It's easy to get lost in the cancer world

Let NCCN Guidelines for Patients® be your guide

✓ Step-by-step guides to the cancer care options likely to have the best results
✓ Based on treatment guidelines used by health care providers worldwide
✓ Designed to help you discuss cancer treatment with your doctors
Endorsed by

American Lung Cancer Screening Initiative

The American Lung Cancer Screening Initiative strongly advocates spreading awareness about the importance of lung cancer screening for high-risk individuals. It is critical to help patients and healthcare providers understand that increasing early detection of lung cancer through low-dose CT screening has been proven to be one of the easiest ways to combat lung cancer. We are determined to empower high-risk individuals, especially those from disadvantaged backgrounds, and provide them with accessible screening and treatment options. Thus, we are proud to collaborate with the NCCN and endorse their Guidelines for Patients. alcsi.org

With generous support from

Nicole and Adam Zion in honor of Mary Ann & Allen Kozin
and Linda & Michael Zion

To make a gift or learn more, please visit NCCNFoundation.org/donate or e-mail PatientGuidelines@NCCN.org.
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Lung cancer starts in the cells of the lungs. Small cell lung cancer forms from neuroendocrine cells that line the inner airways. It is a challenging cancer because it grows fast. Researchers are studying ways to improve treatment.

Common lung cancers

The lungs are the main organs of the respiratory system. They deliver oxygen to the blood and remove carbon dioxide from the blood. The transfer of these gases in and out of the body is called respiration.

Lung cancer is a cancer of lung cells. Other cancers that have spread to the lung are not lung cancers. For example, breast cancer that has spread to the lungs is still breast cancer.

Lung carcinomas

Almost all lung cancers are carcinomas. Carcinomas are cancers of cells that line the inner or outer surfaces of the body. Lung carcinomas form from cells that line the airways of the lungs. The airways of the lungs are called the bronchus, bronchioli, and alveoli. The two most common types of lung carcinomas are:

- Non-small cell lung cancer (NSCLC)
- Small cell lung cancer (SCLC)

SCLC is much less common than NSCLC. It is the focus of this book.

NCCN has two Guidelines for Patients on NSCLC, which can be found at NCCN.org/patientguidelines.

Airways of the lungs

Air moves through your body in a series of airways. It travels down your throat and through the windpipe (trachea). The windpipe splits into 2 airways called bronchi. Inside the lung, each bronchus branches off into the parts of the lung, called lobes. The right lung has 3 lobes, and the left lung has 2 lobes. The bronchi divide into smaller airways called the bronchioli. At the end of the bronchioli are sacs called alveoli. Oxygen is transferred from air into the blood in the alveoli.
Lung neuroendocrine tumors

About 16 out of every 100 people with lung cancer have neuroendocrine tumors. These lung cancers form from neuroendocrine cells that line the airways. Neuroendocrine cells help heal injured cells that are also in this lining. There are 3 main types of lung (also called pulmonary) neuroendocrine tumors:

- SCLC
- Large cell neuroendocrine carcinoma
- Carcinoid tumors

SCLC is the most common type of pulmonary neuroendocrine tumor. This lung tumor often forms in the middle of the chest inside a lung. It grows fast and has usually spread to outside the lung by the time it’s found. There are 2 types of SCLC:

- Small cell carcinoma (formerly called oat cell carcinoma)
- Combined small and non-small cell lung carcinoma

Read about other lung neuroendocrine tumors in NCCN Guidelines for Patients: Neuroendocrine Tumors, available at NCCN.org/patientguidelines.

What is cancer?

Cancer is a disease of cells. When cells become cancerous, they don’t behave like normal cells. They break the rules of cell growth.

- Lung cancer cells make many new cancer cells. They also do not die when they should. This overgrowth of cancer cells becomes a mass of tissue called a tumor.
- Lung cancer cells don’t stay in place. They can grow through the airway and into the lung tissue. They can grow through the lung wall and invade other body parts.
- Lung cancer cells can break away from a tumor and spread. They can enter the bloodstream or a fluid called lymph and spread to other places.

This out-of-control cell growth can harm the body. Cancer cells crowd out and overpower normal cells. Without enough normal cells, cancer cells can cause organs to stop working.

Scientists have learned a great deal about cancer. As a result, today’s treatments work better than treatments in the past. Also, many people with cancer have more than one treatment option.
Causes and risk factors

Smoking cigarettes is the main cause of lung cancer. Almost everyone with SCLC smokes or has smoked. Many people with SCLC have regularly smoked more than a pack a day.

There are other unknown causes of SCLC. Doctors are still learning why some people who smoke never get lung cancer and others who have never smoked do. A person’s chances of getting SCLC are higher when they:

- Are over 70 years of age
- Have had prior radiation therapy to the chest
- Were exposed to cancer-causing chemicals, such as radon and asbestos

If you don’t smoke, don’t start. If you do smoke, it is important to quit. New lung tumors are less likely to develop after quitting smoking.

Nicotine addiction is one of the hardest addictions to stop. The stress of having cancer may make it even harder to quit. There is help. Ask your health care providers about counseling and drugs to help you quit.

“I grew up smoking. Our heroes smoked. After 50 years of smoking, I quit during my cancer treatment. I quit hoping it may help.”

– Steve
  Cancer survivor

“There is no shame in cancer. Seek support and surround yourself with people who are uplifting.”

– Melissa
  Cancer survivor
Signs and symptoms

Small lung tumors often don’t cause symptoms. Symptoms most often occur when the lung tumor is large or the cancer has spread outside the lungs.

SCLC can cause many types of symptoms. Its symptoms depend on where the lung tumor has grown to or spread. Some people also have symptoms from paraneoplastic syndromes, which are caused by an abnormal body response to lung cancer. Some symptoms caused by SCLC are listed in Guide 1.

SCLC is most often found when it is causing symptoms or routine blood work is abnormal.

Less often, it is found in x-rays before symptoms start. Unlike other lung cancers, there is not a good cancer screening program that finds SCLC early.

Your primary care provider may be the first to suspect that you have lung cancer. You will need to see specialists to determine if you do have cancer. Your assessment team may include the following board-certified experts:

- Thoracic radiologist
- Interventional radiologist
- Pulmonologist
- Thoracic surgeon

### Guide 1
**Symptoms of small cell lung cancer**

| Symptoms caused by the lung tumor | • Chronic cough  
|• Bloody lung mucus  
|• Wheezing |
| Symptoms caused by cancer spread in the chest | • Hoarse voice  
|• Trouble swallowing  
|• Chest pain  
|• Swelling  
|• Spinal pain |
| Symptoms caused by cancer spread to the head | • Headache  
|• Confusion  
|• Slurred speech |
| Symptoms caused by cancer spread to the abdomen | • Pain  
|• Yellow-colored eyes or skin  
|• Fatigue  
|• Burning or prickling feeling |
| | • Enlarged chest veins  
|• Trouble breathing  
|• Feeling lightheaded  
|• Lumps near the collarbone  
|• Trouble walking  
|• Lack of coordination  
|• Weakness of a limb  
|• Fever  
|• Muscle weakness  
|• Loss of bowel and bladder control |
Testing of body tissue or fluid is needed to confirm (diagnose) cancer. Small samples will be removed from your body during a procedure called a biopsy. Sometimes, open surgery is needed.

There are many types of biopsies for lung cancer. Some involve a needle while others require cutting through body tissue. Your doctors will decide what tissue should be removed and how best to remove it.

**Treatment team**

Just like for diagnosis, a team of health care providers is involved in treating lung cancer. You may see one or more of the following experts:

- Surgical oncologist
- Radiation oncologist
- Medical oncologist
- Palliative oncologist

These experts are supported by nurses, technicians, and assistants who are often on the frontline of cancer care. Patient navigators can help you through the maze of cancer care.

