



Living With Lung Cancer



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Introduction

We hope this guide booklet will help prepare you for what lies ahead in your journey with lung cancer. Whether you are newly diagnosed with lung cancer or a caregiver who wants to learn more, this guide has resources for everyone.

The first thing to know is there is reason for hope. Much progress is being made for people with lung cancer, with many new treatments being developed and tested every day. There have been tremendous changes in treatment options since our first guide was published.

Of course, you may experience many strong emotions. This is part of the process of dealing with your diagnosis. In this guide we explore emotions both at diagnosis and every day forward.

We also know that a key part of living with lung cancer is learning the facts and staying informed. This booklet will give you an overview that may help you understand your disease and treatment options. Speaking up and asking as many questions as necessary is also part of the process.

If you didn't receive a personalized cancer care plan (a document for you to record your diagnosis and treatment plan, and take notes) from your care team, you can download our care plan at [LCRF.org/care-plan](https://www.lcrf.org/care-plan) or order one for free at [LCRF.org/resources](https://www.lcrf.org/resources). See page 29 for more information about care plans.

Please keep in mind that available treatments are constantly changing. You should rely on your medical team for direct treatment recommendations.

Contents

Introduction	2	Personalized cancer care plan	29
Lung cancer overview	4	Coping with emotions upon diagnosis	30
Types of lung cancer	5	Navigating the stigma	34
Non-small cell lung cancer (NSCLC)	6	Coping with emotions while in treatment	35
Small cell lung cancer (SCLC)	8	Oxygen therapy	36
Biomarker testing	9	Wellness guide	38
Your cancer care team	10	Appendices	
Types of cancer treatment	12	Resource directory	43
Surgery	12	Worksheet: Communicating your needs	44
Radiation therapy	16	Questions to ask your doctor	48
Chemotherapy	17	Glossary	49
Targeted therapy	18		
Monoclonal antibodies	19		
Immunotherapy	19		
Symptoms and side effects	22		
Clinical trials	26		
Understanding palliative care	28		

Lung cancer overview

What are healthy lung cells?

Normal cells in your lungs have very specific jobs and functions. For example, the cells in your lungs have a job—to move oxygen in and carbon dioxide out of your blood. The cells in your bloodstream have different responsibilities. Red blood cells carry oxygen throughout the body. The white blood cells fight infections. Healthy cells eventually stop growing and dividing when they get old. Injured cells can die.

What are lung cancer cells?

Lung cancer cells do not function the same way as healthy cells. They continue to divide and multiply, and do not die. Every cell contains genes, which are the “instructions” that tell the cell what to do. When genes are damaged or changed, they are called mutated. Some mutated genes in cells may cause cancer to develop.

Mutations can happen for several reasons. In families, a mutated gene can pass from parent to child. Others may have mutations due to exposure to cigarette smoke, radon, asbestos, or other things. Cells with these types of mutations are more likely to multiply in an abnormal way. This can result in a mass of cancer tissue called a tumor.



Symptoms of lung cancer can be similar to the side effects from various types of treatment. **See our managing side effects chart on pages 24-25 to learn more.**

How can lung cancer cells spread?

There are different ways that cancer cells can spread throughout the body. Cancer cells can spread through the bloodstream to other organs. Cancer cells can spread also through the **lymph system** by way of the **lymph nodes**. When the cancer cells travel outside of the lungs, they can form new tumors. The term used when cancer has spread is **metastasize**.

If lung cancer **metastasizes**, common sites are:

- brain
- bones
- liver
- adrenal glands (glands that release hormones)

Only cancers that begin in the lung are “lung cancer.” If lung cancer spreads to another organ, such as the brain, it is still considered lung cancer. Lung cancer cells differ in how they behave. This makes them more likely to respond to lung cancer treatment, rather than breast cancer treatment, for example.

The most common symptoms of lung cancer are:

- A cough that does not get better, only worse
- Coughing up blood
- Chest pain that gets worse with deep breathing, coughing, or laughing
- Shortness of breath and wheezing
- Hoarseness
- Loss of appetite
- Unexplained weight loss
- Feeling tired or weak
- Infections such as bronchitis that does not get better, only worse



Types of lung cancer

The two main types of lung cancer are: **small cell lung cancer (SCLC)** and **non-small cell lung cancer (NSCLC)**. The most common subtypes of NSCLC are:

- **Adenocarcinoma**
- **Squamous cell carcinoma**
- **Large cell carcinoma**

The **subtype** of your lung cancer can be determined by a doctor called a **pathologist**, who looks at a sample of your tumor with a microscope. There are also other, less common subtypes of NSCLC.

If you have NSCLC, it is important to know your subtype so that your medical team can develop the right treatment plan for you. The majority of lung cancers (about eight out of ten) are NSCLC, and most cases of NSCLC (about five out of ten) are adenocarcinoma. Small cell lung cancers tend to grow and spread more rapidly and cause symptoms sooner than NSCLC. For these reasons, treatments for SCLC may differ from those for NSCLC (see pages 20-21 for more information on SCLC and NSCLC treatments).

What is the staging process?

After your diagnosis, your doctors will identify the type and stage of lung cancer you have. Staging cancer is a process where your doctors look at:

- tumor size
- location
- signs of spreading

Your doctor will need to run tests to determine the stage. The staging process will help your healthcare team develop your treatment plan and offer more information about your disease.

Questions and conversations are an important part of your care. **For a list of suggested questions for your doctor, see page 48.**



Non-small cell lung cancer (NSCLC)

Stage 1

A tumor up to 5 cm wide that has not spread to any lymph nodes or other organs is classified as stage 1. These tumors are usually **resectable** (able to be removed surgically).

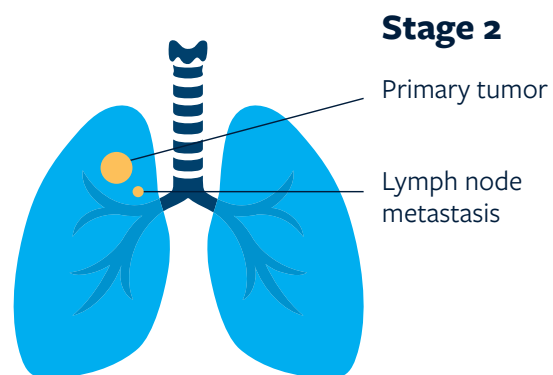
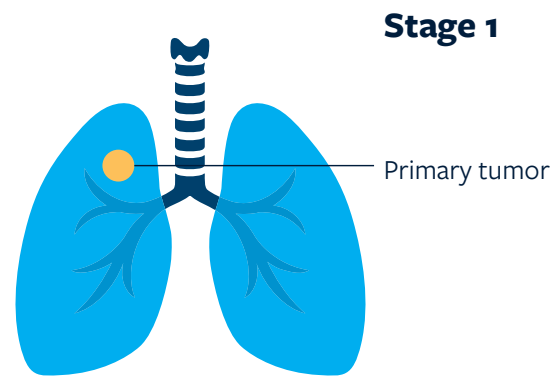
High-dose radiation therapy may also be used for these tumors (see page 16 for more information).

Stage 1A

- tumor 3 cm or smaller

Stage 1B

- tumor 3-5 cm wide in any direction



Stage 2

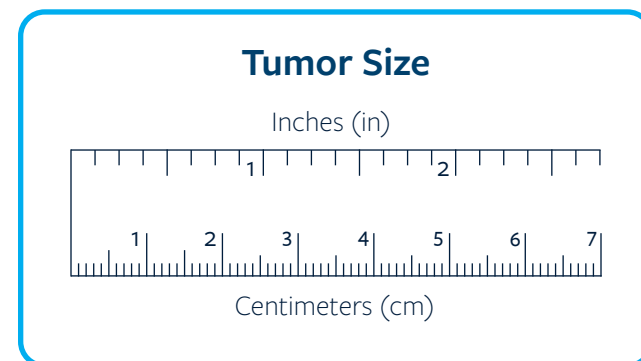
Stage 2 cancers may be a little larger than stage 1, and may have spread to lymph nodes on the same side of the chest (**hilar lymph nodes**), and/or may have begun to invade other structures within the chest. These tumors are usually resectable.

Stage 2A

- tumor 5-7 cm wide in any direction with no spread of cancer to lymph nodes OR
- less than 5 cm, but spread to lymph nodes on the same side of the chest

Stage 2B

- tumor 7 cm or wider in any direction with no spread of cancer to lymph nodes OR
- 5-7 cm wide, but spread to lymph nodes on the same side of the chest OR
- tumor beginning to invade structures within the chest OR
- more than one tumor in the same lobe of the lung



Stage 3

A tumor that has spread to the center of the chest (**mediastinum**) on the same side as the tumor OR has spread to lymph nodes on the other side of the chest, but does not appear to have spread to other organs outside the chest is classified as stage 3. Often, stage III tumors are considered **unresectable** (unable to be removed surgically). Patients with stage 3 disease are assessed individually for resection, which may be performed after chemotherapy and/or radiation.

