when drying your hair.
- After hair loss, you may choose to cover your head:
- Sometimes it helps to find a wig that looks like your own hair. Many hair stylists can help cut the wig to match your hair. It's easiest to do this before your hair falls out so the stylist can see what your hair looks like. Some people like to wear wigs that are very different from their natural hair and have fun with something new. Wigs may be covered by insurance; if not, there are organizations that offer free or reduced-cost wigs.
 - You may choose to use scarves or head coverings. They tend to be very comfortable, and you can choose from many styles, colors, and patterns to meet your sense of style.
 - Wearing a hat is also a common choice that can let you show off your style and personality.

If you choose not to cover your head, be sure to use sunscreen on your scalp when in the sun.

Low Blood Cell Count

Cancer treatments can lower the number of certain blood cells in your body. Your healthcare team will check your blood often to be sure the number of blood cells in your body stays at the right level. When the number of blood cells decreases, it is called myelosuppression.

Anemia (Low Red Blood Cell Count)

Anemia develops when the number of red blood cells in the body becomes very low. Red blood cells carry oxygen through your body. If the number of red blood cells in the blood becomes low, you may feel tired, weak, or dizzy, have cold hands or feet, headaches, or shortness of breath, or a fast heartbeat.

Helpful tips to manage low red blood cell count:

- Get routine bloodwork checks.
- Eat a healthy diet with lots of protein and iron.
- Get good rest.
- Drink a lot of water.

Neutropenia (Low White Blood Cell Count)

Neutropenia occurs when the number of white blood cells in the body becomes very low. The job of white blood cells is to fight infection. If they get too low, you may have a higher risk of infection (and catch a cold or flu, or otherwise get sick).

Helpful tips to manage low white blood cell count:

- Get routine bloodwork checks.
- Wash your hands often.
- If you have a cut or sore, wash it well and put on an antibiotic ointment.
- Bathe daily, brush your teeth twice a day, and floss.
- Stay away from people who are sick.

Common medications:

- Vitamin or mineral supplements such as iron, folic acid, or B12
- Medications such as Neupogen, Neulasta, generic growth factors, and Cosela (trilaciclib), if available

Tell your healthcare team right away if you have a fever over 100.5 F or have “the shakes” or chills. Low blood cell counts can be treated by your healthcare team.

Memory and Thinking Changes

Some people may notice that it is harder to remember things or feel like thoughts are “foggy” after starting cancer treatment.

It may seem a little harder to complete a task or feel like it takes more mental effort to focus. These changes often go away on their own, but it is good to talk to your healthcare team if the changes are making it too hard to manage your daily routine.

Helpful tips to prevent and manage changes in memory and thinking skills:

- Meditation can help your focus and awareness.
- Exercise can improve your thinking, alertness, mood, and focus. Walking, caring for pets, and gardening are examples of light exercises that can help.
- Use a list, reminders, or alarms to keep track of what needs to be done.
- Do the hardest mental tasks when you have the most energy.
- Get enough rest and sleep.
- Set up and follow regular routines, and focus on one task at a time.
- Stay away from alcohol as it may limit mental sharpness.

If you are having changes in your memory or thinking skills, ask your healthcare team if neuropsychology, speech therapy, occupational therapy, or cognitive rehabilitation is right for you.

Mouth Sores

Cancer treatments can sometimes affect the inside of your mouth or gums and cause sores. This can make it hard to eat or talk. The goal is to reduce any pain until your mouth heals.

Helpful tips to prevent and manage mouth sores:

- Suck on ice chips or a frozen pop.
- Gently clean your teeth, gums, and tongue after each meal.
- Get regular dental check-ups.
- Stay away from hot, spicy, or sharp foods.
- Eat small meals throughout the day instead of 3 big meals.
- Use a straw to drink.
- Rinse your mouth with warm salt water.

Common medications:

- Magic mouthwash
- Numbing gels, like Orajel and Zilactin-B
- Over-the-counter pain medication

Nausea and/or Vomiting

Nausea (feeling the need to vomit) and vomiting are common treatment side effects and can lead to loss of appetite, weight loss, fatigue, and dehydration (not enough water in the body). Nausea and vomiting can often be prevented with help from your healthcare team.

Helpful tips to prevent and manage nausea and/or vomiting:

- Eat bland foods.
- Don't eat greasy, salty, spicy, or heavily seasoned foods.
- Stay away from strong odors. Eating foods that don't have strong smells may help to decrease nausea.
- Try ginger products.
- Sit upright for 2 hours after eating.
- Wear clothing that is loose fitting around the waist.

- Try relaxation techniques, such as guided imagery, meditation, and soothing music.
- Distract yourself, and take your mind off your symptoms by listening to music, watching TV, or reading.
- Try acupressure wrist bands (found in drug stores).

Common medications:

- Ativan (lorazepam)
- Reglan (metoclopramide)
- Zofran (ondansetron)
- Compazine (prochlorperazine)
- Anergan or Phenergan (promethazine)

Tell your healthcare team right away if you are not able to hold down food or drink to prevent dehydration.

Nerve Pain and/or Numbness

You may feel numbness or tingling (neuropathy) in your hands and feet. Some people say they feel like they are standing on or holding ice. It may also be hard to feel hot or cold temperatures.

Helpful tips to manage nerve pain and/or numbness:

- Distract yourself by watching TV, reading, or listening to music.
- Use guided meditation.
- Use warm water, since hot or cold water can make symptoms worse.
- Stay away from things that make your neuropathy worse, such as tight shoes, standing for too long, or drinking alcohol.
- If you have numbness in your feet, always wear shoes and check your feet once a day for open sores.

- If you have numbness in your hands, make sure you protect your hands from hot surfaces and sharp objects (use extra care when cooking).

Common Medications:

- Steroids
- Patches or creams of numbing medicine
- Antidepressant medicines
- Anti-seizure medicines

If you have nerve pain or numbness, talk to your healthcare team about whether acupuncture, physical therapy, or occupational therapy may be right for you.

Shortness of Breath – Difficulty Breathing

Shortness of breath is common for people with lung cancer. Breathing can be uncomfortable and you may feel like you can't get enough air into your lungs. It can feel scary, but this can happen even when the levels of oxygen in the blood are normal. Some causes of shortness of breath may be related to your cancer and others may not.

It is important to call your healthcare team if you have any concerns about your breathing. They can determine the cause of your shortness of breath and offer the right kind of help.

Helpful tips to prevent and manage shortness of breath:

- Stay away from smoky places. If you smoke, try to cut back. Your healthcare team can help.
- Try light exercise, if you can, as exercise can help improve the flow of oxygen to your blood.

- Try sleeping with your head raised (on pillows) to help you breathe easier.
- Manage anxiety by taking slow, steady, deep breaths, and try to picture a setting that relaxes and calms you.
- Try breathing exercises. Breathe in through your nose for 4 counts. Hold your breath for 4 counts. Blow out slowly through pursed lips for a count of 8.
- Use a handheld fan to activate facial nerves. This can help you feel like you can breathe easier.

Common medications:

- Medicines used in an inhaler (a tool used to breathe in medicines)
- Medicines used in a nebulizer (a tool that turns liquid medicine into a mist that is breathed in)
- Oxygen

Tell your healthcare team right away if you are having difficulty breathing. Talk to your healthcare team about whether oxygen or an incentive spirometer (a tool designed to increase lung function) could help you.

Skin Reaction

You may notice a rash, redness, very dry skin, changes in your nails, or changes in your hair. Some cancer treatments, such as radiation and immunotherapy, can cause skin reactions that range from mild to severe.

Helpful tips to prevent and manage skin reactions:

- Use mild soaps, pat your skin dry, and use a sensitive skin moisturizer, even before a rash appears.
- Protect your skin from heat and cold.
- Protect your skin from the sun.
- Wear loose, soft clothing.

- Use baby oil spray to reach the skin on your back.
- Avoid using skin products right before your radiation treatment.

Common medications:

- Steroid creams
- Antibiotics
- Antihistamines

Throat Soreness

A sore throat may happen if you are having radiation to your chest. Radiation can cause your throat to become inflamed and feel sore when swallowing. It is even more common if you are having chemotherapy and radiation at the same time.

Helpful tips to prevent and manage throat soreness:

- Eat soft, smooth foods.
- Take small bites, and chew your food very well before you swallow.
- Avoid eating spicy, citrus or acidic foods.
- Avoid alcohol.
- Stay away from smoky places. If you smoke, try to cut back. Your healthcare team can help.
- Try cold foods or foods that are only slightly warm.
- Eat small meals throughout the day instead of 3 big meals.