SCLC is a challenging cancer. It is cured in a small subset of people when the cancer is found early. For many people, though, the cancer has spread far by diagnosis. Lung cancer often responds well to treatment at first. Unfortunately, the cancer often quickly returns, and the next treatment doesn’t work as well.

Treatment has improved in recent years, and clinical trials may offer hope. Ongoing research is studying new ways to control lung cancer based on how the cancer cells grow, survive, and die. This book explains treatment options that are likely to have the best results. Discuss these options with your treatment team.

**Key points**

- The lungs help the body get the air it needs to live.
- The lungs are made of many small airways and sacs.
- Lung cancer often starts in the cells that line the airways. These cancers are called carcinomas.
- SCLC forms from neuroendocrine cells that line the airways. Neuroendocrine cells help heal nearby injured cells.
- SCLC grows fast and has usually spread outside the lung by the time it’s found.
- Smoking cigarettes is the main cause of SCLC, but there are other unknown causes.
- Ask your doctor for help to quit smoking. Quitting may improve treatment results.
- SCLC is most often found when it is causing symptoms. Its symptoms depend on where the cancer is growing in the body.
- A team of experts will work together with you to diagnose and treat the cancer as well as support you.
Lung cancer staging

13 Staging improves treatment
14 VA staging system
15 TNM staging system
16 Combined staging approach
17 Key points
A cancer stage is a rating of the extent of cancer in the body. There are two staging systems for small cell lung cancer. A combined system is better for treatment planning.

Staging improves treatment

Lung cancer staging is based on the growth and spread of cancer cells. Lung cancer cells may:

- Form one or more tumors in the lung
- Grow through the lung wall and into other body tissue
- Spread to and form tumors in other organs

At diagnosis, the degree of lung cancer growth and its spread differ between people. A staging system is a standard way of grouping lung cancers by their growth and spread. Doctors use cancer staging for many things. It is used to:

- Assess the outlook of the cancer called the prognosis
- Identify treatment options for you
- Plan the best treatment for you
- Study groups of cancer in research

There are 2 staging systems for small cell lung cancer (SCLC).

- Veterans Administration (VA) system
- The tumor, node, metastasis (TNM) system

Cancer care involves a team effort among the various health care providers and the patient. It is essential to be knowledgeable about the cancer in order to make educated decisions regarding the care and treatment to be given. With so much on the internet, much of which may be outdated, publications, such as this book, are essential to patients receiving accurate and timely information so that they further understand their disease and treatments.

— Charles
Lung cancer survivor
VA staging system

The VA Lung Study Group created the first staging system for SCLC. It has been used in studies on treatment. The system divides lung cancer into 2 stages:

- Limited stage
- Extensive stage

Limited-stage cancer is found on one side of the chest and can be treated with radiation therapy. That is, the cancer is contained in an area that would fit within one radiation field.

Most people with SCLC have extensive stage. Extensive-stage cancer can’t be treated with high radiation doses intended to cure the cancer. It has spread too much. For example, it may have spread to the other side of the chest, to the fluid around the lungs or heart, or outside the chest.

What's the difference between systemic and local therapy?

Systemic therapy is almost always used to treat SCLC. Based on the cancer stage, some people also receive local therapy. Here’s the difference between the two treatment types:

**Systemic therapy** treats cancer anywhere in the body. Two types of systemic therapy are chemotherapy and immunotherapy:

- Chemotherapy is a class of drugs that kills cancer cells by stopping their process of making more cancer cells.
- Immunotherapy is a class of drugs that uses the body’s disease-fighting (immune) system to kill cancer cells.

**Local therapy** treats cancer in one area or part of the body. Surgery and radiation therapy are local therapies:

- Surgery treats cancer by removing tumors or diseased organs.
- Radiation therapy most often uses high-energy x-rays to treat lung cancer.

Ask as many questions as possible and bring a family member with you to appointments.

— Ben
Cancer survivor
TNM staging system

The American Joint Committee on Cancer (AJCC) developed the TNM staging system. In this system, the TNM letters are used to score different areas of cancer growth. Your doctor will assign a score to each letter.

- The T score describes the growth of the main lung tumor. Lung tumors can grow large, invade other types of body tissue, and form more tumors in the lung.
- The N score describes cancer growth in disease-fighting tissue called lymph nodes. Lung cancer often spreads to lymph nodes in the lungs, between the lungs, and near the collarbone.
- The M score describes if the cancer has spread far from the main tumor. Lung cancer tends to travel to the brain and adrenal gland and from one lung to the other lung.

Cancer stages consist of combinations of TNM scores based on prognosis. The stages of SCLC range from stage 0 to stage 4. The more serious the cancer growth and spread, the higher the stage. Stage 0 cancers are only in the airways and are very rare. Often, the other stages are written with Roman numerals—stages I, II, III, and IV.

**Stage 1**
Stage 1 cancers consist of one small lung tumor and have not spread to other body parts. Stage 1A tumors are 3 centimeters (cm) or smaller. Stage 1B tumors are larger but don’t exceed 4 cm.

**Stage 2**
Stage 2A cancers are like stage 1 cancers except larger (up to 5 cm). Stage 2B cancers are larger (up to 7 cm), have started to invade other body parts, or have multiple tumors in one lobe. Other 2B cancers consist of one lung tumor that is no larger than 5 cm and have spread to lymph nodes inside the lung.

**Stage 3**
Stage 3 is a mixed group of locally advanced cancers. They are further grouped as stage 3A, 3B, and 3C. Many of these cancers include:
- A large lung tumor that is 7 cm or larger.
- A lung tumor that has markedly invaded other tissue.
- Lung tumors in multiple lobes of the lung.
- Cancer spread to lymph nodes between the lungs, in the other lung, or near the collarbone.

**Stage 4**
The cancer has spread far from the main tumor. Stage 4A cancer has spread far within the chest or to only one place outside the chest. Stage 4B cancer has spread to at least two places outside the chest.
Combined staging approach

Most research studies on lung cancer treatment have used the VA system. The benefit of the TNM system is that it better identifies when local therapy—surgery or radiation—can be safely used. NCCN experts of SCLC use a combined staging approach to account for these factors.

- Limited stage includes cancers that are stages 1 to 3 and can be treated with radiation therapy.
- Extensive stage includes any cancers, including stage 4, that can’t be treated with high radiation doses intended to cure.

Until the TNM system is more widely used in research studies, the best approach is a combined staging system. Cancer staging in the following chapters refers to this combined system.

Combined cancer staging

There are two staging systems for SCLC. Using a combined system allows for more precise treatment planning. The image on the left (A) is a limited-stage 3A cancer. The cancer is in lung tissue and in lymph nodes within the lungs. In this case, the main treatment may include radiation therapy. The image on the right (B) depicts extensive-stage 4 cancers, which are mainly treated with cancer drugs.

Wikimedia
Key points

- Cancer cells don’t follow the rules of cell growth. They make many new cancer cells, invade nearby tissue, and spread to other body parts.

- A cancer staging system is a standard way of grouping cancers by their growth and spread. Staging the cancer is needed before treatment.

- The VA staging system groups cancers into either limited stage or extensive stage. It has been used the most in research studies on treatment of lung cancer.

- The TNM system groups cancers into stage 1, 2, 3, or 4. Often, these stages are written with Roman numerals—stages I, II, III, and IV. This system allows for more precise treatment planning.

- NCCN experts of SCLC use a combined staging approach. Limited-stage cancers include stages 1 to 3 that can be treated with radiation therapy. Extensive-stage cancers, such as stage 4, can’t be treated with high radiation doses intended to cure.

Let us know what you think!

Please take a moment to complete an online survey about the NCCN Guidelines for Patients.

