



## Small Cell Lung Cancer

If you or a loved one has been diagnosed with small cell lung cancer, it may be difficult to figure out what resources are available to you. This booklet explains how this cancer is diagnosed, what its stages are, and how it's treated. It also offers questions for you to ask your health care team, talks about potential side effects, and offers additional resources to help you be an active member of your health care team.

**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., but causes the greatest number of deaths.

### TYPES OF LUNG CANCER

There are two main types of lung cancer. They are named for the size and shape of the cancer cells: small cell lung cancer (SCLC) and non-small cell lung cancer (NSCLC). This booklet will focus on small cell lung cancer, which makes up 15% of all lung cancers.

For more information on non-small cell lung cancer visit our lung cancer page at [www.CancerSupportCommunity.org/Lung](http://www.CancerSupportCommunity.org/Lung).



### RISK FACTORS

Most people diagnosed with SCLC have a history of smoking. However, some people who are diagnosed with SCLC have never smoked. Some other risk factors for SCLC are:

- Being over the age of 70
- Exposure to cancer-causing chemicals
- Prior radiation treatment to the chest
- Exposure to secondhand smoke

Smoking increases your risk of lung cancer. Yet people who never smoked get lung cancer, too. If you use tobacco, quitting may help lower your risk of lung cancer. If you have lung cancer, quitting smoking can make treatment more effective.

### SMOKING CESSATION

If you smoke, or feel you might start smoking again, ask your health care team about resources to help you quit. Other organizations can also help:

- CDC 1-800-QUIT-NOW
- National Cancer Institute  
1-877-44U-QUIT  
[www.smokefree.gov](http://www.smokefree.gov)



## Coping with Stigma

There can be blame, shame, and stigma associated with lung cancer. Stigma occurs when a group has negative or unfair beliefs about something. People with lung cancer often are asked, “Did you smoke?” It does not matter if you smoke or used to smoke. No one deserves to get lung cancer.

### COMMON SIGNS AND SYMPTOMS OF LUNG CANCER INCLUDE:

- Chest pain
- Cough that worsens or does not go away
- Coughing up blood or mucus
- Fatigue
- Hoarseness
- Loss of appetite
- Shortness of breath
- Unexplained weight loss

## DIAGNOSIS AND STAGING OF SMALL CELL LUNG CANCER

During diagnosis and staging, your health care team will run tests to learn as much as possible about the cancer.

There are many different types of tests your care team can order to find out about your cancer.

First your doctor will complete a physical exam and learn more about your health history. It is important to be open and honest in your answers. Your doctor will order lab tests to learn more about the potential cancer. A sample of tissue or fluid will be looked at in a lab.



Some common lab tests are:

- Blood tests
- Fine needle aspiration (FNA) biopsy: A needle is used to remove a small part of tissue from the lung or other part of the body
- Sputum cytology: A sample of mucus collected from a cough can be looked at under a microscope
- Bronchoscopy: A flexible tube is used to look down your windpipe and get a tissue sample
- Thoracentesis: If there is fluid build-up around your lungs, your doctor can use a needle to remove some of it. This may help you breathe more easily and also can be sent to the lab to check for cancer cells

Once the cancer is confirmed, your doctor will use imaging to see where the cancer has spread. Common imaging tests are:

- Chest x-ray–A quick and simple image to start the diagnostic process
- CT scan and/or MRI–Provide sharp and clear pictures of specific parts of the body
- PET scan–Used to identify areas of the body affected by cancer
- Bone scan–Used to see if cancer has spread to the bone

Biomarker testing is also used to help guide treatment for SCLC. It can help your doctor match immunotherapy drugs to the specific subtype of cancer you have. Immunotherapy is a type of cancer treatment that uses the body's natural defenses (immune system) to identify, attack, and kill cancer cells.

Biomarkers tell your doctor about the subtype of the cancer in your body. Biomarker testing is also called tumor testing, genomic testing, or molecular testing. In biomarker testing, a sample of the cancer is collected from your blood, bodily fluids, or tissue taken during surgery or biopsy. Your sample is sent to a lab. The test looks for biomarkers in your cancer sample. The test results can be used to help guide your treatment options.

After undergoing testing, your care team will be able to tell you the stage of your cancer. SCLC is often broken up into two stages: limited stage and extensive stage. Limited stage small cell lung cancer is when the cancer is found in only one lung, the area between the lungs, or nearby lymph nodes. Extensive stage small cell lung cancer is when the cancer has spread to both lungs, the fluid surrounding the lungs, or to other parts of the body.



## 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 my treatment options?

Are there clinical trials that I qualify for?

How long will treatment last?

What are the side effects of the treatment?

What can I do to prepare for them?

How will treatment affect my everyday life?

How and when will you determine if the treatment is working?

What support services are available to me, my family, and my caregivers?

How do I go about getting a second opinion?