Stage 3A

- spread to lymph nodes in the center of the chest (**mediastinal lymph nodes**)

Stage 3B

- spread to lymph nodes on the opposite side of the chest or in the lymph nodes above the collarbone OR
- involves major structures, such as the heart or arteries

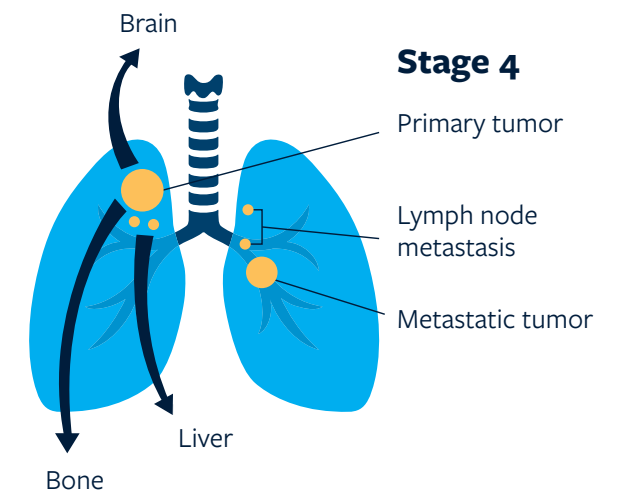
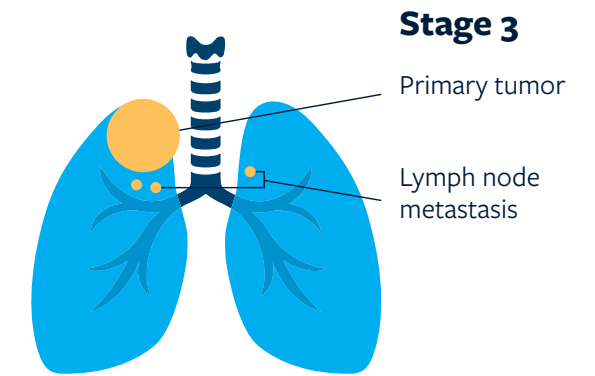
Stage 3C

- same as Stage 3B, but more than one tumor is found AND/OR
- the tumor has spread to other areas in the chest cavity

Stage 4

Cancer accompanied by **pleural effusion** (a fluid build-up between the lungs and the chest wall that has cancer cells) or that has **metastasized** (spread) to other parts of the body is classified as stage 4. Although stage 4 cancers are generally not curable, treatments may help you live longer and with an improved quality of life.

Refer to pages 20-21 for detailed descriptions of treatments for each stage of cancer.

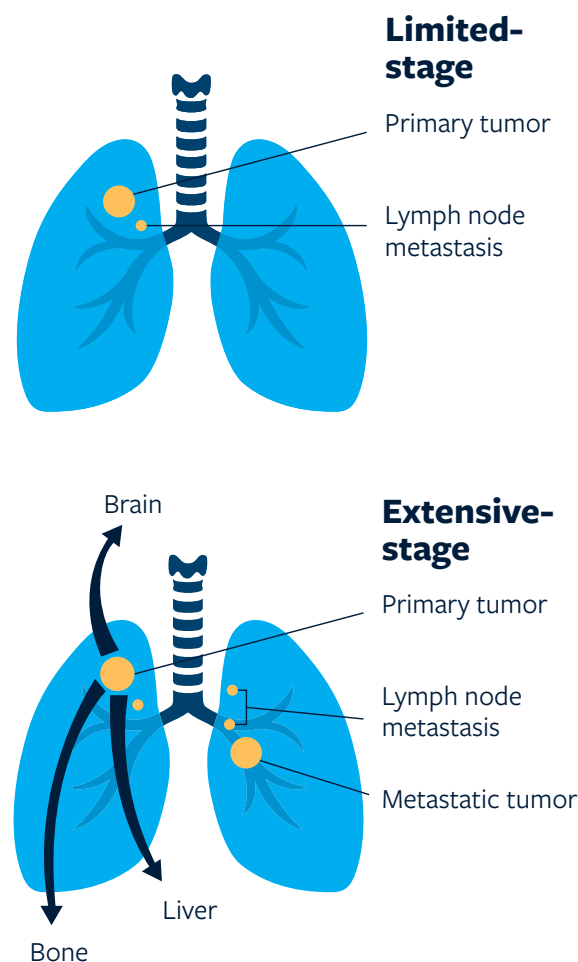


Small cell lung cancer (SCLC)

Limited-stage SCLC is cancer present in only one lung, which may have spread to surrounding lymph nodes. Treatment for limited-stage SCLC generally involves both chemotherapy and radiation therapy.

Extensive-stage SCLC is cancer that has spread to both lungs, lymph nodes far from the original cancer, or other parts of the body. As with other advanced cancers, extensive-stage SCLC is generally not curable, but there are treatments available that may help you live better and longer.

Refer to pages 20-21 for detailed descriptions of treatments for each stage of cancer.



What tests will my doctors do to find out the stage of my cancer?

Your doctors will determine the stage of your cancer by using any combination of several procedures:

- **Computed tomography (CT)** scans are sophisticated x-rays that show the body in cross-sections. These cross-sections are very good at showing the location and size of tumors and enlarged lymph nodes. They may also identify bone lesions or other sites of disease.
- **Positron emission tomography (PET)** scans can help determine where tumors are in the body. Because cancer cells grow faster than normal cells, they consume more sugar. A small amount of special dye that contains sugar is injected into a vein, and a PET machine is used to see where the sugar builds up, which identifies the location of cancer sites.
- **Bronchoscopy** is a procedure in which a doctor puts a small, flexible camera into the airway to look for tumors. The bronchoscope may have tools to remove a small sample (biopsy) of the tumor or lymph nodes for testing.
- **Endobronchial ultrasound (EBUS)** is a specialized type of bronchoscopy that uses sound waves to create an image of the tumor and nearby tissues to help the doctor find tumors or decide what area to biopsy.
- **Navigational bronchoscopy** uses CT scans and computer software to guide the physician to the target tissue. This form of bronchoscopy may be used when a tumor exists in the smallest parts of the airways, or to help doctors better find the right spot to take a standard biopsy.

- **Bone scans** create pictures of the bones. A special dye is injected into a vein, and a camera is used to see the dye. This tells doctors how healthy the bones are and whether they have any tumors in them. If you've recently had a PET scan, you likely will not need a bone scan.
- **Magnetic resonance imaging (MRI)** uses magnetic fields to produce detailed images of the body. MRI is particularly useful for finding abnormal growths in the brain.

- *HER2* mutation
- Epidermal Growth Factor Receptor (*EGFR*) mutations
- *KRAS* mutation
- *MET* mutation
- *NTRK* gene rearrangement
- *RET* mutation
- *ROS1* gene rearrangement
- PD-L1 or PD-1 protein

Biomarker testing

Cancer biomarkers typically refer to proteins, genes, and other molecules that affect how cancer cells grow, multiply, die, and respond to other substances in the body. Your doctor may want more details about your tumor and order biomarker testing to look for **mutations (changes)** in the DNA of the tumor as well as levels of specific proteins. If your doctor looks for all possible mutations, regardless of whether there are drugs for these mutations, it is called comprehensive biomarker testing.

It's all about the targets. When a particular characteristic is found through comprehensive biomarker testing, specific treatment options, called "targeted therapies," may be considered for you. Testing will show if your tumor has certain types of gene changes. Some of these changes are known as mutations. The changes are often found in a subtype of non-small cell lung cancer called adenocarcinoma, which include these subtypes:

Please note this is only a partial list, since more mutations are being discovered through research.

- Anaplastic Lymphoma Kinase (*ALK*) gene rearrangement
- *BRAF* V600E mutation

Here are several questions to help you guide the discussion and get the information you need to plan your treatment:

- What type of biomarker testing do I need?
- Can I still get comprehensive biomarker testing if I've already begun treatment?
- Is there enough biopsy tissue for testing, or will I need another biopsy?
- What is a liquid biopsy?
- How could comprehensive biomarker testing affect my course of treatment?

If your doctor doesn't recommend biomarker testing, it is okay for you to ask, "Why not?" Testing may not be appropriate in all cases, but it is best for you to know soon after diagnosis as much as possible about your disease so that you and your doctors can be full partners in your care.

- **Detection & tissue biopsy**
- **Confirm tumor type & diagnosis**
- **Select biomarker testing**
- **Conduct biomarker testing**
- **Treatment decision & initiation**



Your cancer care team

A variety of specialists may be included in your cancer care team:

Some are doctors called **pulmonologists** who specialize in lung disease, while those focused on cancer are called **oncologists**.

A **pulmonologist** may diagnose and help treat your lung cancer and help manage specific side effects of your lung cancer.

A **respiratory therapist** can help if you have trouble breathing.

Interventional pulmonologists may perform diagnostic tests and help you with side effects from lung cancer or any additional diseases of the lung you may have.

A **medical oncologist** will prescribe the drugs, such as chemotherapy, targeted therapy agents, and supportive care treatments (treatments to help you feel comfortable throughout the entire process) that are needed to help treat your cancer and manage your symptoms.

A **thoracic oncologist** is a medical oncologist who specializes in treating people with lung cancer. The term thoracic means anything to do with the chest area.