NCCN.org/patients/response
3

Tests for lung cancer

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To plan treatment for you, your doctors will order several tests. Some tests will assess your general health. Other tests will assess the cancer. Ask for copies of your test results and discuss the results with your doctors.

### Health history and exams

Your cancer doctors need to have all of your health information. One of the first steps is obtaining a complete report of your health called a medical history. Read Guide 2 on page 20 for a full list of tests that are used to plan treatment.

#### Medical history

Your doctors will ask about any health problems and treatments you’ve had. When you meet with your cancer doctors, be ready to talk about:

- Illnesses
- Injuries
- Health conditions
- Symptoms
- Medications

Bring a list of old and new medications and any over-the-counter medicines, herbals, or supplements you take.

Be prepared to discuss the health problems of your close blood relatives. Such family members include brothers, sisters, parents, and grandparents. Some cancers and other health conditions can run in families.

### Physical exam

After taking your health history, your doctor will perform a physical exam. An exam is done to find signs of disease and decide which treatments may be options. During this exam, expect the following to be checked:

- Your body temperature
- Your blood pressure
- Your pulse and breathing rate
- Your weight
- How your lungs, heart, and gut sound
- How your eyes, skin, nose, ears, and mouth look
- The size of your organs and lymph nodes
- Level of pain when you are touched

#### Performance status

Your doctors will assess how well you can do day-to-day activities—like working, walking, or taking a shower. Your ability to do these activities is called a performance status. The more activities you can do, the better your performance status. Your doctors will use the performance status to assess if you can undergo certain treatments.

Performance status is often measured on a scale that was created by the Eastern Cooperative Oncology Group (ECOG). The scale ranges from 0 to 4. Lower scores mean better performance status.
Guide 2
Tests for small cell lung cancer

| Health history and exams | • Medical history  
|                          | • Physical exam  
|                          | • Performance status  
| Blood tests              | • CBC  
|                          | • Electrolytes  
|                          | • Liver function tests  
|                          | • Blood urea nitrogen  
|                          | • Creatinine  
| Imaging                  | • Diagnostic CT of the chest, abdomen, and pelvis  
|                          | • MRI (preferred) of brain or CT of brain  
|                          | • PET/CT may be ordered by your doctor  
|                          | • Bone imaging if needed  
| Staging biopsies         | If imaging suggests the cancer is limited stage, you may receive:  
|                          | • Thoracentesis if there is pleural effusion  
|                          | • Thoracoscopy if thoracentesis results are unclear  
|                          | • Bone marrow biopsy and aspiration if blood work suggests cancer spread to bone marrow  
|                          | • Biopsy of mediastinal lymph nodes for limited stages 1 and 2A that will be treated with surgery  
| Cancer cell tests        | • Pathology review  
| Pulmonary function tests | • Spirometry  
|                          | • Gas diffusion test  
|                          | • Body plethysmograph  

NCCN Guidelines for Patients®
Small Cell Lung Cancer, 2022
Blood tests

Blood tests measure blood cells, proteins, and chemicals in the bloodstream. Your doctors will use these tests to assess your general health and if the cancer may have spread. They will plan other tests and cancer treatment based on test results.

A blood draw removes a sample of blood for testing. It is done with a needle inserted into a vein. The following tests are needed:

- A complete blood count (CBC) measures parts of the blood, including counts of white blood cells, red blood cells, and platelets.
- Electrolytes are minerals in the blood. They include sodium, calcium, and potassium. Organs, such as your bones, need electrolytes to work well.
- Liver function tests measure chemicals made or processed by the liver.
- Blood urea nitrogen (BUN) is waste made by your body after you eat. Too much BUN in blood could be a sign of kidney damage.
- Creatinine is waste made by muscles. Too much creatinine in blood could be a sign of kidney damage.

Imaging

Imaging makes pictures of the insides of your body. It can show cancer in deep tissue, lymph nodes, or distant body parts outside of the lung. Imaging is helpful for cancer staging and treatment planning.

An injection of a contrast agent is sometimes used to make the pictures clearer. Contrast should not be used if you may be allergic to it. During imaging, you’ll lie on a table that slides into the scanning machine. At least part of your body will be in the machine.

A radiologist is a doctor who’s an expert in reading images. This doctor will convey the test results to your other doctors.

**CT of chest, abdomen, and pelvis**
Most people first get diagnostic computed tomography (CT) of their chest, abdomen, and pelvis. This scan takes many pictures of your body from different angles using x-rays. Contrast will be used. A computer combines the pictures to make a 3-D image.

**Brain imaging**
Magnetic resonance imaging (MRI) can detect small tumors in the brain. It uses a magnetic field and radio waves to make pictures. Contrast will be used. If MRI can’t be done, you may get CT with contrast of your head.

**PET/CT from skull base to knees**
Positron emission tomography (PET) uses a special camera that detects an injected radioactive sugar. Cancer cells quickly use the sugar. Combining PET with CT may detect small cancers that can’t be found by CT alone. Your doctor may order PET/CT to clarify or
check CT results. The scan will extend from the base of your skull to your knees. If PET/CT can’t be done, you may get a bone scan.

**Bone imaging**
If initial imaging suggests a limited-stage cancer, you may undergo bone imaging. X-rays or MRI may be used. If this imaging doesn’t detect cancer, you may get a biopsy.

"Take care of your mental and emotional self. Get organized and be prepared to be your own advocate. Ask the hard questions. Start a notebook and take it to all appointments to note what is said.

– Thom
Cancer survivor"
Staging biopsies

If imaging suggests the cancer is limited stage, your doctor will order more tests for further staging. It is very important to know the correct cancer stage for treatment planning.

Pleural fluid biopsy
The lungs are covered by two layers of tissue called pleura. There is fluid between the two layers. Some people with lung cancer have an excess of this fluid, which is called pleural effusion.

If you have pleural effusion, a biopsy is needed. A needle biopsy, called a thoracentesis, may be used to remove some of the fluid for testing. If results are unclear, a thoracoscopy may be done next. A thoracoscopy involves making small openings called ports into your chest. Small tools are inserted through the ports to remove tissue. Thoracoscopy is also called video-assisted thoracoscopic surgery (VATS).

Bone marrow biopsy
Most bones have a soft center called marrow. Your blood work may suggest that the cancer has spread to your bone marrow. In this case,
tests of bone marrow are needed. There are two methods of removing bone marrow, which may be done at the same time.

- A bone marrow biopsy removes a core of bone and soft bone marrow.
- A bone marrow aspiration removes liquid bone marrow.

**Lymph node biopsy**
The space between your lungs is called the mediastinum. This space has many disease-fighting clumps of tissue called lymph nodes. Lung cancer tends to spread from inside the lung to these nodes.

If stage 1 or 2A cancer may be treated with surgery, a biopsy of mediastinal nodes is needed. The biopsy is used to confirm that there is no cancer in these lymph nodes. These nodes may be biopsied by mediastinoscopy, mediastinotomy, endobronchial or esophageal ultrasound-guided biopsy, or VATS.

**Cancer cell tests**

Body tissue that is removed during biopsy or surgery will be sent to a lab for testing. A pathologist will examine and test the samples. Pathologists are doctors who are experts in tissue and cells and diagnosing cancer.

**Pathology review**
Pathologists study tissue with a microscope to classify the disease. This is called histologic typing. The pathologist will write the results in a report. The pathology report will state if the cancer started in the lung or elsewhere. If the cancer started in the lung, the report will also list the type of lung cancer.

Pathologists study tissue for cancer staging. Before treatment, you may have tissue samples removed other than the lung tumor. An example is lymph nodes. Lymph nodes are also removed during surgical treatment. The pathologist will study the tissue for cancer cells. Doctors use the pathology results to stage the cancer.

