SMALL CELL LUNG CANCER

Patient and Caregiver Guide





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ANATOMY OF THE LUNGS



The above image shows different parts that make up the lungs. Please use this picture to help guide you through the topics discussed in this brochure. Your lungs are 2 sponge-like organs in your chest that are covered by a protective layer called the pleura. The right lung has 3 sections, called lobes and your left lung has 2 lobes. When you breathe in, air enters through your mouth and nose and goes into your lungs through the trachea (windpipe).

The trachea divides into tubes called the bronchi, which enter the lungs and divide into smaller branches called bronchioles. At the end of the bronchioles are tiny air sacs known as alveoli.

SMALL CELL LUNG CANCER

Cancer is a group of diseases in which normal cells change, grow and divide out of control.

Cancer that begins in the lungs — lung cancer — is one of the most commonly diagnosed cancers in the United States.

There are two main types:

- small cell lung cancer (SCLC) and
- non-small cell lung cancer (NSCLC).

SCLC is less common but the most aggressive (fast-growing) type making up about 15% of all lung cancer diagnoses.

SCLC is named for the small, oval-shaped cancer cells seen under a microscope. It is a type of cancer that usually starts in the bronchi in the center of the chest and spreads quickly.

If you smoke, quitting is one of the single most important lifestyle changes you can make to improve your health.

Even if you have lung cancer, quitting or reducing how much you smoke may help improve how you respond to treatment. If you want to quit, help is available. Ask your doctor or other healthcare provider for information.

RISK FACTORS



A HISTORY OF SMOKING

This is the main risk factor for developing lung cancer – particularly SCLC. Cigarettes contain many carcinogens, which are substances that cause lung cancer.



EXPOSURE TO RADON

(an invisible, odorless, tasteless radioactive gas that occurs naturally in soil and rocks).



FAMILY HISTORY of lung cancer.



RADIATION THERAPY to the chest area.



OTHER LUNG ILLNESSES

(such as emphysema, chronic obstructive pulmonary disease [COPD] or tuberculosis).



EXPOSURE TO INDUSTRIAL CHEMICALS including arsenic, asbestos, beryllium uranium and Agent Orange.



EXPOSURE TO SECONDHAND SMOKE (or passive smoking).

YOUR CARE TEAM

WHAT'S THE DIFFERENCE?

A multidisciplinary team approach is when members of the healthcare team discuss your situation and work together to make treatment recommendations. It is thought that this approach improves coordination of care and communication among the team.

MEDICAL ONCOLOGIST: A doctor who specializes in diagnosing and treating cancer.

ONCOLOGY NURSE: A nurse who specializes in helping people with cancer and who may further specialize in the surgical or medical management of a patient's care.

ONCOLOGY SOCIAL WORKER OR COUNSELOR: A social worker or counselor who specializes in helping patients and loved ones cope with the emotional impact of cancer and who may help identify other needed resources.

PALLIATIVE CARE SPECIALIST: A

doctor, nurse or other healthcare professional who works with a patient's healthcare team to provide an extra layer of support such as relief from symptoms, pain and stress of an illness like cancer.

PATHOLOGIST: A doctor who specializes in diagnosing and classifying cancer by studying tissue, fluid or blood samples. **PATIENT ADVOCACY GROUP:** Groups like GO₂ Foundation for Lung Cancer that provide additional education, support and referral services at no cost.

PATIENT NAVIGATOR: A nurse, social worker or trained lay person who assists patients and loved ones on their journey through the healthcare system.

PULMONARY REHABILITATION

SPECIALIST: A specialist who works to reduce symptoms and side effects from diseases of the lung—including lung cancer—and their treatments.

PULMONOLOGIST: A doctor who specializes in treating diseases and conditions involving the lungs.

RADIATION ONCOLOGIST: A doctor who specializes in treating cancer using various forms of radiation by focusing it on the tumor site in the body.

THORACIC SURGEON: A doctor who performs surgeries in the chest region. Some thoracic surgeons specialize in lung cancer.

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DIAGNOSING SCLC

IMAGING

A number of tests provide information on areas of the lungs that do not appear normal. Doctors sometimes refer to these areas as tumors, spots, lesions, nodules or masses. These imaging techniques can provide information beyond what can be seen with a chest X-ray. Imaging can help doctors learn if a suspicious area is cancerous (malignant) or not cancerous (benign). Some imaging tools include the following:

CT (computed tomography) or "CAT" scanning can show tumors that may not be visible on a normal chest X-ray.

LDCT (low-dose computed tomography) scanning is used to screen those who are at high risk every year to see if they have lung cancer.

