



If you or a loved one has lung cancer, you may be feeling overwhelmed. You may have a lot to process and a lot of doctor visits. It can seem sometimes like your health care team is speaking another language. Whether you have decisions to make about your treatment or not, it helps to know what to expect from treatments.

This booklet gives an overview of lung cancer diagnosis, treatment, and how to cope. We hope this will help you learn more about your options, know what questions to ask, and feel more in control of your cancer and your life.

## TALKING ABOUT CANCER

You will hear many words used to describe cancer. Some key ones to know are:

**BENIGN:** Not cancer

**LOCALLY ADVANCED:** Cancer that has spread to nearby tissue or lymph nodes but not outside the chest

**LYMPH NODES:** Glands found all over the body that help fight infection. Cancer often spreads to lymph nodes

**MALIGNANT:** Cancer

**METASTASIS or METASTATIC:** Cancer that has spread to other areas

**PRIMARY SITE OR PRIMARY CANCER:** Part of the body where the cancer starts

**RELAPSE OR RECURRENCE:** Cancer that went away then came back again

**TUMOR:** A mass or lump

Lung cancer starts in the chest and affects the organs that help us breathe. Many people with lung cancer do not notice any symptoms until the cancer has spread outside of the lungs. This is why few lung cancers are caught early.

Lung cancer is the second most common cancer in the U.S. You can get lung cancer whether you smoke or not. Smoking increases your risk of lung cancer. Yet people who never smoked get lung cancer, too. Smokers who quit lower their risk of lung cancer. If you have lung cancer, quitting smoking can make treatment more effective.

## Types of Lung Cancer

There are two main types of lung cancer. They are named for the size and shape of the cancer cells.

### NON-SMALL CELL LUNG CANCER (NSCLC)

- Most lung cancer (85%) is non-small cell
- Common kinds of NSCLC are:
  - Adenocarcinoma
  - Squamous cell carcinoma
  - Large cell carcinoma

### SMALL CELL LUNG CANCER (SCLC)

- 15% of lung cancers are small cell
- Mostly seen in current or former smokers

## Diagnosis and Staging

Your health care team will run tests to learn as much as they can about your lung cancer. This process is called diagnosis and staging.

**DIAGNOSIS** = Is there lung cancer?  
What type of lung cancer?

**STAGING** = Has the lung cancer spread?  
If it has spread, where?

# GETTING A DIAGNOSIS

Your results will help determine the best treatment for you. Diagnosis has 3 parts:



## EXAM

Your doctor will do a physical exam and ask many questions. Describe how you have been feeling and any changes you have noticed. Being open and honest in your answers helps your doctor give you the best care.



## IMAGING

Common tests to see the tumor and where it has spread include:

- **CHEST X-RAY:** Simple and quick, but not a very clear picture
- **CT AND MRI SCANS:** Provide sharper and clearer pictures of parts of your body
- **PET SCANS:** To see if spots seen on other imaging tests are active cancer or not



## LAB TESTS

A sample of tissue or fluid will be looked at in a lab. The results of these tests help your doctors decide what treatments to offer you. Some common lab tests are:

- **NEEDLE BIOPSY:** Removes a small piece of tissue from the lung or other sites
- **SPUTUM CYTOLOGY:** Takes a sample of mucus from a cough
- **THORACENTESIS:** Removes fluid from around the lungs for tests and possibly to improve breathing
- **BRONCHOSCOPY:** Uses a flexible tube to look down your windpipe at the airways and get a tissue sample
- **NAVIGATIONAL BRONCHOSCOPY:** Computer-guided bronchoscopy, used in hard-to-reach parts of the lungs
- **BIOMARKER TESTS:** These tests of your tumor's cells help match you with the best treatments. Biomarker testing is also called tumor testing, genomic testing, mutation testing, or molecular testing. All patients with advanced non-small cell lung cancer should get comprehensive biomarker testing. Ask your doctor if your sample will be sent for biomarker testing. More information on this can be found in Cancer Support Community's *Targeted Therapy and Biomarker Testing for Lung Cancer* booklet ([www.CancerSupportCommunity.org/TargetedLung](http://www.CancerSupportCommunity.org/TargetedLung)).