Common medications:

- Over-the-counter pain medicine
- Throat drops
- Lidocaine
- Magic mouthwash

Tell your healthcare team right away if you are not able to eat or drink due to your sore throat.

Trouble Sleeping

Even though your cancer treatment may make you feel very tired, you still may have trouble sleeping. This can be due to other medicines in your chemotherapy cocktail, stress, anxiety, or even extra napping during the day. It is good to think about your sleep habits and try to see what may be causing the problem.

Helpful tips to prevent and manage difficulty sleeping:

- Go to bed and wake up in the morning at the same time each day.
- Stay away from caffeine and alcohol before bedtime.
- Avoid eating, exercising or using your cell phone, tablet or computer for at least 2 hours before bedtime.
- Choose a restful task before bed, such as taking a warm bath, reading, listening to soft music, or meditation.
- Make sure your bedroom is cool and dark.
- Limit naps to no longer than an hour each day.
- Try a weighted blanket. The weight of the blanket should be no more than 10% of your body weight.
- Repeating sounds may help calm an active mind and help you fall asleep.
- Try a metronome set at 60 BPM, music tuned at 432hz, a fan, or a sound machine.

Common medications:

- Trazodone
- Melatonin
- Benadryl (diphenhydramine)

Side Effects Tracker

You may use this form to track your symptoms and share them with your healthcare team. If you have a symptom that can be seen, like swelling or a rash, take a picture. Your healthcare team can use the photo to see if the symptom has gotten better or worse over time.

Date/Time	What symptoms or side effects are you having?	How severe is it? 1=mild 2=medium 3=severe	What made it better? What made it worse?	Did you take all medicines as prescribed today?

“You will have to figure out how to live with cancer. Take one day at a time. Be positive, think positive thoughts, do positive things.”

—Matt



Other Health Conditions

Other Health Conditions

Having lung cancer and treatment for lung cancer can put you at higher risk for some issues that can be serious. Ask your healthcare team about the conditions described below and what action you should take if you have signs or symptoms.

Pneumonia is an infection that can cause fluid or pus in the lung(s). Cancer and cancer treatment can weaken the immune system and place you at more risk for pneumonia. Pneumonia can be treated with medicine to avoid more serious problems.

Pleural effusion⁸⁷ happens when fluid collects in the layers of tissue that surround the lungs. It can be treated by draining the fluid out of the lung. Sometimes, pleurodesis is needed. **Pleurodesis** involves placing a chest tube with chemicals to seal the lung to the layers of tissue to stop fluid from building up. The chest tube must stay in place until the fluid has fully drained out of the lung.

Some of the signs and symptoms of pneumonia and pleural effusion are alike. They may include a cough that won't go away or gets worse, chest pain, difficulty breathing, or fever.

A **pulmonary embolism** is a blood clot that travels through the bloodstream into the lung. Cancer can make your blood thicker than usual and can increase the risk of a blood clot. It can often be treated with IV medicine.

Deep vein thrombosis is a blood clot that forms in a deep vein, often in the leg. It can often be treated with IV medicine.

The signs and symptoms of a blood clot will depend on where the blood clot is located. A blood clot in the lung can cause shortness of breath, chest pain, and coughing up of blood. This should be treated as a medical emergency. A blood clot in the leg can cause swelling or severe pain in your leg or other body parts and should also be treated as a medical emergency.

Contact your healthcare team right away if you have:

- A new or worsening side effect from treatment.
- Trouble breathing, chest pain, or an increase in coughing.
- Fever of 100.5F or higher.
- Fainting, dizziness, or confusion.
- Diarrhea with bad cramping or pain, blood in the stool or urine, or dark urine.
- Changes in vision, memory, or thinking skills.
- Swelling in any part of the body.

“GO2 for Lung Cancer is tenacious, innovative, collaborative and determined that lung cancer patients will no longer be left behind.”
—Jaimi



Clinical Trials

Clinical Trials

What are they?⁸⁸

Before a new drug is approved for use, it has to pass through a strict testing process. This testing process is called a clinical trial.

A clinical trial is a type of research that is done to study new cancer treatments to learn how well they work and how safe they are. Most of the time, the question researchers are trying to answer is whether the new treatment is better than the current treatments.

Clinical trials are very important because they are the only way new and better treatments can be found. Learn about clinical trials early so you have plenty of time to decide whether one is right for you.

Clinical trials are closely watched by the Food and Drug Administration (FDA), an institutional review board (also known as an ethics committee) at a hospital, research center, or cancer center, and a doctor who is trained to manage clinical trials. Clinical trials can study a new drug, a combination of drugs, a new surgery method, and/or new ways to manage side effects.

A clinical trial may also be called a research study, a study, or a trial. The team that runs the trial is sometimes called the clinical trial team, the research staff, or the study staff.

There are a few different types of clinical trials. They include:

- **Prevention trials** explore how to prevent lung cancer.
- **Screening trials** develop new and better ways to detect lung cancer.
- **Diagnostic trials** develop better tests for diagnosing lung cancer.
- **Treatment trials** find new drugs, radiation treatments, and new surgery methods to treat lung cancer.

- **Supportive care trials** find new treatments to decrease the symptoms and side effects of lung cancer.

Before a drug can be studied in people, it is studied in a lab and with animals. Only after this lengthy process is complete will a drug be approved for use in a clinical trial with people.

Clinical trials are done in phases. Each phase of a trial has a different purpose.

Phase 1 trials:

- The research team studies the amount of the drug to give, any side effects that may occur, and the safety of the drug.
- There are 20–80 people in the study.

Phase 2 trials:

- The research team studies how well the treatment works.
- There are 100–300 people in the study.

Phase 3 trials:

- The research team studies the effects of the drug compared to current cancer treatments.
- There are 300–3,000 people in the study.

Note: If you join a phase 3 trial, you may be randomly assigned to a test group or a control group. If you are selected for a test group, you will receive the drug being studied. If you are selected for the control group, you will receive standard treatment for your type and stage of cancer. Results from the 2 groups will be studied to see which treatment works best and what side effects occur.

Phase 4 trials:

- These trials begin after the FDA has approved the treatment.
- The research team studies how well the treatment works and any side effects and safety issues that may not have been seen in the smaller group of people.

Informed consent⁸⁹ is the process of learning the details about a clinical trial to help you decide if you would like to join the study. The study staff will inform you of all the details of the study. These include:

- The purpose of the study
- How long the study will last
- Any required health tests or procedures
- The risks and benefits of joining the study

Once you have all of the details, you can decide if you want to sign the informed consent form and join the trial. Informed consent is not a contract, and you can leave the trial at any time. The clinical trial staff may also decide to stop treating you if there is a safety issue, if the treatment is not working well, or if the trial is finished.

If you join a clinical trial, your cancer treatment needs will be managed by the clinical trial doctor throughout your time in the trial. You can expect to receive very high-quality care because the staff closely observes you as a part of the study. The staff is also closely watched by the **institutional review board (IRB)** at the hospital, research center, or cancer center. The role of the IRB is to make sure the trial is safe, and all of the rules are being followed.

Clinical trials in the US and around the world are listed in a database found at clinicaltrials.gov. There are thousands of clinical studies in the database that can

be narrowed down to match your needs. If you find a clinical trial you would like to join, it is very important that you discuss it with your healthcare team.

Searching for clinical trials can be very difficult. If you need help finding clinical trials, our LungMATCH navigators can help. Contact our HelpLine at 1-800-298-2436 or email support@go2.org

What else should I know about clinical trials?

Any time you are facing a treatment decision, you can ask about clinical trials that might be right for you. There are trials for all cancer stages. Your healthcare team can help you understand the benefits and risks based on your cancer type and overall health. During a clinical trial, you'll receive either the cancer treatment being studied or cancer treatment as usual with in-depth monitoring of your overall health and progress.

Questions to ask your healthcare team about a clinical trial you are considering:⁹⁰

- What is being studied?
- What phase is this clinical trial?
- What are the risks and benefits?
- How long will the trial last?
- Who pays for the trial?
- What will I be asked to do?
- Can I learn the results of the trial?

“Don’t pay too much attention to the statistics. My doctor said I had a 5% survival rate, so I focused on traveling with my daughter and making memories with her. That was 13 years ago.”