PET (positron emission tomography) scanning shows how a tumor is using glucose (also known as sugar). Since tumors typically use more glucose than surrounding tissue, they appear as "hot spots" (bright areas) in these images. PET scans are often used to see if cancer has spread to other parts of the body.

MRI (magnetic resonance imaging) creates detailed images of the body and can help determine whether a tumor has spread beyond its original location. Used in SCLC to check for spread of cancer to the brain.

BIOPSIES

A biopsy is a procedure in which tissue is removed from the body for testing. The tissue can help doctors diagnose cancer and provide specific information about the suspicious area.

There are several types of biopsy procedures:

NEEDLE BIOPSY OR NEEDLE

ASPIRATION: A hollow needle is inserted through the skin to draw out tissue for testing. The procedure is usually done with the aid of imaging tests such as CT scans, fluoroscopy, ultrasound or MRI to determine where to insert the needle. There are two types of this kind of biopsy:

• Fine Needle Aspiration (FNA):

Tissue is removed using a thin hollow needle. Depending on the location of the tumor, FNA is done during a bronchoscopy procedure (in which a camera-equipped tube is used to view the windpipe and other airways) or through skin. This procedure may be guided by an ultrasound or a CT scan.

• Core Needle Biopsy: Tissue is removed using a wider needle. More tissue can be removed with this procedure than with fine needle aspiration. **THORACENTESIS:** Fluid is removed from the space around the lungs (also called the pleural cavity) using a hollow needle inserted into the chest.

BRONCHOSCOPY: A thin, lighted tube (bronchoscope) is passed down the throat through the mouth or nose and into the center area of the lungs. A needle is then inserted down the tube and samples are removed for testing.

• Endobronchial Ultrasound (EBUS): Uses a bronchoscope and ultrasound (high frequency sound waves) and allows for better examination of the lymph nodes and other structures in the center of the chest to see if cancer has spread.

SURGICAL BIOPSY: Tissue is removed during surgery.

LIQUID BIOPSY: Blood or other fluid is removed for biomarker testing to help with planning treatment. Liquid biopsy is **NOT** used to diagnose lung cancer.

THE LYMPHATIC SYSTEM

LYMPH NODES

THE LYMPHATIC SYSTEM

The lymphatic system includes organs, vessels and nodes that are found throughout the body. The lymphatic system collects excess fluid and returns it to the blood to fight infection.

Similar to blood vessels, **lymph vessels** help circulate lymph fluid throughout the body. Lymph fluid contains white blood cells, which help to fight infection.

Lymph nodes are small, oval-shaped organs within the lymphatic system. The nodes trap and collect harmful organisms so your white blood cells can attack them. Lymph nodes are found throughout the body, but major groups can be found behind the knee and elbow joints in the groin, armpits, neck and chest. A large group that drains lymph fluid from the lungs is found in the center of the chest (mediastinum).

Cancer cells can break off from the main tumor and travel to other parts of the body through the lymphatic system. Some of these cells become trapped within a lymph node and start to grow. If cancer is in the lymph nodes, your doctor can help estimate if the cancer has spread and how far.

STAGING

Knowing the stage of any type of cancer is important for treatment decisions. SCLC stages are commonly referred to as Limited (early) or Extensive (late stage or advanced). However, SCLC can also be staged with the more traditional Stage I (1) to IV (4).

LIMITED-STAGE describes

SCLC that is only found in one lung or nearby lymph nodes.

EXTENSIVE-STAGE describes

SCLC that has spread outside the lung in which it began to spread to other parts of the body.

It is important to know the stage of the cancer. Staging helps doctors create a treatment plan that is best for you.

STAGE The tumor is only in one lung and is no more than 5cm with no spread to nearby lymph nodes.

STAGE II The tumor is only in one lung and may be larger than a stage I tumor. The cancer may have spread to nearby lymph nodes but not beyond.

STAGE III The tumor or tumors are only in one lung and may have grown into other structures within the chest or spread to more lymph nodes.

STAGE IV The tumor may be any size and the cancer has spread to the other lung, the lining of the lung or organs outside the lungs.

TREATMENT OPTIONS

TREATMENT AND CARE FOR SCLC USUALLY INCLUDES MORE THAN ONE OF THE FOLLOWING:

- Chemotherapy
- Radiation
- Immunotherapy
- Surgery
- Clinical Trials
- Palliative Care (care for symptoms and side effects)

TREATMENT DEPENDS ON THE FOLLOWING:

- The stage of the cancer
- How well your lungs are working
- Other health problems
- If you can complete activities like eating, bathing and dressing on your own

CHEMOTHERAPY

Chemotherapy is a treatment that kills cancer's rapidly growing and dividing cells. It is given in cycles followed by a rest period to allow recovery time.