Pathologists study tissue to assess treatment results. If you have surgery for treatment, the pathologist will study the edge of the removed tissue for cancer cells. Doctors use the pathology results to plan the next steps of treatment.

All pathology reports will be sent to your cancer doctors. Ask for a copy of them. Your doctors will review the results with you. Take notes and ask questions. Your doctors will use the reports to plan your treatment.

“Don’t be afraid to ask for help. People will offer but not know how to best help you. Give them tasks they can do to help you.”

– Lauren
Cancer survivor
Pulmonary function tests

Surgery and radiation therapy are sometimes used to treat limited-stage cancer. To receive either treatment, your lungs have to work fairly well. Pulmonary function tests show how well lungs work.

- Spirometry involves blowing into a tube to measure how much air and how fast you breathe.
- A gas diffusion test involves breathing in a harmless gas and measuring how much you breathe out. It tells how much oxygen travels from your lungs into your blood.
- Body plethysmography involves sitting in a small room and breathing into a tube. This test measures how much air your lungs can hold and how much air is left in your lungs after you exhale.

Key points

- Your doctors will order tests to learn about your health and cancer. They will make a treatment plan for you based on the results.
- Be ready to tell your doctors about any health problems and treatments you’ve had in your lifetime.
- Your doctors will examine your body for signs of disease. The exam will include touching parts of your body to see if anything feels abnormal.
- Your doctors will rate your ability to do day-to-day activities in order to decide your treatment options.

Your doctors will order blood tests. Blood tests are used to assess general health and where the cancer may have spread.

CT and MRI scans are first used to look for cancer spread. PET/CT may help detect cancer not found by CT alone. If cancer isn’t detected in bone by initial imaging, you may get x-rays or MRI of bones.

If imaging doesn’t detect cancer outside the lungs, you may get biopsies of pleural fluid, bone marrow, or lymph nodes between the lungs.

Pathologists are doctors who study tissue for cancer cells. They diagnose cancer. After diagnosis, they may study more body tissue to assess for cancer growth and spread and to assess surgery results.

For limited-stage cancer, your lungs will be tested to assess if surgery or radiation therapy are options.
4 Initial treatment

27 Advances in treatment
29 Options for limited-stage cancer
31 Options for extensive-stage cancer
33 Treatment response
34 Additional radiation therapy
34 Clinical trials
36 Supportive care
37 Key points
Initial treatment of small cell lung cancer has good results for many people. Treatment options are based on the cancer stage and other factors. Discuss with your doctors which options in this chapter are right for you.

Advances in treatment

The classic treatment for small cell lung cancer (SCLC) is chemotherapy. Chemotherapy is a type of systemic therapy. It travels in the bloodstream to cancer cells. It works by stopping the process by which cancer cells make more cancer cells.

Researchers have studied which chemotherapy drugs work best. Initial regimens include two chemotherapy drugs, one of which is made with platinum. This is called platinum-doublet chemotherapy.

Stage-based treatment

Cancer staging has changed the practice of treatment. Doctors plan more precise treatment when using cancer stages. NCCN experts use a combined cancer staging that is fully explained in Chapter 2.

- Limited stage includes cancers that are stages 1 to 3 cancers and can be treated with radiation therapy.
- Extensive stage includes any cancers, including stage 4, that can't be treated with high radiation doses intended to cure.

Radiation therapy uses high-energy x-rays to treat lung cancer. It damages cancer cells. The cancer cells either die or stop making

Systemic therapy

Systemic therapy for lung cancer includes chemotherapy and immunotherapy. Most often, chemotherapy is a liquid that is slowly injected into a vein, called an infusion, but sometimes it is a pill. Immunotherapy is given by infusion. Systemic therapy is given in cycles of treatment days followed by days of rest. Cycles give your body a chance to recover after receiving treatment.
new cancer cells. Radiation therapy is a local treatment. Modern techniques shape the radiation dose to the tumor to spare healthy tissue.

Radiation therapy has a role for all stages of lung cancer. It is mainly used to attempt to cure limited-stage cancer, and to reduce certain symptoms caused by extensive-stage cancer. Surgery is another local treatment used to cure some limited-stage cancers.

**New treatments**
Treatment of extensive-stage cancer has improved in recent years. One advance is immunotherapy. Immunotherapy is a systemic therapy like chemotherapy. It uses the body’s defense against disease, called the immune system, to kill cancer cells.

“Your medical team is your greatest asset and friend(s), especially the nurses. They are all highly skilled and sincerely dedicated to help you however they can.

– Steve
Cancer survivor

**Radiation therapy**
External beam radiation therapy (EBRT) is the most common method used for treatment. A large machine makes radiation beams that are shaped to the form of the tumor. The highest radiation dose is aimed at the cancer. A much lower dose is given to nearby tissue. You will not feel anything during the treatment session. Treatment does not make you radioactive.
Options for limited-stage cancer

The goal of initial treatment for limited-stage cancer is to cure the cancer. Chemotherapy is often used with a local treatment. Options for initial treatment of limited-stage cancer are listed in Guide 3.

Most people receive 4 cycles of platinum-doublet chemotherapy. There are typically 21 to 28 days in a cycle. Limited-stage cancer is treated with either cisplatin and etoposide or carboplatin and etoposide.

Chemoradiation
Most limited-stage cancers are treated with both chemotherapy and radiation therapy. This combined treatment is called chemoradiation. Concurrent chemoradiation is the use of both treatments at the same time. Radiation therapy should be started during the first or second cycle of chemotherapy. Sequential chemoradiation is the use of one treatment followed by the other.

Performance status is your ability to do day-to-day activities. Disease can limit what you can do. Doctors use performance status to decide which treatments may be safe for you. The Eastern Cooperative Oncology Group (ECOG) Performance Status consists of five scores ranging from 0 to 4. Lower scores represent a better ability to do self-care. Chemoradiation may not be an option when scores are high.

Guide 3
Options for initial treatment of limited-stage SCLC

Cancer stages 1A, 1B, and 2A
- Concurrent chemoradiation
- Lobectomy and either lymph node dissection or sampling followed by:
  - Chemotherapy if no cancer is found in lymph nodes
  - Chemotherapy, concurrent chemoradiation, or sequential chemoradiation if cancer is found only in lymph nodes within the lungs
  - Concurrent or sequential chemoradiation if cancer is found in lymph nodes between the lungs
  - SABR followed by chemotherapy

Cancer stages 2B, 3A, 3B, and 3C
- Performance score of 0, 1, or 2
  - Concurrent chemoradiation

- Performance score of 3 or 4 caused by the cancer
  - Chemotherapy
  - Concurrent chemoradiation
  - Sequential chemoradiation

- Performance score of 3 or 4 not due to the cancer
  - Individualized treatment including supportive care
Surgery
Some people with limited stage 1 or 2A may be able to have surgery. There must be no cancer in the biopsy samples of mediastinal lymph nodes—the nodes between the lungs. The lung tumor is often removed during a surgery called a lobectomy. A lobectomy removes an entire lobe of the lung.

During surgery, lymph nodes will also be removed to test them for cancer. A lymph node sampling removes some nodes in the lung and between the lungs. A lymph node dissection removes as many nodes as possible from the lung and between the lungs.

After surgery, you will receive chemotherapy to treat any remaining cancer cells. Treatment for this purpose is called adjuvant therapy. Radiation therapy to the chest may also be received at the same time or back-to-back. It may improve results if cancer is in mediastinal lymph nodes.

SABR
Stereotactic ablative radiotherapy (SABR) may be an option for people who don’t have surgery. SABR is also called stereotactic body radiation therapy (SBRT). It delivers a high radiation dose to a precise area. After SABR, you will receive systemic therapy to treat any remaining cancer cells. Treatment for this purpose is called adjuvant therapy.

