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# SMALL CELL LUNG CANCER

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# **Empower yourself through** information and support

mall cell lung cancer (SCLC) is an uncommon form of lung cancer. Although it has traditionally been very challenging to treat, it may be comforting to know that new drugs, treatment strategies and clinical trials are making great strides in how SCLC is treated and managed. The result is more options, and more hope, for people facing this aggressive lung cancer.

#### **HOW LUNGS FUNCTION**

The lungs are a pair of large, spongy, expandable organs in your chest cavity that are surrounded by a thin layer of protective tissue (pleura). The right lung is a little larger with three parts (lobes), and the smaller left lung has two lobes (see Anatomy of the Lungs).

Your lungs expand and contract when you breathe, exchanging oxygen and carbon dioxide. When you inhale, your lungs fill with oxygen-rich air, which is delivered to red blood cells that then deliver the oxygen to the rest of your body. When you exhale, the carbon dioxide that is brought back to the lungs by red blood cells is expelled into the air. Your diaphragm, a dome-shaped muscle underneath your lungs, initiates this cycle of expansion and contraction.

Abnormal cells in the lining of the airways can accumulate to form a tissue mass (primary tumor). A primary tumor may grow into the lining around the lung and form secondary tumors nearby. In advanced disease, lung cancer cells break away to form tumors in the opposite lung and in distant sites such as the liver, brain or bones. These are known as metastases. Even though they are in other parts of the body, they are still considered lung cancer and are treated as such.

#### **TYPES OF LUNG CANCER**

Lung cancer is more complicated than many people realize. There are many types, and they fall into two main classifications: small cell lung cancer (SCLC) and non-small cell lung cancer (NSCLC). NSCLC makes up the majority of lung cancer diagnoses and has several subtypes. Other less common types of lung cancer, which can also begin in other organs, include mesothelioma, sarcoma, lymphoma and others. This guide focuses on SCLC.

SCLC often starts in the central airways (bronchi) in the center of the chest and frequently spreads to distant parts of the body before it is found. It is considered the most common type of neuroendocrine tumor of the lung (see Understanding neuroendocrine tumors).

Cancer is a disease of our genes, which are pieces of DNA in our cells. DNA refers to the molecules inside cells that carry genetic information that is passed from one generation to the next. Cancer forms when genes begin to change, or mutate (change), within the structure of normal cells. Cancers are driven by a mixture of specific mutations, which can either be acquired during a person's lifetime (from environmental factors such as smoking) or are hereditary (inherited from a parent). The mutations found in SCLC are not inherited.

A biopsy sample will be reviewed under a microscope by a pathologist. Molecular/ genomic testing will be performed on the sample to confirm the diagnosis and look for

#### **ANATOMY OF THE LUNGS**



any mutations, which may indicate the SCLC's subtype and whether certain treatments may be more effective.

SCLC is named for its appearance under a microscope. It is aggressive and typically has multiple mutations in the tumor's DNA. The most common are in the TP53 and RB1 tumor suppressor genes and as a deletion in the chromosome arm 3p. A normal tumor suppressor gene makes a protein that helps control cell growth. When that gene is mutated, it can no longer control cell growth, which may lead to cancer. A chromosome that has been changed (in this case, part of it is missing), may also lead to cancer.

In rare cases, SCLC cells can form from NSCLC cells that have molecular alterations.

#### Understanding neuroendocrine tumors

Neuroendocrine tumors (NETs) develop from cells that release hormones into the blood in response to a signal from the nervous system. They may make higher-than-normal amounts of hormones, which can cause many different symptoms. NETs may begin in any part of the body, but they typically develop in the lungs, gastrointestinal tract and pancreas.

Neuroendocrine cells line the bronchi and other parts of the lung. These cells have multiple functions:

- · Controlling air flow and blood flow in the lungs
- · Controlling the growth of other types of lung cells
- Detecting levels of oxygen and carbon dioxide in the air we breathe, and releasing chemical messages to help the lungs adjust to these changes.

SCLC is the most common form of lung neuroendocrine tumor. It is aggressive and is likely to spread. The cells are poorly differentiated (they do not look like normal cells). SCLC can cause cancer in neuroendocrine cells and the submucosal lining of the airways.

Depending on the specific characteristics and health of the patient, a NET lung tumor may be treated differently than most SCLC diagnoses. Therapies may include surgery, chemotherapy, targeted therapy, radiation therapy, a combination of any of these or a clinical trial.

Heidi Hanson had already been treated successfully for breast cancer and bladder cancer before discovering she had Stage IV small cell lung cancer at 71. As a three-time cancer survivor, she knows how important it is to have a positive attitude. With the help of her family, support groups and  $GO_2$  for Lung Cancer, she encourages others with her natural hopefulness.