A **radiation oncologist** uses concentrated x-rays (radiation) to eliminate cancer cells. Radiation and medical oncologists often work together to determine and carry out treatment plans.

Some surgeons are specifically trained to perform surgery on patients with cancer. A **thoracic surgeon** has special training to remove or operate on lung cancer tumors. If no thoracic surgeon is available in your area, ask which nearby surgeon performs the most lung cancer surgeries and make sure they are experienced in minimally invasive techniques (a variety of techniques used by surgeons that generally allow for a quicker recovery time and create less overall damage to the body).

Nurse practitioners and **physician assistants** are specially trained to provide you with medical care ranging from preventive care and physical exams to ordering tests, prescribing certain medications, and assisting with surgery and hospital care. They work with your doctors to check on your overall health and your response to treatment(s).

Oncology nurses are specially trained in the care of cancer patients. Working with your doctors, they will carefully check your progress as partners in your journey. Oncology nurses may also give you the drugs your doctors prescribe. If you are part of a clinical trial testing a new treatment, research nurses will check on you and take any concerns or questions to your doctor.

Oncology social workers provide counseling and support. They work with the whole medical team to address your specific needs, connect you with useful resources, and discuss your emotional well-being. For example, a social worker may help you and your family find a place to stay during treatment if your cancer center is far from home. A social worker might also help you with payment or other cancer-related financial issues.

Nurse navigators or patient navigators help coordinate care with the many different people on your team. They may help ensure that your tests are ordered or appointments are scheduled; work with your insurance on any questions that come up; or help you

find emotional, financial, or other support services. Nurses, nurse practitioners, social workers, or others may act as patient navigators. Your patient navigator is often your key contact when you have questions or problems.

Depending on your needs, other specialists may be part of your cancer team. If you decide to enter a clinical trial, a **clinical research coordinator** will help you get started and check in with you throughout the course of your treatment. A **nutritionist** can discuss foods and supplements that will help keep you healthy while you are in treatment.

A psychologist can help you and your family deal with the emotions surrounding your cancer diagnosis and treatment. A **case manager** may coordinate your lung cancer care. Even though you will be seeing specialists for your cancer treatment, you will still need regular medical care from someone overseeing your general health. Your **primary care physician (PCP)** should be kept informed about your condition and updated about your cancer treatment. For the best care, your oncologist and PCP should work together as a team. Oncologists usually send written reports to your PCP after you visit your cancer care team.

Palliative care specialists may provide care and support as you and your loved ones face the challenges of living with cancer. These doctors and nurses can help you sort through information to make medical decisions; assist with making plans for living well during and after your cancer treatment; or prescribe treatments to control pain, issues with breathing, or other uncomfortable symptoms. These specialists can also help you and your loved ones find the emotional and spiritual support you may need.



Should surgery be part of my treatment plan?

Whether you can be treated with surgery depends on:

- **the type and stage of your cancer.**
If your cancer has spread to other organs, such as the case in stage 4, surgery is generally not recommended.
- **the location and size of your tumor.**
If the surgeon cannot safely remove your tumor, the disease is called inoperable, or unresectable, and surgery may not be an option (stage 3B, stage 4 and some stage 3A NSCLC).
- **if you are otherwise healthy enough to have surgery.**
If you have heart or lung disease in addition to lung cancer, you may not be able to withstand surgery.

Recovery times are different for everyone

Just as many factors influence whether you have surgery, there are **factors that will influence how long it takes for recovery.** Recovery time will vary depending on your particular surgery, your general health, and how well you heal.



Open surgery: If you have lung cancer surgery through the traditional, opened-chest approach, full recovery usually takes 6 to 8 weeks.

Less invasive surgical approaches: Depending on the size and location of your tumor, you may be able to have lung surgery by a minimally invasive approach,

either **video-assisted thoracic surgery (VATS)** or **robotic-assisted thoracic surgery (RATS).** This type of surgery is less invasive because it uses smaller openings and a video camera to guide the surgeon. This procedure results in less injury to your bones and muscles, and possibly a shorter recovery time.

Types of surgery:

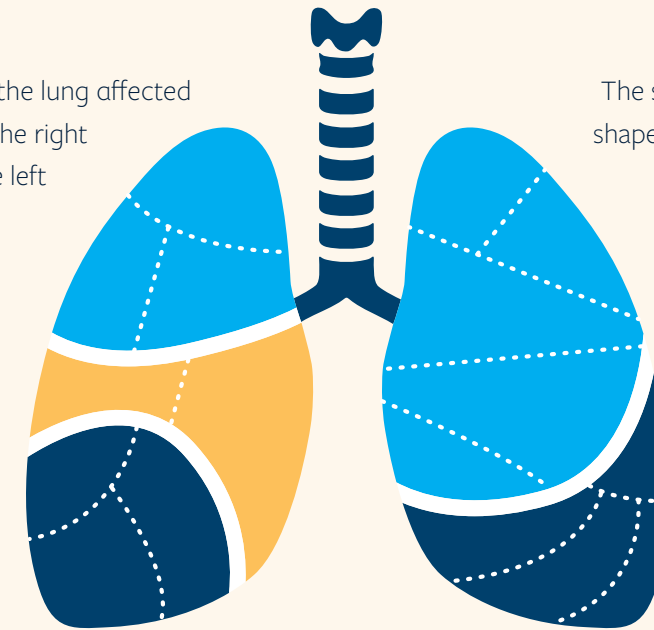
(May be done openly or, in some cases, by minimally invasive surgery)

Lung lobes and segments
(segments defined by dotted lines)

■ Upper lobe ■ Middle lobe ■ Lower lobe

Lobectomy

The entire lobe (portion) of the lung affected by lung cancer is removed. The right lung has three lobes, and the left lung has two, so having a lobectomy allows you to maintain most of your lung function. This is generally the preferred procedure, although it depends on your unique situation.



Wedge resection

The surgeon removes a small wedge-shaped section of the lung containing the tumor and a small amount of healthy tissue around the cancer. This procedure allows you to maintain a majority of your lung function.

Pneumonectomy

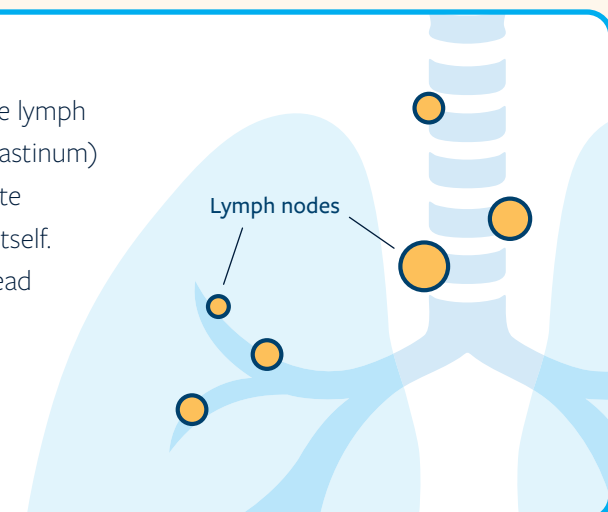
The surgeon completely removes the lung with cancer. This must be done when the tumor is located in the lung's largest airway or very near the trachea (windpipe), or when the cancer affects more than one lobe of the lung. This procedure can significantly reduce lung function, but most people find they can get back to nearly normal activities with the help of physical and respiratory therapy.

Segmentectomy

One or more segments (regions supplied by distinct blood and air supply) of the lung that is affected by the lung cancer are removed. Typically, the amount of lung tissue and lymph nodes removed in a segmentectomy is more than in a wedge resection, but less than in a lobectomy.

Removal of lymph nodes

If you have surgery, your surgeon will likely also remove some lymph nodes from the lung and the center of the chest (your mediastinum) to check them for cancer cells. This can be done as a separate procedure prior to your operation, or during the operation itself. This will help your doctors determine if your cancer has spread elsewhere in your body and may change your staging and treatment plan. If cancer cells are found in the lymph nodes, chemotherapy or immunotherapy may be recommended after your surgery.