Lobectomy
Lobectomy is a type of surgery that removes an entire lobe of the lung. The surgery can be done with one of two methods. The classic method is thoracotomy. This surgery removes tissue through a large opening in the chest. Thoracoscopy is a newer method. It removes tissue through small openings. A small camera and surgical tools are inserted through the openings. Thoracoscopy can be done with or without help from a robot. Thoracoscopy is also called video-assisted thoracoscopic surgery (VATS).
Options for extensive-stage cancer

The goals of treatment for extensive-stage cancer are to control symptoms and prolong life. Systemic therapy is the main treatment. You will likely receive four 21-day cycles of chemoimmunotherapy, but some people receive up to six cycles. This is often followed by immunotherapy alone. Options for initial systemic therapy of extensive-stage cancer are listed in Guide 4.

Chemoimmunotherapy
The preferred treatment for extensive-stage cancer is chemoimmunotherapy. Platinum-doublet chemotherapy is given with an immunotherapy called an immune checkpoint inhibitor. Immune checkpoint inhibitors enable immune cells called T cells to attack cancer cells.

After chemoimmunotherapy, you may stay on the checkpoint inhibitor if treatment results are good. This is called continuation maintenance. The goal of maintenance treatment is to prolong good treatment results.

Maintenance atezolizumab is received every 21 or 28 days depending on the regimen. Maintenance durvalumab is received every 28 days. Often, people get infusions to delay the worsening of cancer.

Chemotherapy
Not all lung cancers should be treated with immunotherapy. Immunotherapy may not be safe if you’re too sick. Also, it may impair your immune system if you have an autoimmune disease. Autoimmune diseases include Crohn’s disease, ulcerative colitis, and lupus. When immunotherapy is not an option, you may receive only chemotherapy.

Radiation therapy
In addition to systemic therapy, you may get radiation therapy. Radiation therapy can

Guide 4
Options for initial systemic therapy of extensive-stage SCLC

| Preferred regimens | • Carboplatin, etoposide, and atezolizumab followed by maintenance atezolizumab  
| | • Carboplatin, etoposide, and durvalumab followed by maintenance durvalumab  
| | • Cisplatin, etoposide, and durvalumab followed by maintenance durvalumab |
| Other regimens | • Carboplatin and etoposide  
| | • Cisplatin and etoposide |
| Sometimes useful | • Carboplatin and irinotecan  
| | • Cisplatin and irinotecan |
reduce (palliate) symptoms caused by lung cancer, such as:

- Swelling caused by the cancer blocking a vein called the superior vena cava
- Bone pain due to the cancer damaging bone
- Back pain from the cancer pressing on the spinal cord
- Trouble breathing due to the cancer blocking airways
- Headaches from lung cancer in the brain

Treatment of the brain usually involves radiation to the entire brain, which is called whole-brain radiation therapy (WBRT). Some people can receive a high radiation dose just to the affected area of the brain.

When lung cancer has spread to the brain, radiation therapy is sometimes received before it causes symptoms. During systemic therapy, your doctor will assess the status of the cancer. After every 2 cycles, you will get either magnetic resonance imaging (MRI) or computed tomography (CT) of the brain. Contrast should be used with CT. If the cancer worsens, radiation therapy of the brain will be started.

What are the techniques of EBRT?

External beam radiation therapy (EBRT) is the most common method used to treat SCLC. It may be delivered by one of several techniques:

- Intensity-modulated radiation therapy (IMRT) delivers x-ray beams that very closely match the shape of the target and spare more normal tissue.
- Volumetric arc-based therapy (VMAT) delivers IMRT in an arc shape around the tumor.
- Three-dimensional conformal radiation therapy (3D-CRT) delivers an x-ray beam that matches the shape of the target but may not be as focused as IMRT.

Cancer treatment with IMRT, VMAT, and 3D-CRT is typically delivered each day Monday through Friday and is finished in about 6 weeks. Radiation therapy for symptoms is finished in 10 or fewer sessions. Newer techniques for small tumors are also finished in a shorter amount of time:

- Stereotactic radiosurgery (SRS) treats small tumors with very precise, high-dose x-ray beams.
- When SRS is used to treat tumors not in the brain or spine, it is called stereotactic ablative radiotherapy (SABR).

SRS is finished in one or a few sessions. SABR is given two to three times per week. Treatment is finished in about 1½ weeks.
Treatment response

A treatment response is the extent that the cancer improves. Many lung cancers respond strongly to initial treatment. The timing of assessing the treatment response differs between treatment types and the cancer stage.

For limited-stage cancer, the treatment response should be assessed after:

- Concurrent chemoradiation is finished
- Every 2 cycles during sequential chemoradiation and after treatment is finished
- Every 2 cycles of systemic therapy (without radiation therapy) and after treatment is finished
- Adjuvant systemic therapy is finished

For extensive-stage cancer, the treatment response should be assessed after:

- Every 2 to 3 cycles of systemic therapy and after treatment is finished

To assess the treatment response, you will repeat some tests that you had before treatment:

- Computed tomography (CT) with contrast of the chest, abdomen, and pelvis
- Magnetic resonance imaging (MRI) of the brain or CT with contrast of the brain
- Blood tests—complete blood count (CBC), electrolytes, liver function tests, blood urea nitrogen (BUN), and creatinine

Your doctors will assess the treatment response based on test results. There are 4 treatment responses:

- Complete remission is the best result. There are no signs of the cancer.
- Partial remission is a good result. The tumors have shrunk and blood results are returning to normal.
- Stable disease is less than a partial remission. The cancer is not getting worse.
- Progressive disease is a worsening of the cancer. Treatment options for progressive disease are the same as for relapse listed in Chapter 5.

"No matter what I look like on the outside, it’s not who I am on the inside. Stay positive and stay strong.

– Carrie
Cancer survivor
Additional radiation therapy

You may receive radiation therapy after the treatment response has been assessed. Prophylactic cranial irradiation (PCI) is an option for limited- and extensive-stage cancer. Some people with extensive-stage cancer may receive radiation therapy to the chest.

Prophylactic cranial irradiation

PCI is a low dose of radiation to the whole brain. It is used to prevent the spread of lung cancer to the brain. It may be an option if these conditions are met:

- A complete or partial remission of cancer was achieved.
- There are no signs or symptoms of lung cancer in the brain.
- You do not have problems with thinking skills like memory.
- Your health doesn’t largely limit your day-to-day activities.

For most limited-stage cancers, PCI can prevent lung cancer tumors in the brain and prolongs life. When lymph nodes are cancer-free, the results of PCI for limited-stage cancer are unknown. For extensive-stage cancer, PCI can prevent lung cancer from forming tumors in the brain.

Radiation therapy to the chest

Chest radiation can treat cancer that remains after systemic therapy. Treatment for this purpose is called consolidation therapy. Systemic therapy must have achieved a complete or partial remission of extensive-stage cancer. Chest radiation may prevent the cancer from returning in the chest and prolong life.

Clinical trials

Despite advances in treatment, more research is needed. Current treatments often extend life for a short period of time. Better treatments are made possible with clinical trials.

A clinical trial is a type of medical research study. After being developed and tested in a laboratory, potential new ways of fighting cancer need to be studied in people. If found to be safe and effective in a clinical trial, a drug, device, or treatment approach may be approved by the U.S. Food and Drug Administration (FDA).

Everyone with cancer should carefully consider all of the treatment options available for their cancer type, including standard treatments and clinical trials. Talk to your doctor about whether a clinical trial may make sense for you.

Phases

Most cancer clinical trials focus on treatment. Treatment trials are done in phases.