It is the most common treatment for SCLC and usually given as a combination of two chemotherapy drugs. The most common combinations are:

- **PLATINOL** (cisplatin) and **VP-16** (etoposide)
- **PARAPLATIN** (carboplatin) and **VP-16** (etoposide)
- **ZEPZELCA** (lurbinectedin) if your cancer continues to grow after other chemotherapy drugs

Other drugs used if SCLC returns include the following:

- **HYCAMTIN** (topotecan), oral or by injection
- TAXOL (paclitaxel)
- TAXOTERE (docetaxel)
- GEMZAR (gemcitabine)
- ADRIAMYCIN (doxorubicin)
- ONCOVIN (vincristine)
- **TEMODAR** (temozolomide)

Note that chemotherapy can also be combined with immunotherapy (see page 13).

SIDE EFFECTS OF CHEMOTHERAPY

The goal of chemotherapy is to kill cancer cells, which are fast growing. Because the cells that make up the hair and the lining of the digestive system are also rapidly growing, chemotherapy can damage them too and cause many common side effects.

Below is a list of possible side effects a person on chemotherapy may experience. Side effects can vary from person to person. It is important to know that in most cases side effects can be prevented or managed. You and your care team should discuss potential side effects you could experience.

Common side effects of drug therapy may include:

- Hair loss
- Nausea and vomiting
- Loss of appetite (anorexia)
- Constipation
- Diarrhea
- Shortness of breath (dyspnea)
- Tiredness (fatigue)
- Numbness or tingling in the hands or feet (neuropathy)
- Low platelets
- Low red/white blood cell count (anemia)

RADIATION THERAPY

Radiation therapy is a treatment that uses high energy beams to kill or shrink the cancer cells. Radiation can be used to manage pain, to shrink a tumor, or to slow down the growth of cancer.

SCLC is usually treated with general external beam radiation, which uses carefully aimed doses of radiation to specific sections of the lungs or surrounding areas.

Be sure to talk with your healthcare team about ways to manage any side effects you may experience.

COMMON SIDE EFFECTS

RADIATION THERAPY TO THE CHEST:

- Tiredness (fatigue)
- Loss of appetite (anorexia)
- Inflammation of the esophagus (esophagitis)
- Inflammation of the lung (pneumonitis)
- Skin irritation
 - Redness
 - Itching
 - Dryness

WHOLE BRAIN RADIATION THERAPY:

When SCLC has spread to the brain, whole brain radiation therapy (WBRT) is typically used as treatment. Tiredness and skin irritation are common. Additional side effects may include:

- Hair loss
- Nausea
- Vomiting
- Headache
- Fever
- Short term memory changes



PROPHYLACTIC CRANIAL IRRADIATION (PCI)

WHAT IS PCI?

SCLC often spreads (metastasizes) to the brain. PCI is radiation to the brain with the goal of preventing cancer from growing in the brain by killing cells too small to see on imaging tests.

PCI used to be common but more recent research has questioned whether it extends survival. It is being studied closely in clinical trials going on now.

WHAT CAN I EXPECT?

PCI usually starts three to four weeks after chemotherapy ends.

During PCI, the head must stay still so the radiation is given the same way each time. To help, a plastic mask is made before treatment starts.

The doses of radiation used in PCI are smaller than those used to treat the cancer if it spreads to the brain. Anxiety or fear of being closed in can be helped by medication. Some centers have ways to help patients stay calm during PCI, such as playing music.

SHORT-TERM SIDE EFFECTS

Due to the low dose of radiation used, side effects are usually mild. Tiredness and hair loss are the most common. Unless tiredness is an issue or anti-anxiety medications are used, a patient may drive home after PCI. Many people are able to work while in PCI treatments.

LONG-TERM EFFECTS

Some people worry that PCI will affect their memory and how they think later in life. Major long-term effects are unlikely. Similar to the normal aging process, concentration and short-term memory seem to be the most affected. Researchers are still studying the use of PCI and how well it works. Talk to your doctor about the risks and benefits of PCI and ask questions if you have concerns.

The idea of radiation to the brain can be scary, especially when no cancer has been found there. Your doctor should talk with you about the risks and benefits of PCI. Be sure to ask questions and discuss any concerns you have.

IMMUNOTHERAPY

An important part of the immune system is its ability to recognize the difference between normal cells in the body and those it sees as "foreign" - like cancer cells. To do this, it uses "checkpoints" on certain immune cells called T- cells, that need to be turned on to start an immune response. However, cancer cells can find ways to use these checkpoints to avoid being attacked by the immune system.