Radiation therapy

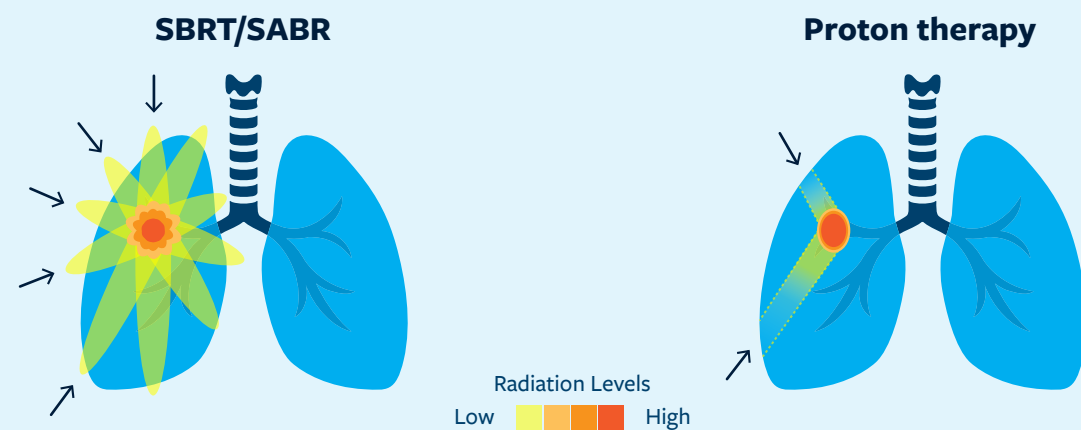
Radiation therapy (also referred to as radiotherapy, x-ray therapy, or irradiation) is the use of x-rays or other high-energy beams (such as protons) to target cancer cells and stop them from growing or multiplying so that they eventually die. Radiation treatment machines are directed to the tumor and the surrounding area and are “on” for a few minutes, delivering radiation that can kill tumor (as well as normal) cells. Sophisticated radiation planning can help to spare the normal tissues from exposure to radiation to selectively kill cancer cells. Like surgery, radiation is a local form of therapy and not a systemic (whole-body) treatment like chemotherapy or targeted therapy. High doses (amounts) of radiation are given when the tumor is confined to one area of the body, with the hope that the radiation will kill all of the tumor cells in that area. This treatment might involve daily doses of radiation for as little as one day or as much as six weeks or longer. **Your physician will determine the best course of action for your tumor.**

If the cancer has spread from the lungs to other parts of the body, radiation may be given in an abbreviated course to relieve symptoms in affected areas, such as the brain, lungs or bones. Radiation given for periods ranging from one day to four weeks can kill enough cancer cells to bring relief from symptoms such as pain, breathing difficulties, and headaches.

Specialized radiation therapy

Your radiation oncologist may recommend a special type of treatment called **Stereotactic Body Radiation Therapy (SBRT)** or **Stereotactic Ablative Radiotherapy (SABR)**; these terms mean the same thing. SBRT/SABR uses radiation from multiple angles, which allows higher doses of radiation to be precisely focused on the tumor, avoiding as much healthy tissue as possible. SBRT/SABR can be used to treat some localized tumors in people who cannot have surgery due to other health conditions or to treat some tumors that cannot be surgically removed because they are in a difficult location. SBRT/SABR can be performed with many different types of machines, and different options may be presented to you depending on the machines available at a given treatment location. Cyberknife® is the brand name for a system that uses high-precision radio surgical and SBRT procedures.

A very focused form of radiation therapy, called **stereotactic radiosurgery**, or SRS is sometimes offered if the cancer has spread to the brain or bones. This type of radiation therapy might be given in only one session. It can be used instead of or along with surgery for single tumors that have spread to the brain. Gamma Knife® is one example of a machine that focuses radiation on the tumor from different angles.



Chemotherapy

Chemotherapy drugs are medications that travel through the bloodstream to kill cancer cells throughout the body. These drugs are administered through the veins via an IV or through a mediport, or rarely, taken orally as pills. Unlike surgery and radiation, which are used to treat disease locally, chemotherapy is systemic; it can affect cancer cells throughout the body.

Keep in mind that chemotherapy is not always used with every patient – chemotherapy is a medication that some people receive as first or second line therapy in their treatment journey for lung cancer. It may differ for you or your loved one.

A number of different chemotherapy drugs are used for lung cancer, including (at the time of this booklet’s publication):

Generic Name	Brand Name
CISPLATIN	PLATINOL®
CARBOPLATIN	PARAPLATIN®
DOCETAXEL	TAXOTERE®
ETOPOSIDE	VP16, VEPESID®
GEMCITABINE	GEMZAR®
NAB PACLITAXEL	ABRAXANE®
PACLITAXEL	TAXOL®
PEMETREXED	ALIMTA®
TOPOTECAN	HYCAMTIN®
VINORELBINE	NAVELBINE®
LURBINECTEDIN	ZEPZELCA®
IRINOTECAN	CAMPTOSAR®

Generally, one platinum-containing agent (cisplatin or carboplatin) is combined with a non-platinum drug. Additional or different combinations of therapies may be prescribed by your doctor depending on their expert opinion on what is likely to work best for you. Still more drugs are in development, and these may be available after the printing of this booklet.

It is important to know that different types of cancers are treated with different types of chemotherapy, and that chemotherapy has changed a lot over the years. If someone tells you what they or a friend went through, remember that your cancer and your treatment — and therefore your experience — may be very different. See pages 23-25 for some possible side effects of chemotherapy and other treatments, and ways to manage these symptoms.

Proton therapy

A specialized form of radiation therapy uses protons to deliver the radiation to the patient. Unlike traditional radiation (known as photons or x-rays), protons do not give radiation to tissue beyond the target area. Consequently, they have the potential to uniquely spare your healthy tissues.

The use of proton-based radiation is being actively explored in lung cancer but is not currently a standard approved therapy.



Targeted therapy

One way in which cancer cells differ from normal cells is that they often have abnormalities (such as mutations and fusion proteins) in their DNA. To help fight cancer, scientists have developed drugs that specifically target cancer cells that have these mutations. By targeting mutations of cancer cells, these drugs can stop or limit the growth and spread of cancer. These drugs are also called “molecular targeted therapies/drugs” or “precision medicines” because they precisely target the mutation that is causing the cancer. Targeted therapies usually come in the form of pills but may also be other types of IV preparations too.

At the time of this publication, the targeted therapies approved to treat NSCLC are:

Mutation	Generic Name	Brand Name
ALK	CERITINIB	ZYKADIA®
	CRIZOTINIB	XALKORI®
	LORLATINIB	LORBRENA®
	ALECTINIB	ALECENSA®
BRAF	BRIGATINIB	ALUNBRIG®
	DABRAFENIB	TAFINLAR®
	TRAMETINIB	MEKINIST®
EGFR	VEMURAFENIB	ZELBORAF®
	ERLOTINIB	TARCEVA®
	AFATINIB	GILOTRIF®
	GEFITINIB	IRESSA®
EGFR EXON 20	OSIMERTINIB	TAGRISSO®
	DACOMITINIB	VIZIMPRO®
	MOBOCERTINIB	EXKIVITY®
HER2	AMIVANTAMAB	RYBRENT®
	TRASTUZUMAB DERUXTECAN	ENHERTU®
KRAS G12C	SOTORASIB	LUMAKRAS®
	ADAGRASIB	KRAZATI®
MET	CAPMATINIB	TABRECTA®
	TEPOTINIB	TEPMETKO®
NTRK	ENTRECTINIB	ROZLYTREK®
	LAROTRECTINIB	VITRAKVI®
RET	SELPERCATINIB	RETEVMO®
	PRALSETINIB	GAVRETO®
ROS1	CERITINIB	ZYKADIA®
	CRIZOTINIB	XALKORI®
	LORLATINIB	LORBRENA®
	ENTRECTINIB	ROZLYTREK®

Because targeted therapies work best for people whose tumors have a specific gene mutation or changes, testing your tumor is very important. These tests can be called molecular, biomarker, genetic or mutation testing. Your doctor may recommend that your tumor be tested for a protein called PD-L1. There are targeted therapies that can treat tumors with high levels of PD-L1.

Some doctors recommend another biopsy or a blood test (liquid biopsy) to see if your tumor has shown **other causes of resistance**. Many drugs are being developed specifically for patient’s whose tumors have developed resistance. Biomarker testing is often needed to see if you are eligible for clinical trials of targeted therapies that address resistance issues.

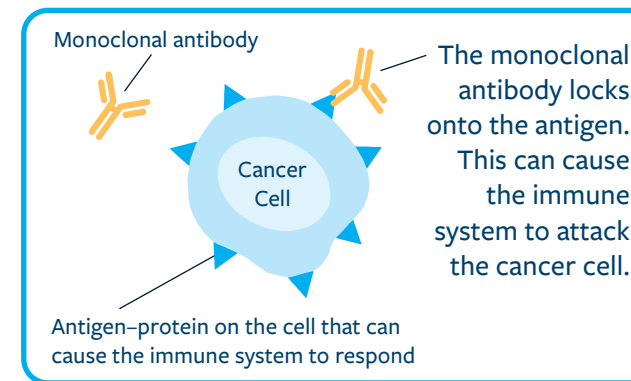
Drugs are getting approved very rapidly, and the list will be changing. **If there’s a drug that isn’t on this list, please ask your doctor about it.** There are a lot of drugs still under development which may be approved soon.

Monoclonal antibodies

Antibodies are important parts of our immune system. As proteins, they can bind to and help fight off viruses and cancer cells. Each monoclonal antibody binds to only one antigen (foreign substance).

Important research has helped with discoveries in this area. Scientists can now make a type of monoclonal antibody that can bind to the abnormal proteins made by cancer cells.

Antibodies can bind to these abnormal proteins and stop them from becoming activated.



The abnormal proteins that cancer cells can make are:

- PDL and PD-L1 (see page 9)
- EGFR (see page 9)
- VEGF (Vascular Endothelial Growth Factor)

At the time of this publication, the monoclonal antibodies approved to treat NSCLC are:

Generic Name	Brand Name
NECITUMUMAB	PORTRAZZA®
BEVACIZUMAB	AVASTIN®
RAMUCIRUMAB	CYRAMZA®

Immunotherapy

Immunotherapy is one of the most exciting new approaches for treating lung cancer. Immunotherapies work by boosting your body’s own natural defenses to fight cancer.