—Marianne



Advanced Lung Cancer

Advanced Lung Cancer

Having scans on a regular schedule is important because it allows your healthcare team to see how well your treatment is working. If your follow-up scan shows that the cancer has gotten smaller or is gone, this assures you and your healthcare team that your treatment is working well. If your scan shows the cancer has grown larger or has spread to other areas, this means it's time to change to a different cancer treatment.

Drug Resistance

When a cancer drug treatment works well at first, then stops working well, it means the cancer cells have changed or mutated. It is common for cancer cells to change over time. They change themselves, so the cancer treatment being used can no longer harm them. This is called **drug resistance** because cancer can resist the effects of the treatment drug that is being used and start to grow again.

Repeat Biomarker and Biomarker Testing

Repeat biopsy⁹¹ and biomarker testing are needed when drug resistance occurs and cancer progresses. Repeat testing looks for new changes or mutations that can be treated better with a different method or drug.

Cancer cells can change over time as the cancer is treated. Cancer one year after diagnosis may not be the same cancer seen under the microscope when you were first diagnosed. One way to know how cancer has changed is to re-biopsy the tissue or perform a liquid biopsy test (see **biopsies**, page 26) to look for new changes.

After the results of the repeat biopsy and biomarker testing return, your healthcare team will discuss the results and your treatment options with you. Sometimes

biomarkers have changed and a different targeted therapy is an option. In some cases, NSCLC⁹² can transform into small cell lung cancer. When this happens, it is called **transformed small cell lung cancer** (tSCLC).

Metastasis

When lung cancer spreads to other parts of the body outside of the lungs, it is called **metastasis or mets**.⁹³ It may also sometimes be called advanced lung cancer. Lung cancer spreads by growing into nearby tissues, or by traveling through blood vessels and the lymph system to distant parts of the body.

When lung cancer spreads to another part of the body, it is still lung cancer. For example, lung cancer that has spread to the bones is not bone cancer. It is lung cancer cells that have spread to the bones.

Most common mets from lung cancer are found in:

- Bones
- Adrenal glands
- Liver
- Brain

If you are having symptoms that affect a new part of your body or body function, always tell a member of your healthcare team right away.

Bone Mets

Lung cancer that spreads to the bones most often goes to the backbone, pelvis, upper arms, upper legs, hands, and feet. People with bone mets often complain of dull pain that gets worse over time and may feel worse at night or with movement. You may feel weak or thirsty or have muscle aches. Your healthcare team may suggest you take a drug that hardens and protects your bones.

Lung cancer can spread to the bone, including to the skull. Mets to the skull are bone mets and not the same as when cancer spreads to the brain.

Adrenal Gland Mets

The adrenal glands are small glands shaped like triangles that sit on top of your kidneys. Your adrenal glands make hormones that manage your blood pressure, metabolism, immune system and stress hormones. When lung cancer spreads to the adrenal glands, it rarely causes symptoms; however, if symptoms are present, they may include:

- Back pain
- Pain in the belly
- Changes in adrenal function, such as low blood pressure, low blood sugar, low sodium, or high potassium

Liver Mets

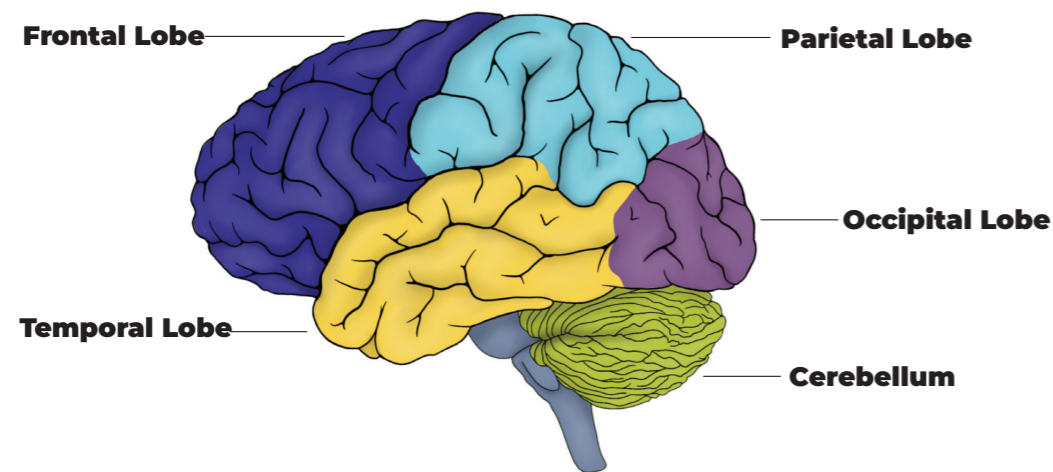
The liver filters the blood in your body and makes a fluid called bile that helps to digest fat and waste. Your liver also helps to balance blood sugar and makes nutrients needed for good health. There are often no symptoms of liver mets. If symptoms are present, they may include:

- Pain under the right side of your ribs or stomach
- Upset stomach
- Lack of appetite
- Weight loss
- Swollen stomach
- Yellowing skin

Brain Mets

Your brain is a very complex organ that allows you to think, talk, move, feel, and remember. Knowing a little bit about the brain and how it works can help you understand the possible effects of brain metastasis.

The brain is divided into sections and each section has its own job. If lung cancer spreads to the brain, it can change how that part of the brain works.⁹⁴



The **frontal lobe** allows us to talk. It also controls our emotions and things such as intelligence, reasoning, behavior, memory, sexual urges, and personality.

The **parietal lobe** processes our body's senses.

The **temporal lobe** helps with our memory, speech, and hearing.

The **occipital lobe** allows us to understand what we see.

The **cerebellum** makes sure that our muscles work together so that we can walk and stand.

Symptoms of Brain Mets

Some symptoms⁹⁵ caused by brain mets can be quite general like a headache, memory problems or feeling very tired. Others can be very specific and are caused by pressure or irritation to a certain part of the brain. The symptoms of brain mets will match the part of the brain where the cancer is located.

Common symptoms⁹⁶ of brain mets can include:

- Speech problems (such as finding words)
- Muscle weakness
- Eye problems or trouble reading
- Pain, numbness, or paralysis (loss of the ability to move in a part of the body)
- Seizures
- Problems with body movements
- Nausea and/or vomiting
- Fatigue (a feeling of being tired that doesn't go away with enough rest or sleep)
- Memory problems
- Headaches

Treatment for Brain Mets

Treatment decisions for brain mets are based on:

- The kind of lung cancer you have
- When the brain mets are found
 - Whether it is before or after lung cancer is diagnosed
 - Whether you are in treatment or after lung cancer treatment has ended
- How many and where the mets are located in your brain
- Your overall health

Treatment for brain mets is very specialized and can include one or more of the following therapies:

Radiation therapy⁹⁷ is often used in the treatment of brain mets. It uses high-energy beams to kill or shrink cancer cells. The beams may be aimed at certain spot(s) in the brain, or the whole brain may receive radiation.

Types of radiation therapy:

- **Whole brain radiation (WBR) or whole brain radiotherapy (WBRT)**⁹⁸ may be needed if there are many tumors in the brain. It works by delivering a low dose of radiation to the whole brain and can treat small amounts of cancer that cannot be seen on imaging tests.

- **Stereotactic radiosurgery (SRS) or stereotactic radiotherapy (SRT)** does not involve actual surgery with a knife. It treats one small part of the brain with a very high dose of radiation using many small radiation beams.⁹⁹
 - During SRS, a head frame is used to keep your head very still. This allows the beams of radiation to enter the tumor from many different angles. It is very precise and helps to protect the healthy brain tissue near the tumor. SRS may be given as a single treatment or over a few sessions.

Sometimes, radiosurgery is used in combination with whole brain radiation therapy. This can work well because whole brain radiation uses a very low dose of radiation to treat cancer that is too small to be seen. Then, radiosurgery gives a high dose to the areas of cancer in the brain that can be seen.

Surgery to remove the cancer¹⁰⁰ may be considered in some cases when there are fewer than 3 spots in the brain. Surgery to the brain is done through a procedure called a craniotomy.

During a **craniotomy**, the surgeon will make an opening in the skull to reach the brain. Treatments with whole brain radiation are often used after surgery. Talk with your healthcare team about whether surgery is an option for you. It is important to understand the risks and benefits of surgery.

Immunotherapy may be used to treat NSCLC and may cross the blood-brain barrier to treat brain mets. Ask your healthcare team if immunotherapy is an option for you.

Chemotherapy can have trouble getting through the blood-brain barrier and is not typically used to treat brain mets.