## STAGES OF LUNG CANCER

Doctors use stages to describe cancer. Stages range from one (I) to four (IV), with four being the most serious. Lung cancer stages are based on the answers to the questions below. This is called a TNM scale.

**TUMOR (T):** How big is the tumor? Where is it?

**LYMPH NODES (N):** Has the cancer spread to the lymph nodes?

**METASTASIS (M):** Has the cancer spread to other parts of the body?

Small cell lung cancer is sometimes described as limited stage and extensive stage. Limited stage is more limited to the chest and easier to treat.

## Treatment Planning

After you find out you have lung cancer, your doctor will tell you which treatments are best for you. Your doctor may ask you what you want to do. This is called **TREATMENT PLANNING**. You may make choices at the start of treatment and again along the way.

### TIPS FOR TREATMENT PLANNING:

- Ask questions. Your health care team will give you a lot of information. Listen closely and ask questions until you understand what is being said.
- Bring a friend or relative to take notes.
- Ask for information in a different language or format if you need it. For example, you can ask your doctor to draw you a picture or compare it to something you already know.

## Getting a “Second Opinion”

The best cancer treatments can be very complicated and change all the time with new discoveries. You want a doctor you trust to take the best care of you. You also want the best treatment. If you are unsure that you have these, ask for a “second opinion” with a doctor who specializes in lung cancer. Talking with a second doctor can help you understand your disease and how to better treat it, or reassure you that the first treatment recommended is best. Let your doctor know if you want a second opinion.

# TALK WITH PEOPLE YOU TRUST

Talk through your choices with your family, friends, and health care team. They can help you think about the pros and cons of different treatments. Also, think about:



## **SIDE EFFECTS:**

Cancer treatments have different side effects. Ask:

- What they are
- When they usually start
- How long they last
- How to manage them



## **EXPENSE:**

- Is this treatment covered by your insurance? If not, can you get help paying for it?
- Are there programs that can help you with other costs (prescriptions, childcare, household costs) while you are in treatment?



## **TIME COMMITMENT:**

- How often will you need to go to the clinic?
- How much work will you miss?
- If you care for children or elderly parents, how long will you need help with that?
- If your only treatment is surgery, how long will you need before you feel well again?



## **TRAVEL:**

- Where will you go for the treatment?
- How will you get there?
- If you are concerned with travel costs, ask about transportation assistance.

## QUESTIONS TO ASK YOUR HEALTH CARE TEAM

- What type of lung cancer do I have?
- What is the stage of my lung cancer?
- Has my tumor been sent for biomarker testing? What are the results for EGFR, ALK, BRAF, ROS1, NTRK, KRAS, RET, MET, and PD-L1? What do the results mean for me?
- What is the goal of my treatment?
- What treatment do you recommend and why? What are the benefits of this treatment?
- What are the risks of this treatment?
- Are there other treatments besides the one you recommend?
- How long will the treatment take?
- What are the side effects of the treatment? What can I do to prepare for them?
- How will treatment affect my everyday life? What will it involve in terms of time and travel?
- How likely is the treatment to work for me?
- How and when will you determine if the treatment is working?
- Are there any support services available to me?
- What are clinical trials? Is there one that might be right for me?
- Is there a targeted therapy or immunotherapy that might work for me?
- How do I go about getting a second opinion?

## Clinical Trials

Be sure to ask about clinical trials. Clinical trials are research studies to test new treatments or learn how to use existing treatments better. Today's newest treatments were studied in yesterday's clinical trials. Today's clinical trials may become tomorrow's newest treatments.

### KEY THINGS TO KNOW:

- A clinical trial may be the only way to get some of the newest, most promising treatments.
- The U.S. Food and Drug Administration and local review boards oversee all U.S. clinical trials to keep patients safe.
- If you join a clinical trial, you can leave at any time.
- Every doctor does not have the same trials.
- Most often, the trial pays the costs of the drug being studied and your health insurance only has to pay for “standard” treatment costs. However, your health insurance may not pay for everything. Be sure to ask.