## Your Health Care Team

You are the expert in your cancer experience. You will work with your care team to get the best care for you. Knowing who is on your team will make it easier to efficiently manage your treatment and find the resources you need. Here are some people you might work with:

- **Medical oncologist:** This doctor is specially trained to diagnose and treat cancer. They use chemotherapy and other drugs to treat cancer.
- **Radiation oncologist:** This doctor is trained in the treatment of cancer using radiation.
- **Thoracic surgeon:** This doctor specializes in performing surgery in the part of the body called the thorax. The thorax is the area between the abdomen and neck (also called the chest).
- **Interventional radiologist:** This doctor performs imaging-guided procedures to diagnose and treat cancer.
- **Nurses:** You will have the most direct contact with your nurses. Oncology nurses have special training in caring for people with cancer.
- **Social workers:** These individuals are trained to assist with social and emotional needs. Social workers can help you and your family members find support groups and mental health resources.

- **Registered dietitian:** This person can help you maintain a healthy diet and get proper nutrition throughout treatment and recovery.
- **Patient or nurse navigator:** Navigators help you manage your care. They help schedule appointments, get answers to your questions, and support you during your treatment.

These people will work with you and your loved ones to manage your care. It can be helpful to keep a list of the members of your health care team and their contact information. When you meet a new member of your care team, make sure to ask what their role is and in what situations you would contact them.



## TREATMENT PLANNING

Your doctor will use the cancer stage, your overall health, and the results of other tests to recommend different treatment options. Your doctor will ask you about your treatment goals and what is important to you.

### LIMITED STAGE

#### SMALL CELL LUNG CANCER:

When the cancer is found to be limited stage, the goal of treatment should be to get rid of the tumor completely. Small cell lung cancer has a higher chance of being cured when it is treated early. Your care team may determine surgery is an option for you. The surgery that is used to treat limited small cell lung cancer is called a lobectomy. In this surgery, the tumor and part of the lung are removed. If there is still cancer after the surgery, or if surgery is not an option for you, your doctor may recommend chemotherapy, radiation, or both.

### EXTENSIVE STAGE

#### SMALL CELL LUNG CANCER:

When the cancer has spread to both lungs or outside of the chest, the goal of treatment may be to get rid of the cancer completely, reduce symptoms, or stop the cancer from spreading. Treatment may include chemotherapy, immunotherapy, and radiation.

**Chemotherapy:** The use of drugs to destroy or damage cancer cells so they cannot divide and multiply

**Radiation Therapy:** Strong energy beams used to shrink tumors, relieve pain and pressure, decrease symptoms, and improve quality of life.

**Immunotherapy:** Treatment that boosts the body's natural defenses to shrink or destroy a tumor.

When chemotherapy and radiation are used at the same time, this is called concurrent treatment. When they are used one after another, it is called sequential treatment.

## COPING WITH THE SIDE EFFECTS OF TREATMENT

Even though cancer treatment is used to stop the cancer, it can make you feel worse both physically and emotionally. Coping with treatment side effects can be difficult. It helps to plan ahead and talk with your care team about what to expect.

- **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. You can find common side effects of lung cancer and ways to manage them in Chapter 5 of our Lung Cancer book at [www.CancerSupportCommunity.org/Lung](http://www.CancerSupportCommunity.org/Lung).
- **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 on our Managing Side Effects page at [www.CancerSupportCommunity.org/managing-side-effects](http://www.CancerSupportCommunity.org/managing-side-effects).



## PALLIATIVE CARE

Maintaining your best possible quality of life is an important goal. Some care you receive may not treat your cancer. Instead, it will address possible symptoms caused by your cancer or side effects from treatment, such as pain. It may help you with social, emotional, or spiritual concerns. This kind of care is called palliative care or supportive care.

## IMPACT OF LUNG CANCER

We hear from patients and caregivers that living with lung cancer can be overwhelming. At times you may feel sad, worried, shocked, stressed, or even panicked. This is normal. In fact, patients with lung cancer have shared with our Cancer Experience registry that:

- More than half were concerned about the future and what lies ahead
- Almost half were concerned about health insurance or money worries
- 4 out of 10 people were concerned about changes in their work, school, or home life
- Almost 4 in 10 people felt guilty because of their diagnosis or believed others thought that having lung cancer is their fault

If you have any of these feelings or concerns, you are not alone. People living with lung cancer often find that talking with others may help them cope with their illness. Some people find support groups helpful. Others prefer to talk with a counselor, social worker, or clergy person or spiritual advisor.

To learn more about SCLC visit **www.CancerSupportCommunity.org/Lung** or call our Helpline at 888-793-9355.

## COST

Cancer treatment and follow-up can be costly. Keeping up with these costs may be overwhelming. 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 and when you need prior authorization before beginning a new treatment. You can find information about coping with the cost of cancer care at **www.CancerSupportCommunity.org/Cost**.



## SCLC INFORMATION AND SUPPORT

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

GO<sup>2</sup> Foundation for Lung Cancer • 800-298-2436 • [www.Go2Foundation.org](http://www.Go2Foundation.org)

Lung Cancer Research Foundation • 844-835-4325 • [www.LCRF.org](http://www.LCRF.org)

LUNgevity Foundation • 888-360-5864 • [www.Lungevity.org](http://www.Lungevity.org)

## 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 9am-9pm ET and Sat-Sun 9am-5pm ET.

**Open to Options®** — Preparing for your next appointment? 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.

**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).

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