Blood-brain barrier

The type of treatment needed for mets in the brain may be different than the treatment you are currently receiving for NSCLC in other parts of your body. This is because the brain has an extra layer of protection, and some treatments can't get through this barrier to fight the cancer.

This barrier is known as the "blood-brain barrier." Its job is to stop harmful substances from reaching the brain while letting helpful ones into the brain. Unfortunately, lung cancer can pass through this barrier. Some cancer treatments can get through the barrier and attack cancer in the brain, but others cannot.

Cachexia¹⁰¹ is a medical term used to describe ongoing weight loss, muscle wasting, loss of appetite, and the extreme fatigue (tiredness) that sometimes happens in people with late-stage cancer. It is caused by the body's response to substances that cancer cells release in late-stage cancer.¹⁰² This means it can't be reversed by simply eating more food. Losing weight and having trouble eating is not your fault. There are some medicines that can increase your appetite or treat other symptoms related to cachexia that can help you feel better and feel more like eating. Ask your healthcare team about these options.

Keeping a healthy weight is important to be able to manage cancer treatment well, maintain your energy, and to be able to enjoy activities that matter to you. For this reason, your healthcare team will watch your weight closely and look for signs of cachexia, so it can be managed early.

Cachexia is being studied in clinical trials to better understand how it happens and to develop more treatments. Ask your healthcare team if a clinical trial is right for you.



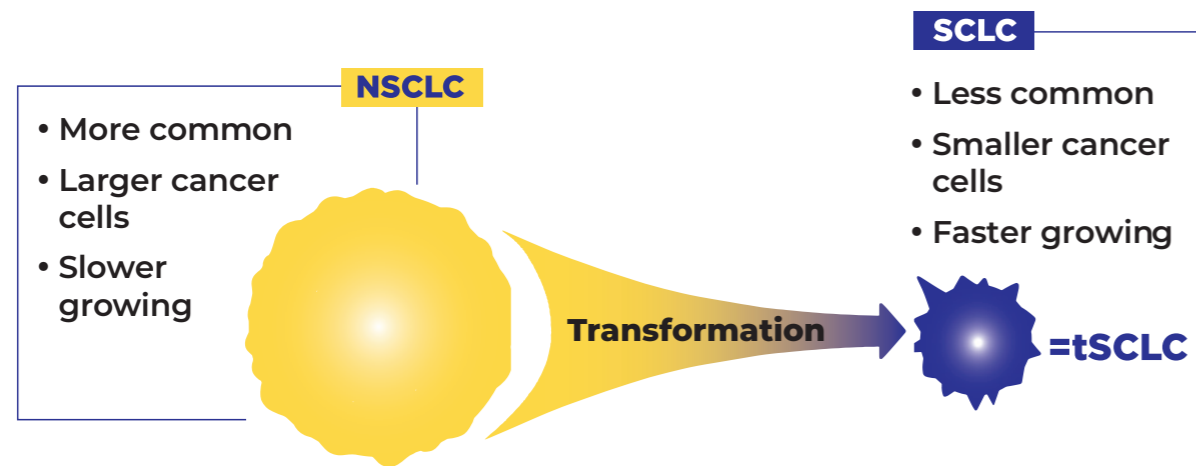
Transformed Small Cell Lung Cancer

Transformed Small Cell Lung Cancer (tSCLC)

In rare cases, NSCLC cells change into SCLC as they try to resist drug treatment. When this happens it's called transformed small cell lung cancer (tSCLC).

Biomarkers are changes or mutations inside cancer cells that make them different from healthy cells. They are what drive cancer cells to grow and spread.¹⁰³

tSCLC occurs most often in people whose NSCLC tumors have a biomarker called EGFR and who are being treated with certain drugs. Researchers are studying to see why this type of change happens in some people and not others. This data will help researchers understand what causes tSCLC, which can lead to more treatment options.



Transformed SCLC may have both NSCLC and SCLC cells as it transforms. For this reason, either SCLC treatment or a combination of SCLC and NSCLC treatments may be used to treat both cell types. Treatment decisions are based on your most recent biopsy results and your health needs.^{104, 105}



Living with Lung Cancer

Living with Lung Cancer

Your life changes after a lung cancer diagnosis. These changes are not easy, but being prepared can help.

Support

A diagnosis of lung cancer can bring a broad range of emotions. Your first reaction may be one of disbelief, denial, or fear. You may feel angry or depressed, especially if you are not feeling well and find that you can't do all of the things you usually do. These are normal feelings. Be kind to yourself during this time and know that you are not alone. Talk to someone you trust about your feelings, and give yourself the time you need to work through and process your emotions.

There are many ways to manage emotions. There will be days when you feel better than others. If you find yourself feeling fearful, anxious, depressed, lacking sleep, losing appetite, and/or fatigued more days than usual, tell your healthcare team and ask to see a mental health professional.

A social worker, nurse, or navigator at your treatment center can help you find a person or group that can support you.

Contact GO2 for Lung Cancer for one-on-one support, to connect with a Phone Buddy, to join our Gathering Hope group, or for other support services. Contact our HelpLine at 1-800-298-2436 or email support@go2.org.

It can be hard to ask for help, but letting people know what you need and allowing someone to help can provide comfort for those who love you. Having help with household tasks and errands can give you time to rest and time to yourself.

If you need time to yourself, you could decide to ask one person to act as a gatekeeper. Your gatekeeper can take phone calls, answer emails, schedule visits, and organize others who want to help.

Others may be able to help with:

- **Meals:** Bringing meals that can be frozen and eaten later is helpful; arranging for meal delivery services can also be helpful.
- **Childcare:** If you have children, have them attend play dates on days you have treatment or when you need a break.
- **Transportation:** Schedule someone to drive you to treatment to conserve your energy.
- **Light housekeeping:** Ask for help with cleaning to conserve your energy.
- **Lodging:** If you need to travel for treatment or other appointments, ask the staff at your treatment facility about places to stay that are reserved for patients and families.
- **Activities:** Arrange for visits with friends, watch a movie, play cards, and games; engage in a hobby, listen to music, or do something else that makes you happy.

Spirituality

Being spiritual can involve being a part of an organized religion, or it can be any practice that connects you with a higher being or brings you peace. Spirituality can include yoga, meditation, and other mind-body practices, or using art or writing to express yourself.

For some, a diagnosis of lung cancer strengthens spiritual beliefs and helps coping with your diagnosis and treatment. Others experience a crisis of faith. As you reflect on your own spiritual beliefs, allow yourself the space to feel, and react in a way that is natural for you. Think about connecting with someone you trust to talk about how you feel. Both insight from others and quiet time for yourself can be helpful.

Daily Activities

It's important for you to find a healthy balance in life, and finding this balance takes time. There may be times when you don't feel well enough to manage all the things you used to do, and that's okay. There will be other times when you feel energetic. Take advantage of the times when you feel your best, and do things that are meaningful to you. There are also little ways you can save energy throughout each day that can help you feel better at the end of the day.

Many people find it helpful to:

- Divide the day into times of rest and times of activity.
- Make a flexible plan for your day or week, and adjust plans based on your energy.
- Do the tasks that take the most energy when you have the most energy.
- Listen to your body, and rest before you become too tired.
- Sit down during tasks instead of standing.

Oxygen

If you find that you are feeling short of breath, talk to your healthcare team. They will assess you and may suggest that you use oxygen. When oxygen levels are too low, you may feel tired, short of breath, or confused. Using oxygen can help you feel better and allow you to complete the tasks you need to do and tasks you want to do.

Some people use oxygen only while doing certain activities, like walking or flying on a plane; others use it throughout the day and night. Some people only need oxygen for a short time while they are healing from surgery or another health problem while others need oxygen long-term. Your healthcare team can order an oxygen tank for your home and one to carry with you when you need it.

Nutrition

Many people with lung cancer and their loved ones are concerned about eating well. Sometimes the disease, the treatment, or side effects from treatment can cause you to lose your appetite or make food taste different. Ask your healthcare team if you can talk to a dietician or nutritionist to find foods that will taste good to you and give you the nutrition you need. They can guide you to foods that may help boost your immune system and get you the calories you need.

The goal is to maintain your weight and energy by eating a well-balanced diet. If cooking is a struggle, using a meal delivery program can be helpful. Ask your healthcare team to help you find a program, or check with local churches or synagogues as some offer meal delivery services.

Travel

Traveling can include driving a couple of hours to see friends or family, or it can include flying to a faraway place. No matter where you're going, planning well for your trip is an important step.