A class of immunotherapies called "checkpoint inhibitors" work to fix the problem by targeting a specific protein on the surface of our T-cells such as PD-1/PD-L1. This keeps the immune system active and working against the cancer (learn more in our Immunotherapy brochure).

The following are the immunotherapies currently approved for SCLC:

FIRST LINE (as your first treatment):

- TECENTRIQ (atezolizumab)
- IMFINZI (durvalumab)

These two drugs are given in combination with chemotherapy as a first treatment for extensive stage lung cancer. Recent research has shown that immunotherapy in combination with chemotherapy as a first treatment can result in better overall survival than chemotherapy alone in patients with late stage SCLC.

SIDE EFFECTS OF IMMUNOTHERAPY

Side effects from immunotherapy are generally caused by the increased activity of the immune system. These may include:

- Tiredness (fatigue)
- Flu-like symptoms
- Rashes
- Diarrhea
- Shortness of breath (dyspnea)
- Inflammation within the lungs, liver, kidneys or hormone-producing glands such as thyroid or pituitary.

Be sure to talk with your healthcare team about ways to manage any side effects you may experience.

SURGERY

Surgery is not often used to treat SCLC. However, for patients with small tumors, such as Stage I (1) surgery may be an option.

When surgery is considered for SCLC, learning as much as possible about the size and location of the cancer is especially important.

Research into immunotherapies, targeted therapies and other new treatments continue to provide promising new approaches to the treatment of SCLC and hope to patients living with the disease.

CLINICAL TRIALS

Clinical trials are also an important option for people diagnosed with SCLC and should be considered every time a treatment decision is made. Clinical trials may allow patients to receive new treatments or combinations of treatment that are still being studied by doctors and researchers.

Clinical trials for SCLC patients include:

- New types of immunotherapy that boost the body's immune system including other checkpoint inhibitors or cancer vaccines.
- Immunotherapy combinations.
- Targeted therapies that target a specific gene or protein found in your cancer.
- Targeted therapies that target genes associated with gene stability meant to take advantage of small cell lung cancer's gene instability.

LungMATCH Cancer Clinical Trial Matching Service

Our goal is to make finding a clinical trial as easy as possible. With information about your diagnosis, such as the stage and type of lung cancer and your treatment history, our Clinical Trial Navigators can help you understand the clinical trial process and find trials that you may be eligible for. Having that information to discuss with your treatment team can help you decide if joining a trial is right for you.

Lung MATCH

Talk to your treatment team about whether a clinical trial is right for you. To see if you may qualify for a research study, call our HelpLine at 1-800-298-2436 or visit lungmatch.org



PALLIATIVE AND SUPPORTIVE CARE

Palliative Care is a supportive service that can help cancer patients find ways to address symptoms and side effects related to the cancer or treatment. Here is a list of problems that palliative care may be able to help with:

- Constipation
- Diarrhea
- Difficulty breathing
- Fatigue
- Loss of appetite
- Mood changes related to treatment
- Nausea
- Pain
- Sleep problems
- Weight loss

WHO PROVIDES PALLIATIVE CARE?

Usually it is provided by a healthcare professional that has special training or experience improving the quality of life for patients with cancer or a chronic disease. Palliative care teams may also include other professionals like nurses, dieticians, social workers, chaplains and therapists.

WHERE IS PALLIATIVE CARE PROVIDED?

Palliative care options vary depending on location and the needs of the patient. Sometimes palliative care is offered in the hospital, outpatient office, long-term care facility or in a patient's home.

WHAT PALLIATIVE CARE IS NOT:

- Palliative care is not a treatment for cancer.
- Palliative care is not hospice. Hospice is a service that is only available to people who are not seeking treatment and are considered terminal (less than six months to live).

FINDING PALLIATIVE CARE:

If you are interested in finding palliative care, ask your oncologist if palliative care is right for you.

ABOUT GO2 FOUNDATION

Founded by patients and survivors, GO2 Foundation for Lung Cancer transforms survivorship as the world's leading organization dedicated to saving, extending, and improving the lives of those vulnerable, at risk, and diagnosed with lung cancer.

GO2 Foundation works to change the reality of living with lung cancer by ending stigma, increasing public and private research funding, and ensuring access to care.

For more information about lung cancer and current treatments, to discuss support options or for referral to other resources, please contact us:

HELPLINE | 1-800-298-2436 or support@go2foundation.org

BIOMARKER TESTING & CLINICAL TRIAL MATCHING PERSONALIZED TREATMENT NAVIGATION | lungmatch.org

WEBSITE | go2foundation.org



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