The immune system is the body’s defense against disease. It has the ability to recognize and destroy not only infections like bacteria and viruses, but also abnormal cells like cancer cells. But cancer cells are sometimes able to hide from or weaken the immune system, so they are not recognized and not destroyed. If cancer cells escape the immune system, they can continue to grow and spread. Scientists have been making breakthrough discoveries about how cancer cells evade the immune system. These discoveries have led to new therapies that may stimulate the immune system to attack cancer or counteract the ways cancer cells hide from or suppress the immune system.

At the time of this publication, the immunotherapies approved to treat NSCLC are:

Generic Name	Brand Name
NIVOLUMAB	OPDIVO®
PEMBROLIZUMAB	KEYTRUDA®
ATEZOLIZUMAB	TECENTRIQ®
DURVALUMAB	IMFINZI®
CEMPIPLIMAB-RWLC	LIBTAYO®
TREMELIMUMAB	IMJUDO®
IPILIMUMAB	YERVOY®

These immunotherapies are given into the vein (intravenously or IV) but differ in how often they are given.

Because immunotherapy drugs work on the immune system, they work differently from chemotherapy. The side effects of immunotherapy drugs are also different from those of chemotherapy. The most common side effects patients experience with immunotherapies can include diarrhea, fatigue, itching, skin rashes, muscle, joint, or bone pain, nausea, shortness of breath, and pneumonitis. Rarely, these drugs can cause the immune system to become too active. This may cause the body to react against normal tissues, such as your lungs, liver, colon, or thyroid.

More immunotherapies are being developed and tested in clinical trials for a variety of lung cancer types and stages.

Small cell lung cancer (SCLC) treatments by stage

Limited stage

Limited-stage SCLC is typically treated with:

- radiation to the chest
- chemotherapy
- PCI*

Extensive-stage

Individuals with extensive-stage SCLC are treated with:

- chemotherapy
- immunotherapy
- PCI*

* **Prophylactic cranial irradiation (PCI)**, radiation to the whole brain used to prevent brain metastases, may also be discussed at either of these stages



Keep in mind that immunotherapy for lung cancer is still new and research to figure out how best to use them – and which people are most likely to benefit – is ongoing. Ask your doctor if immunotherapy treatments or clinical trials might be options for you.

Non-small cell lung cancer (NSCLC) treatments by stage

Because new treatments are rapidly becoming available, please visit [LCRF.org](https://www.lcrf.org) for the most up-to-date information.

Preferably, a patient's treatment decisions will be guided by a multidisciplinary team. Your input as the patient is essential. These conversations are all part of the shared-decision making process between you and your team.

Stage 1

The ideal treatment for stage 1 NSCLC is surgery to remove the tumor. **New research is helping doctors predict which patients with stage 1 NSCLC will need chemotherapy and immunotherapy before or after their surgery and which will not.** High-dose radiation therapy may also be used if you or your doctors feel that you would not tolerate surgery (see page 14 for more information). Osimertinib is approved as adjuvant therapy in stage 1B-3A, and research is ongoing to determine if other targeted therapies should be given as well.

Stage 2

The optimal treatment for stage 2 NSCLC is chemotherapy and immunotherapy followed by surgery, or surgery followed by chemotherapy and immunotherapy. Osimertinib is approved as adjuvant therapy in stage 1B-3A, and research is ongoing to determine if other targeted therapies should be given as well.

Stage 3

Treatment options may differ if surgery can be utilized in combination with chemotherapy and radiation. **Although surgery is generally not recommended for stage 3 lung cancer, it may be considered in specific cases for patients with stage 3A disease.** Treatment for most patients with stage 3A and for all patients with stage 3B or 3C usually include chemotherapy, radiation therapy, and immunotherapy. Chemotherapy and radiation therapy may be given at the same time or one after the other. Immunotherapy is typically given after a combination of chemotherapy and radiation therapy. Osimertinib is approved as adjuvant therapy in stage 1B-3A, and research is ongoing to determine if other targeted therapies should be given as well.

Stage 4

Chemotherapy is often used because it fights the cancer throughout the body. Sometimes immunotherapy is given with it, or depending on one's PD-L1 status, immunotherapy may be given alone. Targeted therapy may be used alone if one's tumor has a positive biomarker. Radiation may be used to shrink tumors that are causing symptoms. **Because stage 4 cancer has spread to other parts of the body, surgery is only recommended in very select cases and usually is for palliation (relief) of certain symptoms.**

Symptoms and side effects

How can I manage my symptoms and side effects?

You may experience symptoms from your cancer or side effects from your cancer treatments.

Be sure to tell your cancer treatment team about any symptoms you are experiencing so they can determine if supportive or palliative care is appropriate. In most cases, these symptoms can be controlled with medications, exercises, or other therapies to help you feel better and continue with your daily life.

Side effects of treatment will vary. Immunotherapy side effects are treated differently than those of chemotherapy. Depending on the side effects, your dose of immunotherapy could be changed, treatment could be stopped, or corticosteroid therapy might be used. Be sure to talk to your doctor about any concerns or side effects you experience.



Possible side effects by treatment type

Surgery



- pain
- cough
- difficulty breathing
- bronchopleural fistula - an abnormal opening between the pleural space and an airway tube of the lung
- collapsed lung
- heart problems
- fatigue
- blood clots

Chemotherapy



- fatigue/constant tiredness
- ongoing infections
- hair loss
- infections
- anemia
- bruising and bleeding
- sore mouth
- loss of appetite
- decreased white blood cell count, called neutropenia
- numbness/tingling/pain/weakness in hands and feet
- changes in liver function tests

Targeted therapy



- skin problems and changes (dry skin)
- high blood pressure
- bleeding or clotting issues
- slow wound healing
- heart damage
- autoimmune reactions
- swelling

Immunotherapy



- diarrhea
- fatigue
- cough
- nausea
- skin rash
- poor appetite
- constipation
- muscle and joint pain

Possible symptom or side effect*	Recommendations
Pain	Take pain medications as prescribed.
	Both long-acting and short-acting pain medications are available. To be most effective, long-acting pain medications need to be taken before you feel the pain and are used on an ongoing basis to prevent and control pain. Short-acting medications can be used for immediate relief.
	It is important to advocate for yourself and tell your doctor if you are having problems with pain. Unless you tell them, your doctor cannot know you are still having problems with pain.
Shortness of breath	Use inhalers or other medications to open up airways or reduce swelling.
	Use portable oxygen when directed by your doctor.
Severe sore throat	Take pain medications or other medications before eating or as prescribed.
	Eat soft, cool foods; avoid citrus and acidic foods, and carbonated or caffeinated drinks.
Skin rash/redness/peeling/itching	Moisturize skin before, during, and after therapy as recommended.
	Wear loose-fitting clothes.
	Stay out of the sun. Use sunscreen when you go outside.
	Use hydrocortisone or antibiotic creams and/or oral antibiotics as prescribed.
Fatigue/tiredness	Be kind to yourself. Rest when you need to and don't take on additional activities.
	Eat a healthy diet to ensure proper nutrition.
	Have your red blood cell levels checked. If they are very low, you may need a transfusion.
	Keep a regular exercise routine. Even light walking can help.

Possible symptom or side effect*	Recommendations
Nausea/vomiting	Take anti-nausea medications as prescribed. These are usually most effective when taken before, during, and after therapy.
	Eat small meals throughout the day.
Hair loss	Plan for hair loss by getting a haircut, wigs, hats, or scarves. Keep in mind that not all treatments cause hair loss.
Weaker immune system	Wash your hands often, wear a mask, and try to avoid being around people who are sick.
Numbness or tingling of hands/feet	Avoid snug socks and shoes.
	Exercise if you are able, including walking and other light activities.
	Dress appropriately, especially for cold weather.
Diarrhea	Drink plenty of non-caffeinated fluids.
	Take anti-diarrhea medications as prescribed.
Constipation	Take stool softeners or laxatives as prescribed.
Weight loss	Work with a nutritionist/dietitian to create a meal plan.
	Avoid heavy and high protein meals prior to treatment.
	Take medications as prescribed.
Chronic cough	Your doctor may recommend treatment to address airway invasion from the cancer.
	Take medications as prescribed.

*If you are on an immunotherapy, your side effects may be treated differently than those of chemotherapy or targeted therapy.

What is a clinical trial?

The term “clinical trial” refers to testing new and promising medications. These studies may also test new ways to prevent or diagnose diseases such as lung cancer.

Clinical trials may include new ways to take medicine, radiation therapy, or surgery. Clinical trial teams make sure you receive the safest and best care. You will either receive the current “gold standard of care” treatment or the new medication.

Sometimes, patients may receive a “sugar pill”, or placebo, in addition to their standard treatment. Placebos are almost never used by themselves. If a placebo is ever used in a cancer clinical trial, all patients will know ahead of time.

When should I consider a clinical trial?

If you are recently diagnosed, **you do not need to wait to consider a clinical trial for your treatment.** No matter where you are in your treatment process, your oncologist may recommend a clinical trial that could be a good option for you.

Keep in mind:

Your particular type and stage of lung cancer and health will determine your options. Talk to your doctor to see which clinical trials are appropriate for you.