Planning for your Trip:

- **Let your healthcare team know when you plan to travel.** They can discuss the timing of your trip and how it fits in with your current health and treatment needs.
- **Make plans that match your energy level.** If your energy is low, be sure you move at a slower pace, and leave plenty of time for rest in your schedule. If you will be walking outside, try to stay on even terrain. Bring a cane or a walker for support and safety.
- **Pack a copy of your medical records and a list of all of your medications.** This information will be needed if you have to get medical care during your trip. Your medicine list should include brand and generic names, drug strength, and how often you take each drug.
- **Bring your healthcare team's contact information.** Your healthcare team will need to be reached if you have to get medical care during your trip.
- **Research travel areas that are outside of the US.** Find out if you need extra vaccinations (shots or drugs to prevent sickness) or if you need to be approved to bring your medicines through customs. Find out how to get medical care, where to get it, and whether you need international health insurance. Always talk to a member of your healthcare team before you receive a vaccination or take a new medicine to ensure its safe for you.

- **Pack your medicines in your carry-on bag when flying or riding on a bus or train.** This will ensure that your medicines are with you anytime you need them. Be sure to carry them in the prescription bottle given to you by the drug store.
 - If your medicines need special storage or climate control, or if you need to bring liquid medicine or needles, you will need to ask for the rules of the airline, train, or bus company you are using, and follow their guidelines.
- **Arrange for any flight (or other travel) needs.** This may include boarding the plane, train, or bus early or help with getting around inside the airport or station.
 - **If you are bringing a portable oxygen concentrator:** Tell the airline, train, or bus company when you make your reservation. They require advance notice to ensure your oxygen system is allowed on board and will give you any other rules or steps you need to follow.

Places that are in areas of high altitude can lower the oxygen level in your blood. If you plan to fly or visit a place that is at high altitude, ask your healthcare team if you should have a High Altitude Simulation Test (HAST) to see if you will need oxygen for your flight or during your trip.

Complementary and Alternative Therapies

If you search for information about lung cancer, you may find sources that discuss complementary and alternative therapies.

Complementary therapies are those used alongside common cancer treatments. They can, for example, include a mind-body approach or diet supplements.¹⁰⁶ Complementary therapies are meant to help with symptoms of cancer, ease the side effects of treatment, or relieve stress and anxiety. Some healthcare teams practice **integrative medicine**, which is the practice of using the usual treatments along with complementary therapies.

Alternative therapies are those used instead of the common treatment that your cancer center offers. Alternative therapies have not been tested or researched in the same way, so it's not known if they are safe and effective. Some may even be harmful. Be careful of online claims of unproven cures that may cost a lot of money and not be helpful.

Before using any complementary or alternative therapy, be sure to talk with your healthcare team as some may be harmful to you.



Paying for Cancer Care

Paying for Cancer Care

You may be worried about how to pay for lung cancer care and treatments. There is help available. Your healthcare team should include a social worker or a certified benefits counselor who can explain your options and help you apply for programs that can assist you.

Below are a few programs that can help with healthcare costs. Ask the social worker or certified benefits counselor at your cancer center which program is best for you.

Medicare

Medicare is a government national health insurance program in the US for people age 65 or older and some younger people who have certain disabilities or end-stage renal disease (ESRD). There are a few Medicare programs that cover different types of healthcare needs. Some are free, and others cost extra. For example, Medicare Part D can help with prescription costs.

Medicaid

Medicaid is a health insurance program for people who have low incomes and people with certain disabilities. Each state has its own program.

Consolidated Omnibus Budget Reconciliation Act (COBRA)

If you have health insurance through your job, the Consolidated Omnibus Budget Reconciliation Act (COBRA) allows you to keep your health insurance for a certain period of time if you are no longer able to work. Learn more at the US Department of Labor website at <http://www.dol.gov/dol/topic/health-plans/cobra.htm> to learn more.

Social Security Disability Insurance (SSDI)

The Social Security Administration (SSA) includes lung cancer in its medical listing. This means you may be able to receive disability insurance to help pay

for your lung cancer treatment. Visit the Social Security Disability program website at <http://ssa.gov/disability/> or call 1-800-772-1213 to find out if you are eligible to receive these benefits.

High-Risk Medical Insurance

Many states offer high-risk medical plans for people with preexisting conditions and a lung cancer diagnosis. Healthcare.gov defines a preexisting condition as a health problem you had before the date that new health coverage starts.¹⁰⁷ For a list of states offering these plans and how the Patient Protection and Affordable Care Act affects you, visit <http://www.healthinsurance.org>.

Special Rates

Many hospitals will work with you and your family to create a payment plan that suits your budget, or you may apply for financial assistance to lower your cost. Call your hospital's billing office to learn more.

Patient Advocate Foundation (PAF)

The Patient Advocate Foundation has a Co-Pay Relief Program that pays insurance co-pays for drugs used to treat NSCLC and SCLC. Visit their website at <http://www.copays.org/resources/lung.php> to learn more.

Patient Access Network (PAN)

The Patient Access Network pays insurance co-pays for drugs used to treat NSCLC and SCLC. You can sign up on their website, <http://www.panfoundation.org/>, or call them toll-free at 866-316-7263.

Healthwell Foundation

The Healthwell Foundation may be able to help you cover coinsurance, copayments, healthcare premiums, and other costs for some treatments. The list of diseases that the foundation supports changes often. Visit their website at <http://healthwellfoundation.org/>, or call 1-800-675-8416 for more information.

Good Days

The Chronic Disease Fund helps pay for drugs, co-pays, and travel to treatment. Visit their website at <https://www.mygooddays.org/>, or call 877-968-7233 for more information.

CancerCare

CancerCare helps with the cost of cancer care in Connecticut, New Jersey, and New York and also offers counseling with certified oncology social workers and support groups for those diagnosed with lung cancer and their caregivers. If you live in one of these states, visit their website at http://www.cancercare.org/diagnosis/lung_cancer for more information.

Pharmaceutical (Drug) Companies

Some pharmaceutical companies will help pay for the cost of their drug if you are having trouble paying for your treatment. The social worker or certified benefits counselor at your cancer center can help you find out the drug company that makes your treatment medicine and can help you apply for help on the company's website.

If you have questions about these programs or need help paying for your cancer treatment, ask to speak to a social worker or certified benefits counselor at your treatment center.



End-of-Life Planning

End-of-Life Planning

In life, we plan for many things. When we are preparing for the future, we think about our beliefs, values, and what is most important to us. Then we make decisions. The thought process is the same when planning for end-of-life.

End-of-life plans include directions on how to manage pain and where you want treatment (such as in a hospice care center, at home, or in a hospital), and preplanning of funeral services. It also includes preparing legal documents, such as an advance directive and a health care proxy. These are forms to complete to make sure your healthcare wishes are in place and known by your loved ones and your healthcare team. You will decide what treatments and medicines you want to receive – and at what point in your treatment you will not want to receive them. You may also want to speak with a lawyer for help in completing these documents.

Your end-of-life plans may be guided by your personal or religious beliefs, by talking with loved ones, or by talking with your healthcare team, pastor, counselor, or other trusted people. Although these kinds of talks are difficult, your loved ones and healthcare team must understand what you want, so they can provide the treatment you would choose for yourself.

Sometimes, what you want for yourself may change over time. That's okay. As your feelings about treatment change, make sure your family and healthcare team know about these changes.

By having your plans in place, you will be able to focus all your attention on your treatment. If possible, try to have these talks early while you still feel healthy so that you and your loved ones aren't trying to make decisions in a time of crisis.¹⁰⁸

Advance Directive

An **advance directive** is a formal, written plan that lets others know your future choices for healthcare and end-of-life care. Creating an advance directive allows you to learn about the healthcare choices you have, decide what you want and don't want, make a formal plan, and share it with your loved ones and healthcare team.

Why is an advance directive important?

Your advance directive states your choices for healthcare and end-of-life care in writing exactly the way you want them. This supports your loved ones and saves them from feeling unsure about making healthcare choices for you. Most important, it ensures your wishes will be followed even if you cannot speak for yourself.

What is included in an advance directive?

An advance directive is a legal record or form that describes your future healthcare choices. It spells out key instructions.

Healthcare Power of Attorney or HealthCare Proxy

This is a person you choose to make healthcare choices for you if you are not able to make them for yourself. If a decision needs to be made that is not listed in your advance directive, this person will make the decision. Be sure to choose someone who knows your wishes and whom you trust.

