

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 start to feel empowered cancer and your life.



CANCER SUPPORT
COMMUNITY.



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 US. 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 blood or tumor 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 OR MOLECULAR TESTS:** These tests of your tumor's cells help match you with the best treatments. Some biomarkers require genetic testing of your tumor. All patients with metastatic adenocarcinoma should have genetic testing. Ask your doctor if your sample will be sent for genetic or other biomarker testing. More information on this can be found in Cancer Support Community's *Frankly Speaking About Lung Cancer* book (www.CancerSupportCommunity.org/LungBook) and our *Treatments for Metastatic Lung Cancer* fact sheet (www.CancerSupportCommunity.org/LungMets).

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. Ask how likely it is for the treatment to work. Also, think about:



SIDE EFFECTS: Cancer treatments

have different side effects. Ask:

- What they are
- When they usually start
- How long they last, and
- 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 stage of lung cancer is it? _____

- Has my tumor been sent for genetic or other biomarker testing? If so, what do the results mean for me? _____

- Can you remove the cancer with surgery, and would that be helpful? _____

- What treatment do you recommend and why? _____

- 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? _____

- How likely is the treatment to work for me? _____
- Are there any support services available to me? _____
- What is a clinical trial? 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 the entire lung

CHEMOTHERAPY uses drugs to attack cancer cells. These very strong drugs can kill many cells at one time and may harm healthy cells too. This is why they tend to have many side effects. Common drugs used to treat lung cancer include:

- Carboplatin (Paraplat[®] or Paraplatin[®])
- Cisplatin (Platinol[®])
- Docetaxel (Taxotere[®])
- Gemcitabine Hydrochloride (Gemzar[®])
- Paclitaxel (Taxol[®])
- Pemetrexed disodium (Alimta[®])
- Vinorelbine Tartrate (Navelbine[®])

IMMUNOTHERAPY works by making the immune system stronger so it can fight cancer better. These drugs have different side effects from other cancer treatments. Ask your doctor what to expect. New drugs include: Nivolumab (Opdivo[®]) and Pembrolizumab (Keytruda[®]). See Cancer Support Community's *Your Immune System and Lung Cancer* fact sheet (www.CancerSupportCommunity.org/IO Lung) for more information.

RADIATION THERAPY uses strong energy beams such as x-rays to shrink tumors where the beam is pointed. 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.

TARGETED THERAPY may be an option for some cancers. Doctors decide to use it based on the findings of biomarker tests, including

genetic testing of your tumor. Targeted drugs aim to block cancer growth "driven" by changes to the tumor's gene. They often have fewer side effects. They include: afatinib (Gilotrif[®]), crizotinib (Xalkori[®]), erlotinib (Tarceva[®]), osimertinib (Tagrisso[™]), and alectinib (Alecensa[®]).

PALLIATIVE THERAPY (also called supportive care) focuses on helping people feel better. It does not treat disease but aims to help with symptoms.

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.

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 health care team about the side effects of the treatments you are considering. Find out how to manage them.

■ **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 side effects and how to manage them can be found in CSC's book (www.CancerSupportCommunity.org/LungBook).

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 clergy person.
- 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

AMERICAN CANCER SOCIETY • 800-227-2345 • www.cancer.org

AMERICAN LUNG ASSOCIATION • 800-586-4872 • www.lung.org

BONNIE J. ADDARIO LUNG CANCER FOUNDATION • www.lungcancerfoundation.org

CANCER LEGAL RESOURCES CENTER • 866-843-2572 • www.cancerlegalresourcescenter.org

CANCER SUPPORT COMMUNITY • 888-793-9355 • www.CancerSupportCommunity.org

CANCERCARE • 800-813-4673 • www.cancercare.org

CANCER.NET • 888-651-3038 • www.cancer.net

FREE TO BREATHE • www.freetobreathe.org

LUNG CANCER ALLIANCE • 800-298-2436 • www.lungcanceralliance.org

LUNGEVITY FOUNDATION • 312-407-6100 • www.LUNGevity.org

NATIONAL CANCER INSTITUTE • 800-422-6237 • www.cancer.gov

PATIENT ADVOCATE FOUNDATION • 800-532-5274 • www.patientadvocate.org

Lung Cancer Clinical Trials Information

CANCER SUPPORT COMMUNITY

888-793-9355 • www.CancerSupportCommunity.org/clinicaltrials

LUNG CANCER ALLIANCE CLINICAL TRIAL MATCHING SERVICE

800-698-0931 • www.LungCancerAlliance.org/clinicaltrials

LUNGEVITY FOUNDATION CLINICAL TRIAL MATCHING SERVICE • 800-698-0931

LUNGEVITY FOUNDATION CLINICAL TRIAL FINDER • www.ClinicalTrials.Lungevity.org

NATIONAL CANCER INSTITUTE • 800-422-6237 • Trials.cancer.gov

NATIONAL INSTITUTE OF HEALTH'S CLINICAL TRIAL SEARCH • www.ClinicalTrials.gov

This booklet is available to download and print yourself at www.CancerSupportCommunity.org/LungFS.

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

Orders.CancerSupportCommunity.org.

Cancer Support Community Resources

The Cancer Support Community's (CSC) resources and programs are available free of charge. To access any of these resources below call 888-793-9355 or visit www.CancerSupportCommunity.org

CANCER SUPPORT HELPLINE®

Whether you are newly diagnosed with cancer, a long-time cancer survivor, caring for someone with cancer, or a health care professional looking for resources, CSC's toll-free Cancer Support Helpline (888-793-9355) is staffed by licensed counselors, available to assist you Mon-Fri 9am - 9pm ET.

OPEN TO OPTIONS®

If you are facing a cancer treatment decision, this research-proven program can help you. In less than an hour, our trained specialists can help you create a written list of specific questions about your concerns for your doctor. Appointments can be made by calling 888-793-9355, visiting www.CancerSupportCommunity.org or by contacting an Affiliate providing this service.

CANCER EXPERIENCE REGISTRY®

The Registry is a community of people touched by cancer. The primary focus of the Registry is on collecting, analyzing and sharing information about the experience and needs of patients and their families. To join, go to www.CancerExperienceRegistry.org.

FRANKLY SPEAKING ABOUT CANCER®

CSC's landmark cancer education series provides trusted information for cancer patients and their loved ones. Information is available through publications, online, and in-person programs.

AFFILIATE NETWORK SERVICES

More than 50 locations plus 120 satellite locations around the country offer on-site support groups, educational workshops, and healthy lifestyle programs specifically designed for people affected by cancer at no cost to the member.

THE LIVING ROOM, ONLINE

Here you will find support and connection with others on discussion boards, a special space for teens, and personal web pages to keep your family and friends up-to-date.

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.

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