Timing. You can stop at any time you choose, for any reason, and return to the standard treatment.



Safety first. Protection for patients in clinical trials is the number one priority. Experts review all the studies to make sure the patients’ health and well-being are at the center.



Scheduling. Participation in a clinical trial may mean more office visits, tests, or procedures. Be sure you understand the time commitment with a trial as you make your decision.



Pros & cons. As with any cancer treatment option, clinical trials have potential risks and benefits. Discuss these with your doctor or healthcare team as you make decisions.

Are there additional costs to be in a clinical trial?

Your insurance will usually pay for the costs associated with “standard” treatments and the trial itself will usually pay for any extra trial-related costs. Ask your doctor’s office to help you understand your coverage before you start a clinical trial.

How do I find a clinical trial?

Visit us at [LCRF.org/clinicaltrials](https://www.lcrf.org/clinicaltrials) for our comprehensive guide for patients and families. You can find information about concerns such as finding a trial, help with communicating about trial participation, and questions to ask both your provider and trial team.

You may also call the Lung Cancer Support Line toll-free at (844) 835-4325 or contact us at support@LCRF.org

What are the benefits?



Get exceptional care

In clinical trials, patients report they get even more attention from the study team. Patients share the increased office visits or check-ins have offered extra guidance.

Early access to promising new treatment

Clinical trials introduce patients to the most promising cancer treatments. Many of the latest innovative treatments are only available through clinical trials.

Feel empowered

Patients and caregivers shared that an added benefit is their role in research. By participating, they learned more, helped future patients, and received treatment at the same time.

Understanding palliative care

What is it?

From early on in your patient experience, you may hear the terms “palliative or supportive care.” Palliative care is an additional layer of supportive therapy—one that is designed to help you manage issues that affect your quality of life. Palliative care addresses patients’ needs with symptom control and can address issues on psychological, social, and spiritual levels.

Although this type of care has been strongly associated with end of life care (also known as **hospice** care), it is important to note that palliative care is available any time and not limited to patients with advanced cancers. Palliative care had been found to improve quality of life and lengthen patients’ lives. If you would like to meet with a palliative care specialist, ask to see one. You do not need to wait.

How can I be referred? When do I see my supportive care team?

It depends on the type of help you are seeking. Palliative care specialists work with your healthcare team to determine how to best help you. In general, these specialists can help with understanding the complicated decisions and challenges involved in living with cancer.



Your palliative care/supportive care team may include (but is not limited to):

- Palliative care physicians & nurses
- Social workers
- Primary medical team
- Occupational therapists
- Physical therapists
- Spiritual counselors
- Psychologists and counselors
- Nutritionist/dietitian
- Speech-language pathologist
- Clinical pharmacist



Personalized cancer care plan

You may wish to work with your doctor and/or nurse to develop a **personalized cancer care plan**, which serves as a one-stop reference for information relating to your treatment and care. This plan will include your initial treatment plan, which is a list of your cancer treatments; other medicines or therapies you will need to help your treatments work best; possible side effects; and symptoms to watch for. Once your initial treatment is complete, you may wish to update your care plan with information on any medicines you are continuing to take, any ongoing medical issues that may need to be addressed, and when to return for check-ups.

A basic outline for a personalized care plan includes the following:

- Treatment provided
- Treatment purpose (cancer treatment, bone strengthener, ease of breathing, etc.)
- When to take (daily, weekly, specific dates)
- How to take (after meals, before bed, with water, etc.)
- When and where you need to go for treatments
- Reactions to look out for
- Follow-up needed
- Follow-up date(s)



Side effects?

Palliative care can include working with a dietitian



Emotional support?

Palliative care can include working with social workers and counselors



Spiritual support?

Palliative care can include working with a chaplain



Managing pain?

Palliative care can include working with a specialized palliative care physician



Keep in mind that your plan can always change, based on your experience. That is why it is so important to speak up about side effects and ask as many questions as you need.

Coping with emotions upon diagnosis

What to expect?

Living with lung cancer is not just about managing treatment and side effects—it's about coping and navigating yourself through an intense time.

Everyone processes their emotions differently. Some people may...

- dive straight into learning as much as they can about their particular lung cancer
- isolate themselves and not seek support
- go right into protection mode, assuring everyone around them that they're okay
- start building a practical support network for day-to-day concerns, but not their emotions
- seek guidance from mental health professionals
- seek comfort and insight from their spiritual communities

Some people do all of these. There is no one way to handle the emotions that come with a diagnosis of lung cancer. All emotions are real and they are valid.

These are your emotions and this is your journey but it can help to know you are not alone in how you are feeling and perhaps even more helpful to know there are truly positive steps you can take to deal with these feelings.



Here are some of the most common emotions:



1. Overwhelmed

A cancer diagnosis of any kind is a lot to absorb. People need to take the time and space they need to think through issues that are physical, practical, emotional, and even financial.

Communicating about these feelings is the first step in establishing your support network and learning about programs and services that were developed to help you. Whether it's expressing your emotions to your healthcare team, a social worker or therapist, your closest friend, or to your immediate family, it's a step towards feeling less overwhelmed and more in control.

Ways to feel in control

- Learn as much as you can about your type of lung cancer.
- Ask questions, as many as you need to. The answers will help you plan.
- Consider taking a friend or relative with you to help take notes and remember what questions you had.
- Ask if the facility has a lung cancer patient navigator. This is someone who will often be your prime contact with your doctor's office and will be able to coordinate and help with all aspects of your cancer care.
- Consider the type of support you will need and who you know that may be able to help. If you don't know of anyone, seek patient navigation from the hospital or trusted online sources such as active chapters of the American Lung Association (ALA) and American Cancer Society (ACS) in your community.
- Make a list of things you "wish everyone could know" about what you are going through and what you need. This list will help you figure out how comfortable you are discussing your cancer and your overall needs, and can bring out the ways you may ask others to support you during this time.
- Stay active, stay engaged. See the wellness section for options and ideas.



2. Anger

- Anger is a healthy, normal reaction to a diagnosis. You may find yourself asking why this has happened to you. All questions are fair game as you sort out your feelings and next steps. **It's important to remember that no one deserves cancer.** Research has been uncovering many reasons, such as environment and genetics, that play a role in why we develop cancer.
- For some, the energy that comes along with anger has served as fuel for them to become more informed, ask more questions, and carve out more opportunities for wellness.
- Your anger may reveal itself in ways you did not anticipate. You may become less patient with things that didn't bother you prior to your diagnosis. Whether it's a traffic jam or a slow customer service call, this is normal. It can be helpful to identify these moments so you can help yourself reframe thoughts or communicate to those around you if your anger is misplaced.
- Admitting you are angry is not a weakness in your ability to cope. It's what you do with the anger that affects your ability to feel support from others and help move forward.



3. Fear and worry

As you are sorting through your feelings, fear and worry may rise to the top. How will I react to treatment? How will I balance this with my job? How will I take care of my children, spouse, or my family? How will I know what to say to people?

There is great comfort in knowing the next steps. As you learn more about your treatment plan and your schedule, you will be able to make more informed choices about the support you need and what to communicate. Consider your treatment plan like a roadmap.

If you are still sitting with your diagnosis and do not have a plan yet, know there are resources to help you navigate through this period of time. There are local and online support resources that are specific to living with lung cancer such as those at LCRF.org.



4. Anxiety and depression

Your diagnosis is a lot for the mind and body to process. It's important to recognize the signs of anxiety and/or depression so you can get the help you need. Here are a few common symptoms of each:

Anxiety	Depression
Faster heartbeat	Constant feeling of sadness
Muscle aches	Feeling emotionally empty or numb
Stomach discomfort	Feeling unworthy, or being a bother
Tightness in the throat and chest	Weight changes
Not able to sleep	Feeling helpless or hopeless about life in general
Easily distracted and unable to focus	Crying throughout each day
	Feeling the urge to harm yourself



5. Guilt

Many cancer patients express feelings of guilt regarding how their illness will impact others. Some may ask, "What have I done?" And the answer is, cancer is no one's fault. Those same support programs and resources that may help you can also help your loved ones.



6. Loneliness

- You may find yourself wanting more time alone than usual. As you tackle all of your emotions, it's normal to feel isolated and unsure if anyone else can understand what you are going through. Many others have felt this way. You are not alone. Online support groups may help you bridge the gap between wanting to stay home and needing to connect.
- Conversations with friends and family can be initially awkward as people realize they are not sure of the right thing to say. Emotions may run high and you may feel the need to protect them or help them feel better. This is not your responsibility. Once you are confident in the types of support you need, you have every right to let them know. Statements such as, "It would be very helpful to me if you focused on what I can do instead of what I cannot do." Or, "I know you're worried about me and I appreciate that, but I need to stay positive and these conversations are not helping me with that."
- Emotional support comes in many different flavors. For you, it may be someone you can call at any hour, for others it could be watching funny movies or attending music concerts. You can decide for yourself how your support network can best help you. By communicating that, you are letting them know how they can uniquely help you.
- Express your feelings in whatever way is most comfortable. Be genuine about a bad day if you are having one. Owning how you feel can help you release it. It's much more difficult on your body to hold the stress inside.