Living Will

A living will is a list of the treatments you want and don't want when end-of-life is near. It may include your choices about medicines, treatments for pain, a tube for breathing, or donating organs. Each state has a format for a living will. You can find the form for your state online using the resources listed below, or you may choose to use a lawyer to help you write your own.

Do-Not-Resuscitate (DNR) and Do-Not-Intubate (DNI)

DNR and DNI orders tell your healthcare team your choices about getting help with breathing or restarting your heart if end-of-life is near.

A do-not resuscitate (DNR) order means that you do not want help to restart your heart if it stops. A do-not-intubate (DNI) order means that you do not want a breathing tube inserted to restore normal breathing. Ask your doctor or member of your healthcare team to explain how this may apply to your care.

Your healthcare team can provide the forms for you to complete together. The completed forms are kept in your medical chart and/or in your home. You can change either decision at any time before, during, or after treatment. Be sure your healthcare team has a copy of your current wishes.

Free Online Resources

There are websites where you can create an advance directive that will be legal in your state. When you have completed the advance directive document, be sure to share copies with your family, healthcare team, hospital, and healthcare proxy.

- **Aging with Dignity Five Wishes** (agingwithdignity.org) allows you to complete the form online or print a blank copy to complete by hand.

- **Do Your Own Will** (doyourownwill.com) allows you to download the living will specific to your state. This site is also a good resource for general information about wills and estate planning.
- **Caring Connections** (caringinfo.org) is an organization that offers a number of resources, including a free advance directive document specific to your state.
- **Cancer Legal Resource Center (CLRC)** (thedrlc.org) is sponsored by the Loyola Law School of Los Angeles and the Disability Rights Legal Center. The center offers estate planning and a toll-free support line (866-THE-CLRC).
- **National Cancer Institute (NCI)** at the National Institutes of Health (cancer.gov) assists with planning your care and managing symptoms at the end of life.

Preplanning Funeral or Memorial Services

Some people find it helpful for themselves and their families to preplan funeral or memorial services. Planning for a service before it is needed can often make the process easier for all those involved.

- **The LIVESTRONG Foundation** (livestrong.org) can walk you step-by-step through the preplanning process. This includes funeral costs and options for paying for the funeral.

Hospice and Palliative Care

Hospice is a caring support system. The Hospice Foundation of America¹⁰⁹ describes hospice as the “something more” that can be done for the patient and the family when an illness cannot be cured. It is a concept based on comfort-oriented care.

Hospice care includes, but is different than, palliative care:

Palliative care can begin at diagnosis and continue as long as it is needed. It may be provided in any environment. The goal of palliative care is to prevent and/or relieve the effects of cancer and the side effects of cancer treatment. The desired outcome of palliative care is always that your quality of life will be improved.¹¹⁰

Hospice care is typically given when the illness cannot be cured and treatment is no longer provided. Although many people do not enter hospice until the final days of their lives, hospice care can be provided to people who are believed to have up to 6 months remaining. Hospice care includes palliative care and focuses on a person’s physical, emotional, and spiritual needs. Hospice care can be provided in your home or at a hospice care center. If you think hospice may be a good fit for you and your loved ones, talk to your healthcare team and insurance company to find out what services you may need and what is available to you. You can also visit the Hospice Foundation site at hospicefoundation.org/ to learn more about how to find hospice care in your area.^{111, 112}

Grief

Grief is simply a feeling of loss and is completely normal. You may feel a sense of grief some days and not others, or you may feel grief over something very specific to you and your life. You may experience grief at any time, from when you are first diagnosed, during your treatment, and/or when you are making end-of-life plans. You may also feel shock, disbelief, anger, or sadness. Acknowledging what you are feeling and experiencing will help you to heal and move forward.¹¹³

The 5 stages of grief include:

Denial: “The diagnosis is not correct.”— This stage includes shock and disbelief.

Anger: “What did I do to deserve this?” — This stage includes feelings of resentment.

Bargaining: “If you make this not happen, I will become a better person.” — This stage includes feelings of fear and guilt.

Depression: “I am so sad/upset/down I cannot get up in the morning.” — This stage may include fatigue, insomnia, nausea, and vomiting.

Acceptance: “I can deal with this no matter what happens.” — This stage includes feelings of relief and peace.

The grieving process is unique to each person. You may feel these different phases of grief out of order or in different patterns. Many people find it helpful to talk to a loved one, another person who has been diagnosed with lung cancer, or a counselor, therapist, or social worker.¹¹⁴ Support groups can also provide ways to cope and work through grief. It is okay to grieve in the way that feels right for you. However, if you feel that you cannot move forward in life and that you are struggling to cope, do not be afraid to reach out for support.

To find help, locate a support group, or get connected to a GO2 Phone Buddy, contact our HelpLine at 1-800-298-2436 or email support@go2.org.

Bereavement Care

Bereavement is the period of grief and mourning after a loss. Bereavement care is a type of care meant for people experiencing grief and loss. It can help you to identify what you are feeling and work through those emotions. It is meant to offer strength and support. For caregivers, some hospice programs will also offer bereavement care for up to 13 months after the loss of a loved one. Talk to a community hospice program in your area to see what resources are available.

If you feel as though you are in crisis and need immediate emotional support or help, please dial 988 to call the National Crisis Lifeline.



Thank You from a Daughter

In 2003, my mom, Bonnie J. Addario, was diagnosed with lung cancer. Her life changed from one filled with business and family obligations to a life defined by doctor visits, chemo and radiation therapy, and surgery. When my mom was diagnosed with lung cancer, my world changed as well. I was a wife, a mother, and an entrepreneur. Suddenly, I was the daughter of a cancer patient trying to support my mom on a daily basis while trying to find answers to complex healthcare questions.

This handbook is the culmination of years of conversations with people affected by lung cancer, doctors, researchers, and just about anyone with any information relating to lung cancer. I am grateful to our generous supporters without whom this handbook would not exist. Thanks to their willingness to support us and the lung cancer community at large, we are getting closer to our goal of making lung cancer a survivable disease.

I want you to know that I understand the experience you are going through and I am willing to help. To contact me, please call our HelpLine 1-800-298-2436..

Sincerely,

Danielle Hicks, Chief Patient Officer

“My final piece of advice is to find a cancer support group. These groups offer connection and opportunity for real, meaningful friendships.”

— Lindy



Glossary

Glossary

Adenocarcinoma: One of the most common types of non-small cell lung cancer. It begins in the tissue that lines the outside of the lungs.

Adjuvant therapy: A cancer treatment that is given after surgery.

Advance directive: A formal, written plan that lets others know your future choices for healthcare and end-of-life care.

Alternative therapies: Treatments or therapies used instead of the usual, recommended treatment your cancer center offers.

Alveoli: Tiny air sacs at the end of each of the smallest air tubes in the lungs that bring oxygen into the bloodstream.

Autofluorescence bronchoscopy: A type of bronchoscopy that uses a special light to make cancer or pre-cancer tissue appear in a different color than other tissue.

Benign: A term that means not cancer.

Bereavement care: A type of care meant for people who are grieving that can help identify feelings and work through emotions.

Biomarker: Mutations or changes inside cancer cells that make them different from healthy cells.

Biomarker testing: A test that looks for the type of changes or mutations inside cancer cells for the purpose of finding the best treatment.

Biopsy: A test or procedure that confirms cancer is or is not present and shows the exact type of cancer.

Blood-brain barrier: Protective barrier or “shield” that stops some substances from going into brain tissue.

Bronchi: The 2 main air tubes that branch off from the windpipe (trachea) and enter each lung.

Bronchioles: Smaller air tubes that branch off from the larger air tubes (bronchi) inside each lung.

Bronchoscopy: A procedure that places a flexible tube through the nose or mouth and into the tubes of the lungs to help diagnose lung cancer. The scope allows the doctor to see the lungs and take a tissue sample at the same time.

Cachexia: Medical term used to describe ongoing weight loss, muscle wasting, loss of appetite, and extreme fatigue (tiredness) that sometimes occurs in people with late-stage cancer.

Cancer: Unhealthy cells that have a mistake (or mutation) in them that grow and spread.

Carcinoid tumor: A type of cancer that can affect the lung that usually begins in the endocrine (hormone) cells and grows slowly.

Cells: The tiniest basic building blocks that make up your body.

Cerebellum: An area of the brain that helps our muscles work together so that we move smoothly.

Checkpoint inhibitor: A type of immunotherapy that works by blocking the immune cells from attaching to cancer cells.

Chemotherapy: A type of cancer treatment that kills fast-growing and dividing cells.

Chemotherapy regiment: A combination of chemotherapy drugs that make up a treatment.