## Treatment for Lung Cancer

Both small cell and non-small cell lung cancer are treated using one or more of the following therapies.

**SURGERY** is an operation to remove the cancer. It is not always possible or helpful. When it is, it is often the first treatment. Some doctors now use video, dyes, or mini robots to

help see the cancer. Your doctor may suggest one of these operations:

**WEDGE OR SEGMENTAL RESECTION:** removal of a small part of the lung

**SEGMENTECTOMY:** removal of one or more segments of the lung

**LOBECTOMY:** removal of a whole section (a lobe) of the lung

**BILOBECTOMY:** removal of two lobes of the same lung

**PNEUMONECTOMY:** removal of an entire lung

**CHEMOTHERAPY** (also called chemo) uses drugs to attack and kill cancer cells. These very strong drugs attack fast-growing cells like cancer. Chemo can cause side effects like hair loss, nausea, mouth sores, and low white blood cell counts.

**IMMUNOTHERAPY** works by making the immune system stronger so it can fight cancer better. The immune system helps your body fight infections and other diseases, like cancer. But sometimes cancers learn how to avoid the immune system and grow anyway. Immunotherapy works to turn the immune system back on to fight the cancer. Common side effects include fatigue, skin problems, fever, and shortness of breath. Most side effects are mild, but some can be severe.

**RADIATION THERAPY** uses energy beams, such as very strong x-rays, electrons, or protons, to kill cancer cells and shrink tumors. If your cancer hasn't spread far, radiation can be used to try to cure it. Radiation is also used to treat pain or other

symptoms. You may experience redness, burns, or hair loss in the area being treated. Other possible side effects include fatigue, loss of appetite, and nausea.

**TARGETED THERAPY** targets specific cell processes that cause cancers to grow, divide, or spread. Doctors test tumors for biomarkers to find out if targeted therapy should work. Diarrhea and skin problems, including rashes, are the most common side effects.

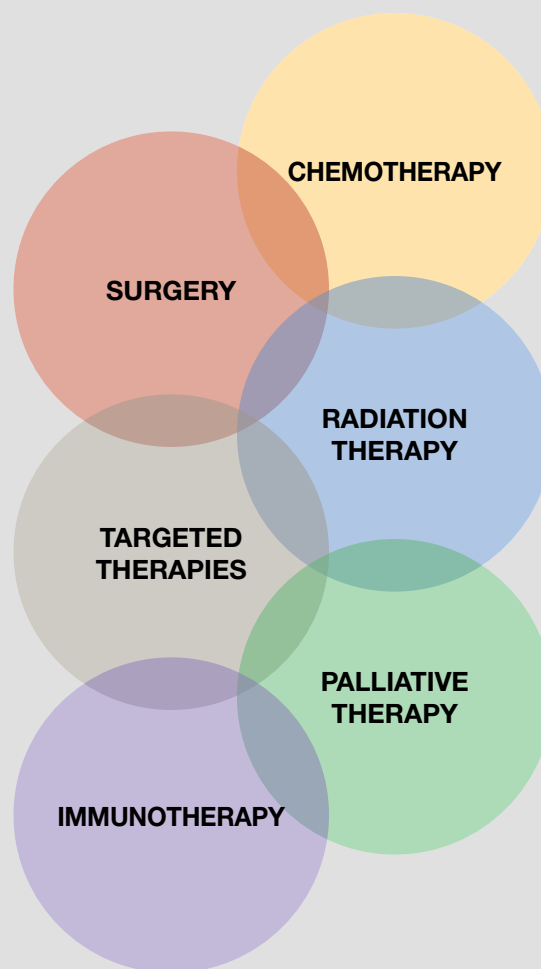
**PALLIATIVE (SUPPORTIVE) CARE** focuses on helping you feel better. It is not treatment for the lung cancer itself. It can be given at any age and at any stage. You can get it along with cancer treatment. The goal is to improve quality of life for both the patient and the family.