- **Phase I** trials study the dose, safety, and side effects of an investigational drug or treatment approach. They also look for early signs that the drug or approach is helpful.
- **Phase II** trials study how well the drug or approach works against a specific type of cancer.
- **Phase III** trials test the drug or approach against a standard treatment. If the results are good, it may be approved by the FDA.
- **Phase IV** trials study the long-term safety and benefit of an FDA-approved treatment.
Who can enroll?
Every clinical trial has rules for joining, called eligibility criteria. The rules may be about age, cancer type and stage, treatment history, or general health. These requirements ensure that participants are alike in specific ways and that the trial is as safe as possible for the participants.

Informed consent
Clinical trials are managed by a group of experts called a research team. The research team will review the study with you in detail, including its purpose and the risks and benefits of joining. All of this information is also provided in an informed consent form. Read the form carefully and ask questions before signing it. Take time to discuss with family, friends, or others whom you trust. Keep in mind that you can leave and seek treatment outside of the clinical trial at any time.

Start the conversation
Don’t wait for your doctor to bring up clinical trials. Start the conversation and learn about all of your treatment options. If you find a study that you may be eligible for, ask your treatment team if you meet the requirements. If you have already started standard treatment you may not be eligible for certain clinical trials. Try not to be discouraged if you cannot join. New clinical trials are always becoming available.

Frequently asked questions
There are many myths and misconceptions surrounding clinical trials. The possible benefits and risks are not well understood by many with cancer.

Will I get a placebo?
Placebos (inactive versions of real medicines) are almost never used alone in cancer clinical trials. It is common to receive either a placebo with a standard treatment or a new drug with a standard treatment. You will be informed, verbally and in writing, if a placebo is part of a clinical trial before you enroll.

Do I have to pay to be in a clinical trial?
Rarely. It depends on the study, your health insurance, and the state in which you live. Your treatment team and the research team can help determine if you are responsible for any costs.
Supportive care

Supportive care aims to improve your quality of life. It is also sometimes called palliative care. Supportive care is important for everyone, not just people at the end of life.

Supportive care can address many needs. It includes care for health problems caused by cancer or cancer treatment. You can get help with making treatment decisions. You can get help with coordination of care between health providers.

Your palliative care doctor will work with your oncologists to provide you with the best care. Other specialists that may be involved in your care include:

- Respiratory therapists
- Rehabilitation specialists
- Registered dieticians
- Social workers

Side effects

All cancer treatments can cause unwanted health issues. Such health issues are called side effects. Some side effects may be harmful to your health. Others may just be unpleasant.

Side effects depend on many factors. These factors include the treatment type, length or dose of treatment, and the person. Many effects of treatment resolve after treatment ends, such as:

- Nausea and vomiting from chemotherapy
- Skin rash from an immune checkpoint inhibitor
- Fatigue and skin changes from radiation therapy
- Pain and swelling from surgery

Long-term effects start during treatment and persist after treatment is done. Less often, effects start long after treatment has ended. Ask your treatment team for a complete list of side effects of your treatments.

Also, tell your treatment team about any new or worse symptoms you get. There may be ways to help you feel better. There are also ways to prevent some side effects. An example is a medication called memantine that helps to prevent a decline in thinking skills after PCI. There is also medication that helps prevent nausea from chemotherapy.

“Ask your oncologist for a list of possible side effects right before each treatment. Track your side effects and report them to your doctor.”

– Phil
Cancer survivor
Key points

- Advances in lung cancer treatment have been made using staging systems and through the use of new medicines.
- Options for initial treatment of limited-stage cancer include chemoradiation, stereotactic ablative radiotherapy (SABR), and surgery. After SABR, chemotherapy is received. After surgery, chemotherapy with or without radiation therapy is received.
- Options for initial treatment of extensive-stage cancer are chemoimmunotherapy and chemotherapy. Some people receive radiation therapy to prevent or relieve symptoms caused by the cancer.
- The response to treatment will be assessed. You may get radiation therapy to the brain or chest if the cancer has shrunk.
- Clinical trials are a type of research. New ways of fighting cancer are studied among people in clinical trials. A clinical trial may be an option in addition to standard treatment.
- Supportive care is for everyone. It may improve your quality of life. One aspect of supportive care is to relieve symptoms caused by cancer treatment.

NCCN Guidelines for Patients on supportive care

Cancer in the bone and chemotherapy can cause a drop in red and white blood cells. Read about these side effects in NCCN Guidelines for Patients: Anemia and Neutropenia. A treatment for low blood cell counts called GM-CSF should not be used while undergoing concurrent chemoradiation.

Immune checkpoint inhibitors can cause your immune cells to attack your healthy cells. Immune-related side effects can occur during or after treatment. Read about these side effects in NCCN Guidelines for Patients: Immunotherapy Side Effects: Immune Checkpoint Inhibitors.

Everyone with cancer feels distress at some point. It is normal to be worried. Read about treatment for distress in NCCN Guidelines for Patients: Distress During Cancer Care.

The full library of NCCN Guidelines for Patients is available at NCCN.org/patientguidelines.
5 Surveillance and subsequent treatment

- 39 Follow-up visits
- 40 Healthy living
- 40 Treatment for relapse
- 42 Key points
Your cancer doctors will give you a care plan at the end of initial treatment. Your care plan will include follow-up visits, possible late effects, and goals for healthy living.

Follow-up visits

You will meet with your cancer doctor often after treatment ends. It is very important to monitor for the return of the cancer. The return of cancer is called a relapse or recurrence. Routine testing for cancer relapse is called surveillance. It may find cancer early and allow for timely treatment.

At follow-up visits, your doctor will perform a medical history and a physical exam. Blood tests may be ordered if needed. See Guide 5 for a schedule of visits with your cancer doctor.

Imaging

Your doctor will order computed tomography (CT). It may detect a relapse. CT of the chest may be done every 2 to 6 months as well as CT of the abdomen and pelvis. If a new lung nodule is detected, more testing is needed to confirm if it is cancer.

Magnetic resonance imaging (MRI) may show small brain tumors that aren’t causing symptoms. Contrast should be used. If MRI can’t be done, you may get CT with contrast of your head. Brain MRI or CT of the head should be done every 3 to 4 months during the first year after treatment. During the second year, this imaging should be done every 6 months.

Managing side effects

All cancer treatments can cause health issues called side effects. Many effects of treatment quickly resolve after treatment ends. An example is nausea and vomiting. Long-term effects start during treatment and persist after

Guide 5
How often to see your cancer doctor after treatment

<table>
<thead>
<tr>
<th>Time after treatment</th>
<th>Limited-stage cancer</th>
<th>Extensive-stage cancer</th>
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</thead>
<tbody>
<tr>
<td>During first year</td>
<td>Every 3 months</td>
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<tr>
<td>During second year</td>
<td>Every 3 months</td>
<td>Every 3 to 4 months</td>
</tr>
<tr>
<td>During third year</td>
<td>Every 6 months</td>
<td>Every 3 to 4 months</td>
</tr>
<tr>
<td>During fourth year</td>
<td>Once a year</td>
<td>Every 6 months</td>
</tr>
<tr>
<td>During fifth year</td>
<td>Once a year</td>
<td>Every 6 months</td>
</tr>
<tr>
<td>During sixth year and beyond</td>
<td>Once a year</td>
<td>Once a year</td>
</tr>
</tbody>
</table>

NCCN Guidelines for Patients®
Small Cell Lung Cancer, 2022
treatment is done. Less often, effects start long after treatment has ended. These are called late effects.

During follow-up visits, your health care providers will assess for side effects. They will provide treatment for side effects as needed.

Read about common effects in *NCCN Guidelines for Patients: Survivorship Care for Cancer-Related Late and Long-Term Effects*, available at [NCCN.org/patientguidelines](https://www.nccn.org/patientguidelines).