Clinical trial: Research studies that test a new drug or blend of drugs, procedure, or medical device to find out if it is safe and effective.

Complementary therapies: Treatments or therapies used along with usual cancer treatments and can include a mind-body approach or diet supplements.

Complete blood count (CBC): A blood test that measures many types of blood cells.

Comprehensive biomarker test: A test that uses cancer tissue or a blood sample (liquid biopsy) to look for all known mutations or changes in cancer cells at one time.

Continuation maintenance: A method of using chemotherapy that continues using at least one of the drugs that were received during the first line of treatment.

Core biopsy: A biopsy procedure that uses a needle to remove a small piece of tissue from the tumor or area where cancer may be located.

Craniotomy: An opening in the skull made during surgery to reach the brain.

Deep vein thrombosis: A blood clot that forms in a deep vein of the leg.

Diagnostic trial: A type of clinical trial that develops better tests for diagnosing lung cancer.

DNA (deoxyribonucleic acid): A “map” inside our cells that tells the cells what to do.

Genetic fusion: When 2 genes inside a cell stick together and create a new cancer-causing gene.

Do-Not-Intubate (DNI): A decision in writing that tells your healthcare team and family of your choices about getting help with breathing if end-of-life is near.

Do-Not-Resuscitate (DNR): A decision in writing that tells your healthcare team and family of your choices about getting help with restarting the heart if end-of-life is near.

Electromagnetic navigation bronchoscopy: A type of bronchoscopy test that uses electromagnetic energy and tiny instruments to steer a small tube through the mouth and into the lungs.

Endobronchial ultrasound: A type of bronchoscopy test that uses a robotic controller, like a video game, that makes it easy to guide a small tube through the mouth and into the lungs into hard-to-reach areas.

Endocrine cells: Cells in the body that put out hormones.

Epidural: An injection in the back to control pain.

Fine needle aspiration (FNA): A biopsy procedure that uses a small needle to remove cells from the tumor or area where cancer may be located to help with diagnosis.

Frontal lobe: A lobe or section of the brain that controls our emotions and skills such as intelligence, reasoning, behavior, memory, sexual urges, and personality and helps with talking.

HealthCare Power of Attorney or HealthCare Proxy: A person you choose to make healthcare choices for you if you are not able to make them for yourself.

High-grade cancer: Cancer cells that look a lot different than normal cells and tend to grow and spread quickly.

Hospice care: A group of services that are provided when an illness cannot be cured. It is a concept based on comfort-oriented care and offers a wide range of services and support.

Immunotherapy: A type of cancer treatment that helps the body's own immune system fight cancer.

Informed consent: The process of learning the details about a clinical trial to help you decide if you would like to join the study.

Institutional review board (IRB): A group of people who make sure a clinical trial is safe and is being managed properly.

Integrative medicine: The practice of using usual treatments along with complementary therapies.

Large cell carcinoma: One of the 3 most common types of NSCLC. It often begins in the outer regions of the lungs.

Liquid biopsy: A method of biopsy or biomarker testing that uses a blood sample rather than a tissue sample from a tumor to examine cancer cells.

Living will: Written instructions that inform family and healthcare team members what treatments you want and don't want when end-of-life is near.

Lobes: Sections of the lung.

Lobectomy: A type of surgery that removes an entire lobe of the lung.

Local therapy: Cancer treatments that remove or destroy cancer in a small area of the body. Examples are surgery and radiation therapy.

Low-grade cancer: Cancer cells that look a lot like normal cells and tend to grow and spread slowly.

Lymph nodes: Pea-sized part of the body's lymph system whose job it is to clean the waste out of the fluid that passes through them.

Lymph node dissection or lymphadenectomy: A type of surgery that removes several lymph nodes around a tumor to see if cancer cells are inside of them.

Lymph system: Groups of small pea-sized lymph nodes that clean the waste out of the fluid that passes through them.

Malignant: A term that means cancer.

Mediastinoscopy: A diagnostic test that uses a tube with a camera, called a mediascope, to see inside the chest and around the outside of the lungs.

Mesothelioma: A type of cancer that affects the lung. It begins in the lining that covers organs in the chest and abdomen.

Metastasis or mets: A term that means cancer has spread from its initial spot to other organs.

Mutation: A change or damage that happens inside a cell that makes it unhealthy.

Neoadjuvant therapy: A cancer treatment that is given before surgery.

Next Generation Sequencing (NGS): A tool for biomarker testing that can sequence (analyze) large amounts of genes quickly and accurately to see if there are any mutations or changes in cells.

Occipital lobe: A lobe or section of the brain that allows us to understand what we see.

Palliative care: A group of services that help to prevent and/or relieve the side effects of cancer and cancer treatment with the goal to improve quality of life.

Paraneoplastic syndrome: A group of symptoms that occur as a result of cancer but are not directly related to the cancer cells and often involve the hormone system and/or neurological system.

Parietal lobe: A lobe or section of the brain that processes our body's senses.

Pathologist: A doctor who specializes in diagnosing disease by examining tissue or body fluids.

Pleural effusion: A diagnosis of fluid collecting in the tissue layers that surround the lungs.

Pleurodesis: A treatment for pleural effusion that seals the lung to the lining to stop fluid from collecting.

Port: Intravenous line (IV): Soft, flexible tube placed inside a vein to take out blood or fluid or to give medicine or fluid.

Pneumonia: An infection that can cause fluid or pus in the lung(s).

Pneumonectomy: A type of surgery where the entire lung is removed.

Prevention trial: A type of clinical trial that explores how to prevent lung cancer.

Primary tumor: The first tumor where cancer began to grow.

Prophylactic cranial irradiation (PCI): A type of brain radiation treatment is sometimes used to decrease the risk of cancer spreading to the brain.¹¹⁰

Pulmonary embolism: A blood clot that travels through the bloodstream into the lung.

Radiation therapy: A type of cancer treatment that uses high-energy x-ray beams to kill tumors.

Radioactive isotopes: A substance that puts out a very small amount of radiation that cancer cells absorb and makes them easier to see with some scans.

Risk factor: Something that increases the chance of a disease occurring such as being exposed to a toxin.

Robotic bronchoscopy: A type of bronchoscopy that uses a robotic controller, like a video game, to guide a small tube through the mouth and into the hard-to-reach areas of the lung.

Sarcoma: A type of cancer that begins in the tissues all over the body and can also be found in the lung.

Scans: Tests (such as an x-ray, CT, MRI, PET) that give a detailed picture of the body to see the areas affected by cancer.

Screening trial: A type of clinical trial that develops new and better ways to detect lung cancer.

Second opinion: Making an appointment with a different cancer specialist to hear what that person feels is the best treatment for you.

Segmental resection or segmentectomy: A piece of the lung is removed that is larger than a wedge resection but smaller than an entire lobe.

Side effects: An unwanted effect of a drug or treatment.

Sign: A health effect that can be seen by someone else; for example, a rash is a sign.

Specialty doctor: A doctor who is highly trained in one special area of medicine.

Specialty nurse: A nurse who is highly trained in one special area of medicine.

Specialty professional: A health professional who is highly trained in one special area of medicine.

Squamous cell carcinoma: One of the most common types of NSCLC. It begins in the thin, flat cells that line the breathing tubes.

Standard genomic testing: A test that examines one or a small set of cancer-related genes.

Stereotactic radiosurgery: A type of radiation treatment that treats one small part of the brain or body with a very high dose of radiation using many small radiation beams.

Supportive care trials: A type of clinical trial that finds new treatments to decrease the symptoms and side effects of lung cancer.

Switch maintenance: A method of maintaining the use of chemotherapy but using one that is different from the one used in the first line of treatment.

Symptom: A health effect that cannot be seen by someone else but must be described by the person; for example, a headache is a symptom.

Systemic therapy: Types of cancer treatment that work through the whole body at the same time. Examples are chemotherapy and targeted therapy.

Targeted therapy: A type of cancer treatment given by a pill or through a vein that works by attacking a “target” on cancer cells called a biomarker.

Temporal lobe: A lobe or section of the brain that controls memory, speech, and hearing.

Thoracentesis: A type of biopsy used for diagnosing lung cancer that uses a thin needle to remove fluid that may have gathered in the chest or outside of the lungs.

Trachea: The tube that brings air from the mouth into the lungs. Also called the windpipe.

Transformed small cell lung cancer: A type of lung cancer that begins as NSCLC and then later changes or transforms into SCLC.

Treatment trial: A type of clinical trial that finds new drugs, treatments, and procedures to treat lung cancer.