Navigating resources online can be overwhelming. There is a large amount of information available and not all websites have accurate or are up-to-date. Ask your healthcare team for suggested websites that they trust. Websites such as LCRF.org offer medically reviewed content and ongoing review, which is different than a single person's patient-journey website.

The online communities can help many patients or caregivers, especially those developed by trusted sources. Sharing information with other patients can be helpful but it can also be confusing if you are not sure whether the information is correct. Always ask for resources when you can. Posting a response such as, "That's interesting and I would like to learn more. Can you share with me how you found this information?" can be a helpful way to question without making the person defensive.

While information is critical, so is support. Online communities have been helping patients connect across the globe. For information on the Lung Cancer Research Foundation's online support community, go to LCRF.org/facebookgroup.

Navigating the stigma

Over the years, the lung cancer community has faced stigma due to lack of information on this disease. General knowledge about lung cancer has been mostly linked to risk behaviors such as smoking; however, anyone can be diagnosed with lung cancer regardless of behaviors. A person who smokes, doesn't smoke, and never smoked are all at risk. This stigma has played a role in underfunding research, lowering emotional well-being, and worsening patient outcomes.

Many patients with lung cancer find it daunting to have the same conversation repeatedly about whether or not they smoked or dealt with nicotine addiction. Increased education about how lung cancer can happen to anyone will help decrease stigma over time.

You may feel it is necessary to have a short talking point ready for these conversations. This way you can answer the question and address the stigma issue at the same time.

Examples of this include:

"I understand why you are asking about smoking, but anyone can be diagnosed with lung cancer."

"Yes, smoking is a risk factor, but more research is showing that issues like the environment or genetics also play a role in patients with lung cancer."



Coping with emotions while in treatment

If you were struggling with certain emotions before treatment, it is likely they will feel more intense around this time. Just as you balanced your emotions around the time of your diagnosis, treatment can cause new ones to emerge. Issues from treatment such as breathing problems, pain, fatigue, and nausea can make day-to-day living far more challenging. This is a time for your support network and community resources to help you manage your strength through treatment.

Control

As your body recovers from surgery/radiation or processes your medication, you will likely experience new limitations. Daily tasks and responsibilities may need to be modified or put on hold. In many cases, it is a critical time to rely on others in your support network. Giving up control is not an easy process, but the benefits of accepting help can be significant in your healing. If you are uncomfortable asking those around you for help, consider contacting local resources. These organizations are staffed with volunteers committed to help you so you can be in control again.

Independence

During treatment you may find yourself more dependent on others than you wish. Accepting help for tasks you used to do for yourself can be humbling, but it is also part of self-care. The more others can help you, the more energy your body can save. This does not mean you will always need this level of help or that you are giving up your independence. Remember all those people who asked how they could help? This is your time to let them know exactly how they can support you.

Asking for help

When asking for help, find your comfort zone. If you want to use humor when you call someone or would feel better asking via text, then do what works for you. Some conversation starters to help the process include:

"It was so nice of you to offer to help, there are a few ways that you can."

"Thank you for offering. Please let me know if any of these opportunities work with your schedule."

"You're so good with my kids, would you be up to taking them for the afternoon?"

"I need to laugh, and you always make me laugh. Can you come over this afternoon?"

Please see worksheets on pages 45-47 to help you connect the right friend, family member or service with your needs.





Oxygen therapy

Staying active, getting around

There are many resources for people with lung cancer to create a “new normal” lifestyle or return to activities they enjoyed before treatment. During cancer treatment some patients may not have engaged in wellness programs because of their schedule or limitations due to their treatment experience. These programs are always available no matter when people with lung cancer can participate.

Oxygen therapy may be an option for many people with lung cancer. Oxygen can help reduce breathing difficulties and in turn, fatigue. By increasing energy, those with lung cancer can explore more opportunities for wellness and palliative care services. Speak with your healthcare team about this option and whether it is an appropriate therapy for you.

The three types of oxygen systems currently available are:

- Compressed gas systems: Small tanks of oxygen gas under pressure that can be carried
- Portable oxygen concentrators (POCs): Using battery or electricity from an outlet, a POC uses the air around you
- Liquid oxygen systems: In a portable tank for you to carry or pull, this device uses low temperature gas

Wondering about how you can travel while taking in oxygen?

No matter how you travel, it’s best to call ahead and ask about oxygen device rules as well as have access to your oxygen prescription paperwork. Here are some helpful facts depending on how you need to get around:



Air: You can only use an FAA-approved portable oxygen concentrator (POC) on airplanes. By contacting the airline, you can plan ahead of time for any fees or paperwork that is needed before you travel.



Car: Use the floor on the seat beside you as your space for the oxygen unit. If you can place it in a seat next to you, make sure it is upright and secured with a seat belt. When you are driving with your oxygen device, leave the windows down a little so air can circulate. It is dangerous to leave oxygen units in a hot car.



Train/bus: Local bus and train offices will ask for your information at least three days before you depart. There are certain train lines that require you to bring your own power source, so it’s best to speak with the station staff ahead of time to be prepared.



Cruise: Although some people prefer to travel on cruises specifically for people who use oxygen, they may not always be available. In general, cruise lines require four- to six-weeks’ notice about your oxygen needs. Your oxygen supplier company will be able to assist you in planning for visits to ports of call.

Wellness guide

Check to see if any of these resources are available in your neighborhood:

- Acupuncture
- Aromatherapy
- Art therapy
- Music therapy
- Counseling
- Energy therapies
- Hypnotherapy
- Life coaching
- Massage
- Relaxation and meditation
- Tai chi
- Qigong
- Yoga, pilates, and strength training





Acupuncture

This is a technique in which practitioners insert fine needles into the skin to treat health problems. Acupuncture has been in use in some form for at least 2,500 years and is a form of traditional Chinese medicine.



Aromatherapy

Aromatherapy is the use of essential oils from plants (flowers, herbs, or trees) as an approach to help with relaxation. They are used in massage work, baths, inhalations or vaporizers.



Art therapy

Art therapy is a way of using visual art techniques to express feelings. An art therapist can help people explore and create images that represent feelings and concerns about their health.



Music therapy

Similar to art therapy, the practice of music therapy uses music to help people engage and process emotions and concerns about their health.



Counseling

Certified counselors, psychologists and social workers work one on one or in group settings with patients to identify issues that need to be processed on deeper levels.



Energy therapies

Energy therapies use techniques to redirect energies that can help the individual body heal. Techniques include Reiki, healing touch and polarity therapy.



Hypnotherapy

This deep relaxation technique works to overcome mental blocks associated with anxiety, fear or unhealthy habits.



Life coaching

Life coaching is guidance offered to help people with problem-solving, behavior-change and goal-setting. Life coaches have specific certifications just as therapists and counselors do.



Massage

Massage involves moving (manipulating) muscles and soft tissues to manage a health condition or enhance wellness. For cancer patients, pressure used in massage therapy may need to be modified for areas that have increased sensitivity.



Relaxation and meditation

Meditation, an ancient practice, is a general term for relaxation methods which focus on calmness as well as helping the mind-body connection. Types of meditation include breathing, sounds, guided imagery and helpful repeated phrases.



Tai chi

Like qigong, tai chi is both physical and psychological. Once part of martial arts practice, it is now used to build stability in both mind and body. Tai chi involves a cycle of slow gentle movements and poses while meditating and controlling one's breath.



Qigong

Qigong – pronounced “chee gong,” is a traditional Chinese medicine method that is both physical and psychological. Qigong focuses on controlled breathing, movement and posture.



Yoga, pilates, and strength training

See page 42 for more information.

- **Pilates:** An exercise program that uses breathing and posture to strengthen core muscles. This method also helps retrain body postures and habits that are causing negative effects such as pain and limited mobility.
- **Lifting weights:** Resistance training uses everything from free weights and water bottles to your own body weight in order to exercise the muscles. This form of exercise has multiple cycles of lifting at a lower weight than in strength training.

Worksheet: Communicating your needs

It may be easier to ask for help after you have identified what you need. This worksheet is designed to help you link your friend/family/community resources to common needs you may experience during lung cancer treatment.