### Healthy living

Another part of follow-up care is to prevent diseases. Such care can include getting immunization shots for the flu, herpes, shingles, and other diseases. Dental cleaning and exams on a regular basis can prevent disease, too. Other common goals for healthy living include:

- Seeing a primary care provider on a regular basis.
- Being physically active and avoiding inactivity.
- Eating healthful foods.
- Limiting or avoiding drinking alcohol.
- Achieving and maintaining a normal body weight.
- Not using tobacco.
- Avoiding infections and getting vaccines as recommended.

Read about preventing poor health in *NCCN Guidelines for Patients: Survivorship Care for Healthy Living*, available at [NCCN.org/patientguidelines](https://www.nccn.org/patientguidelines).

### Treatment for relapse

SCLC relapses in most people. Doctors use performance status to decide which treatments may be safe for you. Performance status is your ability to do day-to-day activities.

The Eastern Cooperative Oncology Group (ECOG) Performance Status consists of five scores ranging from 0 to 4. Lower scores represent a better ability to do self-care.

A treatment option for people with performance scores of 0 to 2 is systemic therapy. Options differ based on a relapse that occurred less or more than 6 months after systemic therapy. Read Guide 6 for a list of treatment options of relapse disease.

If a relapse occurred before 6 months, the preferred options are chemotherapy and a clinical trial. If a relapse occurred after 6 months, the preferred option is the systemic therapy used for initial treatment. Other options are chemotherapy and immunotherapy. Pembrolizumab (Keytruda®) and nivolumab (Opdivo®) are immune checkpoint inhibitors.
A second option for people with performance scores of 0 to 2 is supportive care. Supportive care aims to improve quality of life. It is also called palliative care. Supportive care may include radiation therapy for relief of symptoms. Supportive care is also an option when performance scores are 3 or 4.

### Guide 6
**Subsequent systemic therapy**

<table>
<thead>
<tr>
<th>Preferred options</th>
<th>Relapse less than 6 months after initial treatment</th>
<th>Relapse more than 6 months after initial treatment</th>
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</thead>
<tbody>
<tr>
<td>Topotecan</td>
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<td></td>
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<tr>
<td>Lurbinectedin</td>
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<td></td>
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<tr>
<td>Clinical trial</td>
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<tr>
<td>Initial treatment</td>
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<tr>
<td><strong>Other options</strong></td>
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</tr>
<tr>
<td>Paclitaxel</td>
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</tr>
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<td>Docetaxel</td>
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<td>●</td>
</tr>
<tr>
<td>Irinotecan</td>
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<td>●</td>
</tr>
<tr>
<td>Temozolomide</td>
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<td>●</td>
</tr>
<tr>
<td>Cyclophosphamide, doxorubicin, and vincristine (CAV)</td>
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<td>●</td>
</tr>
<tr>
<td>Oral etoposide</td>
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<td>●</td>
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<td>Vinorelbine</td>
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<td>Nivolumab</td>
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<td>●</td>
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<tr>
<td>Pembrolizumab</td>
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<td>●</td>
</tr>
<tr>
<td>Bendamustine</td>
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<td>●</td>
</tr>
<tr>
<td>Topotecan</td>
<td></td>
<td>●</td>
</tr>
<tr>
<td>Lurbinectedin</td>
<td></td>
<td>●</td>
</tr>
</tbody>
</table>
Key points

- Your cancer doctors will monitor for a return of lung cancer. Regular testing for a cancer relapse is called surveillance.

- Some side effects of treatment are long-term or may appear years later. At follow-up visits, your doctor will assess for side effects. Tell your doctor about any new or worse symptoms. There may be ways to prevent or treat side effects.

- Preventing diseases is a part of follow-up care. Such care can include getting immunization shots and dental cleaning. Healthy living may improve your health and prevent disease. If you have a high risk for certain cancers, you may enroll in a screening program.

- Treatment for a relapse includes chemotherapy, immunotherapy, and clinical trials. If treatment may do more harm than good, supportive care to improve your quality of life is an option.

"Please allow yourself to accept hard days, difficult moments, or disappointments. Speaking with a behavioral health specialist can help you to prepare for the emotional changes that you may face.

– Rich Cancer survivor"
6
Making treatment decisions

44 It’s your choice
45 Questions to ask your doctors
49 Resources
It is important to be comfortable with the cancer treatment you choose. This choice starts with having an open and honest conversation with your doctor.

**It’s your choice**

In shared decision-making, you and your doctors share information, discuss the options, and agree on a treatment plan. It starts with an open and honest conversation between you and your doctor.

Treatment decisions are very personal. What is important to you may not be important to someone else.

Some things that may play a role in your decision-making:

- What you want and how that might differ from what others want
- Your religious and spiritual beliefs
- Your feelings about certain treatments like surgery or chemotherapy
- Your feelings about pain or side effects such as nausea and vomiting
- Cost of treatment, travel to treatment centers, and time away from work
- Quality of life and length of life
- How active you are and the activities that are important to you

Think about what you want from treatment. Discuss openly the risks and benefits of specific treatments and procedures. Weigh options and share concerns with your doctor.

If you take the time to build a relationship with your doctor, it will help you feel supported when considering options and making treatment decisions.

**Second opinion**

It is normal to want to start treatment as soon as possible. While cancer can’t be ignored, there is time to have another doctor review your test results and suggest a treatment plan. This is called getting a second opinion, and it’s a normal part of cancer care. Even doctors get second opinions!

Things you can do to prepare:

- Check with your insurance company about its rules on second opinions. There may be out-of-pocket costs to see doctors who are not part of your insurance plan.
- Make plans to have copies of all your records sent to the doctor you will see for your second opinion.

**Support groups**

Many people diagnosed with cancer find support groups to be helpful. Support groups often include people at different stages of treatment. Some people may be newly diagnosed, while others may be finished with treatment. If your hospital or community doesn’t have support groups for people with cancer, check out the websites listed in this book.
Questions to ask your doctors

Possible questions to ask your doctors are listed on the following pages. Feel free to use these or come up with your own. Be clear about your goals for treatment and find out what to expect from treatment. Keep a notebook handy to record answers to your questions.

Questions to ask about testing and staging

1. What tests will I have?

2. Do I need a biopsy? What kind of biopsy do I need? Will enough tissue be removed for future testing? What are the risks?

3. How do I prepare for testing?

4. What if I am pregnant?

5. Where do I go to get tested? How long will the tests take and will any test hurt?

6. Should I bring someone with me? Should I bring a list of my medications?

7. How soon will I know the results and who will explain them to me?

8. Would you give me a copy of the pathology report and other test results?

9. What type of lung cancer do I have? What is the stage? Has the cancer spread far?

10. Can this cancer be cured? If not, how well can treatment stop the cancer from growing?

11. Who will talk with me about the next steps? When?
Questions to ask about treatment options

1. What are my treatment options? Are you suggesting options other than what NCCN recommends? If yes, why?

2. Do your suggested options include clinical trials? Please explain why.

3. What will happen if I do nothing?

4. How do my age, overall health, and other factors affect my options? What if I am pregnant or planning to get pregnant?

5. Does any option offer a cure or long-term cancer control? Are my chances any better for one option than another? Less time-consuming? Less expensive?