Tumor grade: A part of cancer diagnosis that describes how similar or different cancer cells look to healthy cells. The tumor grade is related to how fast cancer will grow.

Wedge resection: A type of surgery in which a small wedge-shaped piece of the lung is removed.

Whole brain radiation: A method of brain radiation that uses a very low dose of radiation on the entire brain to treat cancer that is too small to be seen.

X-rays: Gives a detailed view of the body to see the areas affected by cancer.



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“I want to find a cure.”
— Ellis

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“In my book, living with lung cancer can fill hundreds of pages. The key to it all, is to be a copious note taker and do not be embarrassed to ask tons of questions.”

— Patrick



Appendices

Appendix A

Known Biomarker Symbols and Names

Biomarker Symbol	Biomarker Name
PD-L1	Programmed death-ligand 1 (also known as cluster of differentiation 274)
CTLA-4	Cytotoxic T-Lymphocyte Associated protein 4
TMB	Tumor Mutational Burden
EGFR	epidermal growth factor receptor
ALK	anaplastic lymphoma receptor tyrosine kinase
ROS1	ROS proto-oncogene 1, receptor tyrosine kinase
BRAF	B-Raf proto-oncogene, serine/threonine kinase
RET	ret proto-oncogene
MET	MET proto-oncogene, receptor tyrosine kinase

Biomarker Symbol	Biomarker Name
NTRK1,2,3	neurotrophic receptor tyrosine kinase 1, 2, and 3
VEGFR	vascular endothelial growth factor receptor
KRAS	Kirsten rat sarcoma viral oncogene homolog
ERBB2/HER2	erb-b2 receptor tyrosine kinase 2 (also known as human epidermal growth factor receptor 2)
PARP	Poly ADP-ribose polymerase
STK11	Serine/threonine kinase 11
NRG1	Neuregulin 1
FGFR1	fibroblast growth factor receptor 1
PIK3CA	phosphatidylinositol-4,5-bisphosphate 3-kinase catalytic subunit alpha
DLL3	delta like ligand 3

Please visit the American Cancer Society website, <https://www.cancer.org/cancer/lung-cancer/detection-diagnosis-staging/how-diagnosed.html>, for more information on biomarkers.

Appendix B

TNM Cancer Staging System

TNM Definitions

T = Tumor

This chart describes the size of the tumor, where it is located, and whether it has spread.

TX	Tumors are too small for testing or their exact location cannot be found with tests.
T0	No primary or original tumor has been found.
Tis	There are abnormal or cancer cells in the top layer of cells in the breathing tubes that have not spread to other lung tissue.
T1	Tumors are only in the lungs and are smaller than 3cm (the size of one grape).
T1mi	Tumors grow only along the surface of lung tissue and are less than 0.5cm deep into the tissue of the lung.
T1a	Tumors are smaller than 1cm (the size of a pea) and have not reached the tissues that surround lungs or the main branches of the airways.
T1b	Tumors are between 1cm (size of a pea) and 2cm (size of a peanut) and have not reached the tissues that surround the lungs or the main branches of the airways.
T1c	Tumors are between 2cm (size of a peanut) and 3cm (size of a grape) and have not reached the tissues that surround the lungs or the main branches of the airways.

T2	Tumors are between 3cm (size of a grape) and 5cm (size of a lime) and/or have grown into the main bronchus (the two airway tubes that split off of the windpipe) and/or have grown into the lung's inner lining (visceral pleura) and/or have caused lung collapse (atelectasis) or swelling (pneumonitis).
T2a	Tumors are between 3cm (size of a grape) and 4cm (size of a walnut) and have grown into the main airways and/or the tissue around the lungs.
T2b	Tumors are between 4cm (size of a walnut) and 5cm (size of a lime) and have grown into the main airways and/or the tissue around the lungs.
T3	Tumors are between 5cm (size of a lime) and 7cm (size of a peach) and/or have grown into the chest wall, or nearby sites and/or there are other tumors in the same lobe of the lung.
T4	Tumors are larger than 7cm (size of a peach) and/or has grown into the center of the chest, to the diaphragm, heart or its major blood vessel, windpipe, area where the windpipe divides, esophagus (food tube), or spine (backbone) and/or there are other tumors in the same lobe of the lung.

N = Lymph Node

This describes whether cancer has spread to the lymph nodes in and around the lungs.

NO	There is no cancer in lymph nodes near the cancer.
N1	Cancer has spread to the lymph nodes near the area where the windpipe divides and/or to nodes in the center of the chest and in the lung with the primary tumor.
N2	Cancer has spread to other nodes in the center of the chest near the lung with the original tumor.
N3	Cancer has spread to nodes in the center of the chest near the lung without the primary tumor OR to any nodes in the neck or near the collarbone.

M = Metastasis

This describes whether cancer has spread to the lymph nodes in and around the lungs.

M0	Cancer has not spread to far away sites.
M1	Cancer has spread to far away sites.
M1a	Cancer has spread from one lung into the other OR into the lining and has formed nodule(s) OR into the lining of the heart and has formed nodule(s) OR into the fluid around the lungs or the heart.
M1b	Cancer has spread to one site outside the chest area.
M1c	Cancer has spread to more than one site outside the chest area.

Stages

After the Tumor (T), Lymph Nodes (N) and Metastasis (M) are known, cancer then is staged:

Overall Stage	T	N	M
Stage 0	Tis (in situ)	NO	MO
Stage IA1	T1mi, a	NO	MO
Stage IA2	T1b	NO	MO
Stage IA3	T1c	NO	MO
Stage IB	T2a	NO	MO
Stage IIA (2A)	T2b	NO	MO
Stage IIB (2B)	T1a	N1	MO
	T1b	N1	MO
	T1c	N1	MO
	T2a	N1	MO
	T2b	N1	MO
	T3	NO	MO
Stage IIIA (3A)	T1a	N2	MO
	T1b	N2	MO
	T1c	N2	MO
	T2a	N2	MO
	T2b	N2	MO
	T3	N1	MO
	T4	NO	MO
	T4	N1	MO

Overall Stage	T	N	M
Stage IIIB (3B)	T1a	N3	MO
	T1b	N3	MO
	T1c	N3	MO
	T2a	N3	MO
	T2b	N3	MO
	T3	N2	MO
	T4	N2	MO
Stage IIIC (3C)	T3	N3	MO
	T4	N3	MO
Stage IVA (4A)	Any T	Any N	M1a
	Any T	Any N	M1a
Stage IVB (4B)	Any T	Any N	M1c

The 8th Lung Cancer TNM Classification and Clinical Staging System: Review of the Changes and Clinical Implications (<https://qims.amegroups.com/article/view/20898/20640>)

29 Questions to Ask Your Oncologist and Healthcare Team

- 1 What type of lung cancer do I have?
- 2 How does the type of cancer I have affect my treatment options?
- 3 What stage is my cancer?
- 4 If my cancer has spread, where else is it in my body?
- 5 How does the stage affect my treatment options?
- 6 Do I need more tests before we talk about what my treatment plan will be?
- 7 Has my biopsy tissue been sent out for comprehensive biomarker testing?
- 8 Which testing was my tissue sent out for and how is that decided?
- 9 If biomarkers are found, how will that impact my treatment plan?
- 10 How can I learn more about my treatment options? i.e.: chemo, surgery, radiation, immunotherapy, and targeted therapy.
- 11 If the best treatment for me is not covered by my insurance, what resources are available to help with access/payment?
- 12 Are there any clinical trials I should know about?
- 13 What cancer centers or universities specialize in my type of cancer?
- 14 Can I get a second opinion at one of these centers and still be treated by you?
- 15 How long will I be on treatment before I know it is working?
- 16 How often are my follow-up scans?
- 17 When should we re-biopsy and is liquid biopsy an option for me?
- 18 What are the side effects of my treatment?
- 19 How are these side effects managed?

29 Questions to Ask Your Oncologist and Healthcare Team, cont.

- 20 Will my treatment affect my daily routine?
- 21 I want children in my future. Should I consider fertility preservation before starting treatment?
- 22 Can I still work during treatment?
- 23 Can I travel during treatment?
- 24 Will I need oxygen for certain activities or for traveling by plane?
- 25 What resources are provided for people with lung cancer?
- 26 Who is my contact person here for any questions I may have?
- 27 Are there support groups available for me and my loved ones?
- 28 Where can I get treatment-related help, such as wigs or transportation to appointments?
- 29 Is there a social worker or patient navigator that can help me?



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