# Having a positive attitude is everything

► For about a week, I had been wobbly on my feet. I suspected it was allergies, but when it didn't go away, I called my general practitioner. She recommended I go to the ER right away, which I did. They ran a battery of tests including an MRI and PET. One doctor asked me to touch my nose, and to my surprise, when doing so, I immediately threw up. I knew something was terribly wrong. The doctor said I would need to stay overnight for monitoring.

The next day, the doctor on call, who just happened to be the top neurosurgeon in our area, said scans showed a large mass in my brain that required surgery to remove it. I was shocked. I didn't have much time to process the information before they rushed me into the operating room for a seven-hour surgery to remove the mass. It was the size of an orange in the lower stem of my brain. I spent two days in the ICU recuperating. The staff made sure I got up and could walk and talk before sending me home the next day. Then we waited for test results to identify the mass.

It took about a week to get results. In the meantime, I was referred to an oncologist. I suspected that my previous breast cancer or bladder cancer had returned and metastasized to my brain. I did not expect to hear I had a third cancer. The oncologist said that the cells in the mass were a metastasis from small cell lung cancer, which meant it was Stage IV.

The surgeon believed he removed all of the tumor in my brain. A scan immediately after the surgery showed a tumor in my right lung. The next steps included chemotherapy and five months of physical therapy to regain my balance and strength after the surgery. I never had them both on the same day. I also had brain radiation to kill any microscopic tumor cells left behind after the brain surgery. My oncologist also added immunotherapy to my regimen.

I tolerated the chemotherapy well with only a little bit of nausea. The only real change was losing my long blonde hair and having it grow back gray and curly. I think what helped me avoid some side effects was staying hydrated and moving.

At a follow-up appointment, a PET scan showed the tumor was completely gone. But later, a new spot was found in my right lung in a different location than the original. My radiation



oncologist ordered several rounds of radiation therapy to my chest. Fortunately, I didn't have chest radiation with my breast cancer diagnosis, so I was still eligible to have it.

When a recent scan still showed something on my lung, I was referred to a pulmonologist who did a biopsy and confirmed it was scar tissue from the previous radiation to my chest. I also have a brain MRI/PET every three months to help monitor my cancer. No matter what, it is crucial to stay on top of all appointments and follow-ups.

I have finished chemotherapy and radiation therapy, but I will remain on immunotherapy for as long as it keeps the cancer at bay. If I need to, I will definitely consider joining a clinical trial in the future.

While I went through treatment, my mother passed away. Five years earlier my husband was diagnosed with multiple myeloma and amyloidosis. He was enormously helpful and supportive because he had been through treatment himself. I made myself find support groups so that I would not feel alone. My social worker connected me with  $GO_2$  for Lung Cancer and LUNGevity. They helped me stay hopeful.

When you first find out you have cancer, it's important to acknowledge it. You have to own it and speak it out loud. Then you can reach out for help and be a participant in your treatment. Being in denial is not helpful. This cancer can really make people isolate themselves, and support is vital for getting through everything.

Having a positive attitude and surrounding myself with friends and family made all the difference. My brother-in-law has been my rock through everything. He is an orthopedic oncologist, and I consulted him every step of the way. I'm also extremely grateful for my medical team. They are all wonderful! I feel blessed I had the best medical care.

When a doctor, nurse or social worker asks you how you are feeling, tell them the truth. I finally admitted to them that I was scared to death. Scanxiety is a real issue you may face when you're waiting for test results for cancer that is notorious for coming back. I've found that distracting my attention until the results are ready is helpful. If the fear is unbearable, talk to your doctor about it.

Find what works best for you. And try to stay positive.

# **Determining the extent of cancer aids in treatment planning**

· Physical exam.

body fluids.

doctor will consider the results of the following:

tomography (PET), computed tomography

(CT) of the chest and magnetic resonance

imaging (MRI) of the brain are routine.

• Laboratory tests of your blood, urine and

· Imaging studies. A positron emission

**ollowing diagnosis**, your doctor uses a process called staging to better understand your type of cancer. Staging takes into account the size and location of the cancer and whether it has metastasized (spread) to nearby organs, tissues or lymph nodes, or to other parts of your body. Your doctor uses this information to develop a prognosis (outlook) and design a treatment plan, including identifying potential clinical trials that may be appropriate for you.

Staging provides a common language for doctors to communicate and collaborate on a patient's cancer. For example, staging allows doctors to group patients who have a similar prognosis. This approach enables them to more accurately predict outcomes and help determine the type of treatment patients will receive.