6. How do you know if treatment is working? How will I know if treatment is working?

7. What are my options if treatment stops working?

8. What are the possible complications? What are the short- and long-term side effects of treatment?

9. What can be done to prevent or relieve the side effects of treatment?

10. What supportive care services are available to me during and after treatment?

11. Can I stop treatment at any time? What will happen if I stop treatment?
Questions to ask about clinical trials

1. Are there clinical trials for my type of cancer?
2. What are the treatments used in the clinical trial?
3. What does the treatment do?
4. Has the treatment been used before? Has it been used for other types of cancer?
5. What are the risks and benefits of this treatment?
6. What side effects should I expect? How will the side effects be controlled?
7. How long will I be in the clinical trial?
8. Will I be able to get other treatment if this doesn’t work?
9. How will you know the treatment is working?
10. Will the clinical trial cost me anything? If so, how much?
Questions to ask about getting treated

1. Will I have to go to the hospital or elsewhere? How often? How long is each visit?

2. What do I need to think about if I will travel for treatment?

3. Do I have a choice of when to begin treatment? Can I choose the days and times of treatment?

4. How do I prepare for treatment? Do I have to stop taking any of my medicines? Are there foods I will have to avoid?

5. Should I bring someone with me when I get treated?

6. Will the treatment hurt?

7. What should I do if a side effect gets bad when my cancer center is closed?

8. How much will the treatment cost me? What does my insurance cover?

9. Will I miss work or school? Will I be able to drive?

10. Is home care after treatment needed? If yes, what type?

11. How soon will I be able to manage my own health?

12. When will I be able to return to my normal activities?
Resources

American Cancer Society

American Lung Cancer Screening Initiative
[alcsi.org](alcsi.org)

Free ME from Lung Cancer
[freeMEfromLungCancer.org](freeMEfromLungCancer.org)

LUNGevity Foundation
[LUNGevity.org](LUNGevity.org)

National Cancer Institute (NCI)
[cancer.gov/types/lung](cancer.gov/types/lung)

National Coalition for Cancer Survivorship
[canceradvocacy.org/toolbox](canceradvocacy.org/toolbox)

NCCN Patient Resources
[nccn.org/patientresources](nccn.org/patientresources)

share with us.

Take our [survey](#)
And help make the NCCN Guidelines for Patients better for everyone!

[NCCN.org/patients/comments](NCCN.org/patients/comments)
Words to know

AJCC
American Joint Committee on Cancer

alveoli
The tiny sacs in the lungs where gases are transferred in and out of the blood.

biomarker testing
Tests of any molecule in your body that can be measured to assess your health.

biopsy
A procedure that removes fluid or tissue samples to be tested for a disease.

blood urea nitrogen (BUN)
The amount of urea nitrogen—a waste product—in blood.

board certified
A status for doctors who finished training in a specialized field of medicine.

body plethysmograph
A test of how much air is in your lungs after inhaling or exhaling.

bronchi
The two airways extending from the windpipe into the lungs.

bronchioli
Small airways within the lungs.

bronchus
One of the two main airways that extends into the lungs.

cancer stage
A rating of the outlook of a cancer based on its growth and spread.

carcinoma
A cancer of cells that line the inner or outer surfaces of the body.

chemoradiation
A cancer treatment with both cell-killing drugs and high-energy rays.

chemotherapy
Cancer drugs that stop the cell life cycle so cells don’t increase in number.

clinical stage
The rating of the extent of cancer before treatment is started.

clinical trial
A type of research that assesses how well health tests or treatments work in people.

complete blood count (CBC)
A lab test that measures the parts of the blood.

computed tomography (CT)
A test that uses x-rays from many angles to make a picture of the insides of the body.

contrast
A dye put into your body to make clearer pictures during imaging.

creatinine
A waste product of muscles that is filtered out of blood into urine by the kidneys.

diagnosis
An identification of an illness based on tests.

ECOG
Eastern Cooperative Oncology Group

endobronchial ultrasound–guided biopsy
A procedure that removes lung tissue with a needle on an imaging device guided down the windpipe.

esophageal ultrasound–guided biopsy
A procedure that removes lung tissue with a needle on an imaging device guided down the food pipe (esophagus).
Words to know

**external beam radiation therapy (EBRT)**
A cancer treatment with radiation delivered from a machine outside the body.

**gas diffusion**
A test that uses harmless gas to measure how much you can breathe out.

**immunotherapy**
A treatment with drugs that help the body find and destroy cancer cells.

**intensity-modulated radiation therapy (IMRT)**
Treatment with radiation that uses small beams of different strengths.

**invasion**
The growth of cancer cells from where it started into another tissue.

**liver function tests**
A lab test that measures chemicals made or processed by the liver.

**lobe**
A clearly seen division in an organ.

**lobectomy**
An operation that removes a whole lobe of an organ.

**lymph node**
A small, bean-shaped, disease-fighting structure.

**magnetic resonance imaging (MRI)**
A test that uses radio waves and powerful magnets to make pictures of the insides of the body.

**maintenance therapy**
A treatment phase that is given to prolong good treatment results.

**mediastinoscopy**
A procedure to do work in the chest with a device passed through a small cut in the skin.

**mediastinum**
The area of the chest between the lungs.

**medical history**
A report of all your health events and medications.

**metastasis**
The spread of cancer from the first tumor to a new site.

**NCCN**
National Comprehensive Cancer Network

**neuroendocrine cell**
A cell that helps heal injured cells.

**non-small cell lung cancer (NSCLC)**
A cancer that starts in lung cells that are not small in size.

**pathologist**
A doctor who’s an expert in testing cells and tissue to find disease.

**patient navigator**
A professional who helps people get health information and the services they need.

**performance status**
A rating of one’s ability to do daily activities.

**physical exam**
A review of the body by a health expert for signs of disease.

**platinum-doublet chemotherapy**
A treatment with two cell-killing drugs, one of which contains the chemical platinum.

**positron emission tomography (PET)**
A test that uses radioactive material to see the shape and function of body parts.

**positron emission tomography/computed tomography (PET/CT)**
A test that uses two picture-making methods to show the shape and function of tissue.
primary tumor
The main mass of a certain type of cancer cells.

prognosis
The likely course and outcome of a disease based on tests.

prophylactic cranial irradiation (PCI)
Prevention of cancer spread to the brain using radiation therapy.

pulmonary function tests
A set of breathing tests to test the strength of the lungs.

pulmonologist
A doctor who's an expert in lung diseases.

radiation oncologist
A doctor who's an expert in treating cancer with radiation.

radiation therapy
A treatment that uses intense energy to kill cancer cells.

respiratory system
The group of organs that transfers gases in and out of the body.

stereotactic ablative radiotherapy (SABR)
Treatment with high-dose radiation within one or a few sessions. Also called stereotactic body radiation therapy (SBRT).

side effect
An unhealthy or unpleasant physical or emotional response to treatment.

small cell lung cancer (SCLC)
A cancer of small, round lung cells.

spirometry
A test that uses a tube to measure how fast you breathe.

stereotactic radiosurgery (SRS)
Treatment of a brain tumor with high-dose radiation within one or a few sessions.

supportive care
Health care that includes symptom relief but not cancer treatment. Also sometimes called palliative care.

surgery
An operation to remove or repair a part of the body.

thoracic radiologist
A doctor who’s an expert in reading imaging tests of the chest.

thoracic surgeon
A doctor who’s an expert in operating on organs inside the chest.

thoracoscopy
A procedure to do work in the chest with a device passed through a small cut in the skin. Also called video-assisted thoracoscopic surgery (VATS).

three-dimensional conformal radiation therapy (3D-CRT)
A treatment with radiation that uses beams matched to the shape of the tumor.

tumor, node, metastasis (TNM) system
A staging system for cancer based on three areas of cancer growth.

ultrasound
A test that uses sound waves to take pictures of the inside of the body.

Veterans Administration (VA) system
The first system created to stage small cell lung cancer.

volumetric modulated arc therapy (VMAT)
A treatment with radiation that is delivered in an arc shape around the tumor.

whole-brain radiation therapy (WBRT)
Treatment of the entire brain with radiation.
This patient guide is based on the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®) for Small Cell Lung Cancer, Version 1.2022. It was adapted, reviewed, and published with help from the following people:

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