**ARE THERE OTHER TREATMENTS THAT MAY WORK?** You may hear of special diets or other treatments from friends or the internet. Many of these are not based in science. Some can be very costly and even cause harm or interfere with treatment. Talk with your health care team about anything you are doing or considering doing to help with lung cancer or the side effects of treatment.

For more information, see Cancer Support Community's *Lung Cancer* book, and the booklets *Immunotherapy and Lung Cancer* and *Targeted Therapy and Biomarkers for Lung Cancer* at [www.CancerSupportCommunity.org/Lung](http://www.CancerSupportCommunity.org/Lung). You can also mail order these books by calling CSC's Helpline (888-793-9355).

## TREATMENT OPTIONS

Standard treatment for lung cancer often involves a combination of these approaches, together or in sequence.



## Side Effects of Treatment

Even when you are getting better, cancer treatment can make you feel worse (at least temporarily) both physically and emotionally. Coping with the side effects of treatment can be one of the hardest parts of cancer. It helps to plan in advance and talk with your health care team.



- **BEFORE YOU START TREATMENT**, ask your care team about the side effects of the treatments you are considering. Find out how to manage them and when to report them to your team.
- **AFTER YOU START TREATMENT**, try to keep track of how you feel. Write down when you notice a problem, how long it lasts, and if there is anything that makes it better. It is important to let someone know. There may be medicine or other ways to manage side effects that will help you feel better.

More information on treatment side effects and how to manage them can be found in CSC's book *Frankly Speaking about Cancer: Lung Cancer* ([www.CancerSupportCommunity.org/LungBook](http://www.CancerSupportCommunity.org/LungBook)).

## Cost and Expenses

Lung cancer treatment and follow-up can be costly. Keeping up with these costs may be overwhelming. Many families facing cancer say that financial worries are a big source of stress.

You can ask your health care team if there is a social worker or financial navigator who can help you manage costs. If you have health insurance, it is important to learn what your policy covers. For other tips on coping with cancer costs, visit [www.CancerSupportCommunity.org/Cost](http://www.CancerSupportCommunity.org/Cost) or call our Helpline at 888-793-9355.

## Coping with Cancer

Cancer stirs up many feelings. It affects people who have it, their families, and loved ones. It is normal to feel sad, worried,

shocked, stressed, or even panicked. The feelings may be mild or more serious.

People with lung cancer sometimes blame themselves. Remember that cancer can affect anyone. No one deserves cancer. And everyone with cancer deserves good care.

### IT CAN HELP TO

- **Share your feelings.**  
Talk with friends, family members, a counselor, or a clergyperson.
- **Join a support group.**  
You may feel better when you talk with other people who have cancer.
- **Ask for help and support.**
- **Find ways to relax and reduce stress.**
- **Do things you enjoy.**
- **Stay hopeful.**  
Hope can come from within or from talking with others. You can hope for big things or small, related to your health or not. Look for sources of hope and focus on them.
- **Take care of your body.**  
Eat healthy foods. Exercise. Get enough rest. If you smoke, try to stop.



**Ginni**  
**Helping Others and Helping Yourself**

Ginni knows the emotional burden that comes with an illness. She was diagnosed with lung cancer three years ago. In addition, she is also a caregiver to her husband, who was diagnosed with leukemia, and has experienced grief with the passing of close family members due to other health conditions.

“Through my experience, I’ve learned to be faithful and journal daily. It’s between me and God. I also love to knit and crochet. I made a hat and wore it during a chemo session; a woman complimented me on it and I gave it to her. I thought to myself, there must be others who would like to receive hats as well. So I knit and crochet hats and give them all away. It helps me to know that I am helping other people.”