Daily living	Who can I ask?  (person/community resource)
<p>Transportation <i>Who will drive me to and from treatment? Who will take me shopping for things I need?</i></p>	
<p>Childcare or eldercare <i>Who will help with carpooling for my kids? Who will take my mom to her weekly physical therapy appointment?</i></p>	
<p>Understanding medical information <i>Who will come with me to appointments and help clarify things I may not understand?</i></p>	
<p>Financial arrangements <i>Who can I turn to for questions about paying healthcare costs?</i></p>	
<p>Understanding coverage <i>Who can I ask questions to about what is covered and what is not?</i></p>	
<p>Paperwork <i>There are so many forms. Who do I know that can help me make sure everything is completed correctly?</i></p>	
<p>Local errands <i>Which friends or family members can help with the errands I am now too tired to do? Which of these people are running the same types of errands?</i></p>	
<p>Housework <i>Are there community services to help with housework? Who do I know that is good at organizing or loves to clean?</i></p>	
<p>Food preparation <i>Who makes the best smoothies? Who makes the best soup? Who is really good at making casseroles my family can heat up?</i></p>	

Treatment	Who can I ask?  (person/community resource)
<p>Expectations <i>Who can I talk to when I find myself getting nervous about treatment? Who is someone that can set my mind at ease?</i></p>	
<p>Symptom questions <i>Who in my family and circle of friends do I feel comfortable talking about symptoms?</i></p>	
<p>Treatment schedule <i>Who can help organize meals and errands for me while I am in treatment?</i></p>	
<p>Condition management <i>Who is someone I can trust with news and share it with when I don't have the energy?</i></p>	
<p>Support <i>Who can I count on for listening and giving good advice? Who can I count on to research things for me from trusted sources? Which of my friends or family knows about community resources?</i></p>	

Emotion	Who can I ask?  (person/community resource)
<p>New normal <i>Who can I count on to help me embrace new aspects of my life? Which friend do I want with me to buy new clothes?</i></p>	
<p>Body image <i>Who can I let my guard down with and speak honestly about my body and its changes?</i></p>	
<p>Comfort <i>Who can I count on to comfort me when I need it? Who makes the best comfort food? Who will talk about movies or books or sports with me for hours at a time?</i></p>	
<p>Laughter <i>Who will make me laugh? Who will understand how cancer has affected my sense of humor? Who will get my jokes?</i></p>	
<p>Social needs <i>Which friends or family members can I count on for helping my family stay involved with social activities while I am recovering? Which friends can I count on to help me be social at my own pace?</i></p>	
<p>Loneliness <i>Which friends or family members will understand when I want to be alone or when I am struggling with loneliness? Who is someone that can be flexible about plans to visit with me?</i></p>	



Questions to ask my doctor

- What type of lung cancer do I have?
- What stage is my cancer?
- Do we have all the necessary test results we need to determine my treatment plan?
- If my cancer has spread, where else is it in my body?
- Has my biopsy tissue been sent out for comprehensive biomarker testing?
- If the best treatment for me is not covered by my insurance, what resources are available to help with access/payment?
- Are there any clinical trials I should consider?
- Can I get a second opinion at an NCI-designated cancer center and still be treated here locally by you?
- If I cannot afford a second opinion at an NCI-designated cancer center, is there someone local you could recommend?
- How often will I need to have follow-up scans?
- What types of side effects should I expect with the treatment you are recommending?
- Who on my team should I contact for questions and concerns about side effects? Is someone available to me after hours or on weekends?
- Before I begin treatment, should I consider fertility preservation?
- Can I still work during treatment?
- Can I travel during treatment? What kind of travel accommodations will I need?

Notes

Glossary

Adenocarcinoma

Cancer that begins in the tissues of a gland. These tissues create fluids in the body, such as mucus or breast milk.

Adjuvant therapy

Additional cancer treatment given after the main treatment (usually surgery or high-dose radiation therapy) to lower the risk that the cancer will come back. Adjuvant therapy may include chemotherapy, radiation therapy, hormone therapy, targeted therapy, or biological therapy.

Biomarkers

Genes, proteins, or hormones in the blood or in the tumor that can be tested to learn important details about a cancer and help with treatment planning.

Biopsy

A procedure done to remove a sample of tumor tissue to see if cancer cells are present.

Consolidation therapy

Once the initial treatment is completed, patients may need additional therapy called consolidation therapy. This is the treatment given to combat any lingering cancer cells left in the body. Treatment types include chemotherapy, immunotherapy and radiation therapy.

First-line therapy (also called primary therapy, primary treatment, or induction therapy)

The first treatment given for a disease. It is often part of a standard set of treatments, such as surgery followed by chemotherapy and radiation. When used by itself, first-line therapy is the one accepted as the

best treatment. If the first-line treatment does not work or has stopped working, then second-line and further lines of therapy may be used. For some patients, a second-line therapy is considered if side effects are not manageable, or a new treatment is available.

Fusion protein

An abnormality in the DNA, where the part of one gene moves to another gene, creating what is known as an abnormal “fusion protein.” ALK is an example of a fusion protein.

Genes

Genes can be found within chromosomes in the body’s cells. Genes have information on inherited traits such as hair or eye color, as well as possible mutations that could increase risk for disease.

Inoperable

When a tumor cannot be treated by surgery, it is viewed as inoperable.

Large cell carcinoma

A non-small cell lung cancer in which the cells are larger than cells found in other tumors such as adenocarcinoma or squamous cell carcinoma.

Localized cancer

The cancer has not obviously spread from the original tissue or organ to other areas of the body in amounts that are too small to detect.

Lymph nodes

Lymph nodes or glands are part of the lymphatic system. They are small, bean-shaped structures found throughout the body, including inside the chest and abdomen. They filter substances in the lymph.

Lymphatic system

The lymphatic system is the part of the immune system that moves fluid (called lymph) and cells to and from the lymph nodes throughout the body. It creates the tissues and organs that create, house, and move white blood cells that fight infections and diseases. It is made up of a network of thin tubes that branch into all the tissues in the body.

Maintenance therapy

Maintenance therapy may be given to prevent the cancer from coming back. This type of therapy may be necessary for a long treatment period. Different methods of treatment such as vaccines and antibodies may be used.

Mediastinum

This area contains the heart and is found behind the breastbone and between the lungs. The nodes located in this area are called mediastinal lymph nodes.

Metastasize

To move from one part of the body to another. This occurs when cancer cells spread from where they began to other parts of the body through the lymph system or bloodstream. Once these cells have spread, the cancer has metastasized, and the cancer is called metastatic.

Minimally invasive surgery

Surgery that is done using small incisions (cuts) and few stitches. During minimally invasive surgery, one or more small incisions may be made in the body. A laparoscope (thin, tube-like instrument with a light and a lens for viewing) is inserted through one opening to guide the surgery. Tiny surgical instruments are inserted through other openings to do the surgery. Minimally invasive surgery may cause less pain, scarring, and damage to healthy tissue, and the patient may have a faster recovery than with traditional surgery.

Monoclonal antibodies

A protein, developed in a lab, that can bind to certain targets in the body, such as antigens (substance recognized by the immune system).

Mutations

A type of change to the DNA in a gene contained in a cell is known as a mutation, or variant. Although cancer can start from a mutated cell, not all mutations lead to cancer.

Neoadjuvant therapy

Treatment used to shrink a tumor before the main treatment, which is usually surgery, is given. Examples of neoadjuvant therapy include chemotherapy, radiation therapy, and immunotherapy. It is a type of induction therapy/first-line treatment.

Open surgery

This traditional type of surgery involves the cutting of skin and tissues so that the surgeon can “open up” the body part and have a full view of the structures or organs involved. It can likely cause pain, scarring, and usually requires a longer recovery time than minimally invasive surgery.

Outcomes

Patient outcomes are the results from care and treatments that patients have received. These outcomes can be clinical, emotional, and practical.

Pathologist

A doctor who specializes in diagnosing and classifying diseases by lab tests and by looking at tissues and cells with a microscope. The pathologist determines whether a tumor is cancer, and, if it is cancer, the exact cell type (where it started) and grade (how fast it likely will grow).

Platinum-containing agent

This term refers to certain chemotherapy drugs that are effective at treating slow-growing cancers. The drugs (either cisplatin or carboplatin) are made up of platinum and other elements that work by damaging the DNA of cancer cells so they can no longer multiply.

Pleural effusion

This occurs when fluid abnormally collects between the thin layers of tissue (called pleura) lining the lung and the wall of the chest cavity.

Primary site

Primary cancers are typically named for the organ or area in which the cancer first appears. Treatment decisions will continue to be based on the primary cancer type even when cancer spreads to other organs.

Precision (precision medicine)

A medical approach that uses information about a person’s genes to prevent, diagnose, or treat disease.

Proteins

Molecules created by genes with specific instructions to help the body function properly.

Proton

High-energy subatomic particle that is used for radiation treatment.

Rearrangement

A genetic abnormality that causes DNA in a cell to relocate (move from its normal position) and not work properly.

Resistance

Cancer can be resistant at the beginning of treatment, or it may become resistant during treatment. When this happens, the patient and healthcare provider can talk about a new treatment plan.

Squamous cell carcinoma

Cancer that begins in the squamous cells, which are commonly found in the skin or the lining of the organs.

Staging

The method used to locate and determine how much cancer is in a person’s body. It is usually defined by the size and location of the tumor, and whether it has spread to any lymph nodes or other places in the body.

Stereotactic

A computer and 3-dimensional (3D) tool that can scan on different levels in the body to find a tumor and help surgeons remove the correct tissue.

Subtype

When a type of cancer can be divided into smaller groups, those groups are known as subtypes. Knowing the subtype of one’s cancer can help with treatment planning.

Tumor

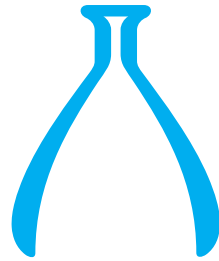
An abnormal growth or mass of tissue. Some tumors are very slow growing, and are not considered cancerous. Most tumors, however, are rapidly growing and are considered cancerous.

Unresectable

When a tumor cannot be fully removed with surgery, it is viewed as unresectable.

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