## Lung Cancer Information, Survivorship & Support

**Cancer Support Community** • 888-793-9355 • [www.CancerSupportCommunity.org](http://www.CancerSupportCommunity.org)

**American Cancer Society** • 800-227-2345 • [www.cancer.org](http://www.cancer.org)

**American Lung Association** • 800-586-4872 • [www.lung.org](http://www.lung.org)

**CancerCare** • 800-813-4673 • [www.cancercare.org](http://www.cancercare.org)

**Cancer.net** • 888-651-3038 • [www.cancer.net](http://www.cancer.net)

**GO<sub>2</sub> Foundation for Lung Cancer** • 800-298-2436 • [www.go2foundation.org](http://www.go2foundation.org)

**Lung Cancer Research Foundation** • 212-588-1580 • [www.lungcancerresearchfoundation.org](http://www.lungcancerresearchfoundation.org)

**LUNGevity Foundation** • 321-407-6100 • [www.LUNGevity.org](http://www.LUNGevity.org)

**National Cancer Institute (NCI)** • 800-422-6237 • [www.cancer.gov](http://www.cancer.gov)

**Patient Advocate Foundation** • 800-532-5274 • [www.patientadvocate.org](http://www.patientadvocate.org)

## Lung Cancer Clinical Trials Information

**Cancer Support Community's Clinical Trials Resources** • 888-793-9355 • [www.CancerSupportCommunity.org/Finding-Clinical-Trial](http://www.CancerSupportCommunity.org/Finding-Clinical-Trial)

**GO<sub>2</sub> Foundation for Lung Cancer** • Clinical Trial Matching Service called LungMATCH • 800-298-2436 • [www.lungmatch.org](http://www.lungmatch.org)

**LUNGevity Foundation** • Clinical Trial Finder • [clinicaltrials.lungevity.org](http://clinicaltrials.lungevity.org)

**National Cancer Institute** • 800-422-6237 • [www.cancer.gov/clinicaltrials](http://www.cancer.gov/clinicaltrials)

The Cancer Support Community provides this information as a service. This publication is not intended to take the place of medical care or the advice of your doctor. We strongly suggest consulting your doctor or other health care professionals to answer questions and learn more.

# Cancer Support Community Resources

**Cancer Support Helpline®** — Have questions, concerns or looking for resources? Call CSC's toll-free Cancer Support Helpline (888-793-9355), available in 200 languages Mon – Fri, 9 am – 9 pm ET.

**Open to Options®** — Need help making a cancer treatment decision? Our trained specialists can help you create a list of questions to share with your doctor. Make an appointment by calling 888-793-9355 or by contacting your local CSC or Gilda's Club.

**Frankly Speaking About Cancer®** — Trusted information for cancer patients and their loved ones is available through publications, online, and in-person programs.

[www.CancerSupportCommunity.org/FranklySpeakingAboutCancer](http://www.CancerSupportCommunity.org/FranklySpeakingAboutCancer)

**Services at Local CSCs and Gilda's Clubs** — With the help of 170 locations, CSC and Gilda's Club affiliates provide services free of charge to people touched by cancer. Attend support groups, educational sessions, wellness programs, and more at a location near you.

[www.CancerSupportCommunity.org/FindLocation](http://www.CancerSupportCommunity.org/FindLocation).

**Cancer Experience Registry®** — Help others by sharing your cancer patient or cancer caregiver experience via survey at [www.CancerExperienceRegistry.org](http://www.CancerExperienceRegistry.org).

**MyLifeLine** — CSC's private, online community allows patients and caregivers to easily connect with friends and family to receive social, emotional, and practical support throughout the cancer journey and beyond. Sign up at [www.MyLifeLine.org](http://www.MyLifeLine.org).

**Grassroots Network** — Make sure your voice is heard by federal and state policy makers on issues affecting cancer patients and survivors by joining our Network at [www.CancerSupportCommunity.org/become-advocate](http://www.CancerSupportCommunity.org/become-advocate).

**FRANKLY SPEAKING ABOUT LUNG CANCER WAS UPDATED WITH GENEROUS SUPPORT FROM:**



**ORIGINALLY DEVELOPED WITH GENEROUS SUPPORT FROM:**



This booklet is available to download and print yourself at [www.CancerSupportCommunity.org/LungFS](http://www.CancerSupportCommunity.org/LungFS).

For print copies of this booklet or other information about coping with cancer, visit

[Orders.CancerSupportCommunity.org](http://Orders.CancerSupportCommunity.org).

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