To determine the stage of your cancer, your

#### A TABLE 1 AJCC TNM SYSTEM FOR CLASSIFYING LUNG CANCER Classification Definition

Tumor (T)	
ТХ	Primary tumor cannot be assessed, or tumor proven by the presence of malignant (cancerous) cells in sputum (mucus that has been coughed up) or bronchial washings (cells collected from inside the airways) but not visualized by imaging or bronchoscopy.
ТО	No evidence of primary tumor.
Tis	Carcinoma in situ. Squamous cell carcinoma in situ (SCIS). Adenocarcinoma in situ (AIS): adenocarcinoma with pure lepidic pattern (on the alveolar lining), ≤ (not more than) 3 cm in greatest dimension.
T1 T1mi T1a T1b T1c	$ \begin{array}{l} Tumor \leq (not more than) 3 \ cm \ in \ greatest \ dimension, \ surrounded \ by \ lung \ or \ visceral \ pleura \ (membrane \ surrounding \ the \ lung), \ without \ bronchoscopic \ evidence \ of \ invasion \ more \ proximal \ than \ the \ lobar \ bronchus \ (i.e., not \ in \ the \ main \ bronchus). \ Minimally \ invasive \ adenocarcinoma: \ adenocarcinoma \ (\leq \ fnot \ more \ than) 3 \ cm \ ingreatest \ dimension) \ with \ a \ predominantly \ lepidic \ pattern \ (on \ the \ alvector \ adenocarcinoma: \ adenocarcinoma \ (s \ fnot \ more \ than) 3 \ cm \ ingreatest \ dimension) \ with \ a \ predominantly \ lepidic \ pattern \ (on \ the \ alvector \ adenocarcinoma: \ adenocarcinoma \ (s \ fnot \ more \ than) 3 \ cm \ ingreatest \ dimension. \ Tumor \ (nore \ than) 1 \ cm \ ingreatest \ dimension. \ Tumor \ (more \ than) 1 \ cm \ but \ (on \ thore \ than) 2 \ cm \ ingreatest \ dimension. \ Tumor \ (more \ than) 1 \ cm \ than \ but \ (on \ thore \ than) 2 \ cm \ ingreatest \ dimension. \ Tumor \ (more \ than) 1 \ cm \ than \ but \ (on \ thore \ than) 3 \ cm \ ingreatest \ dimension. \ Tumor \ (more \ than) 1 \ cm \ than \ but \ (on \ thore \ than) 3 \ cm \ ingreatest \ dimension. \ Tumor \ (more \ than) 2 \ cm \ but \ (on \ thore \ than) 3 \ cm \ ingreatest \ dimension. \ than \ but \ (on \ than) 3 \ cm \ ingreatest \ dimension. \ than \ but \ (on \ than \ than \ than \ but \ (on \ than \ tha$
T2 T2a T2b	<ul> <li>Tumor &gt; (more than) 3 cm but ≤ (not more than) 5 cm or having any of the following features:</li> <li>Involves the main bronchus regardless of distance to the carina (ridge at the base of the trachea), but without involvement of the carina.</li> <li>Invades visceral pleura (membrane surrounding the lung).</li> <li>Associated with atelectasis (collapse of part of the lung) or obstructive pneumonitis (inflammation of lung tissues) that extends to the hilar region, involving part or all of the lung.</li> <li>Tumor &gt; (more than) 3 cm but ≤ (not more than) 4 cm in greatest dimension.</li> </ul>
Т3	Tumor > (more than) 5 cm but $\leq$ (not more than) 7 cm in greatest dimension or directly invading any of the following: parietal pleura (outer lung membrane), chest wall (including superior sulcus tumors), phrenic nerve (nerve that helps control breathing), parietal pericardium; or separate tumor nodule(s) in the same lobe as the primary.
T4	Tumor > (more than) 7 cm or tumor of any size invading one or more of the following: diaphragm, mediastinum (area between the lungs), heart, great vessels, trachea (windpipe), recurrent laryngeal nerve (nerve that helps speech), esophagus, vertebral body, or carina (at base of the trachea); separate tumor nodule(s) in an ipsilateral lobe (lobe that is on the same side of the body) different from that of the primary.
Node (N)	
NX	Regional lymph nodes cannot be assessed.
NO	No regional lymph node metastasis.
N1	Metastasis in ipsilateral (on the same side) peribronchial and/or ipsilateral hilar lymph nodes and intrapulmonary nodes, including involvement by direct extension.
N2	Metastasis in ipsilateral (on the same side) mediastinal and/or subcarinal lymph node(s).
N3	Metastasis in contralateral (on the opposite side) mediastinal, contralateral hilar, ipsilateral (on the same side) or contralateral scalene, or supraclavicular lymph node(s) (located above the collarbone).
Metastasis (I	M)
MO	No distant metastasis.
M1 M1a M1b M1c	Distant metastasis. Separate tumor nodule(s) in a contralateral (on the opposite side) lobe; tumor with pleural or pericardial nodules or malignant pleural or pericardial effusion. Single extrathoracic (outside of the lung) metastasis in a single organ (including involvement of a single nonregional node). Multiple extrathoracic (outside of the lung) metastases in a single organ or in multiple organs.

Used with permission of the American Joint Committee on Cancer (AJCC), Chicago, Illinois. The original and primary source for this information is the AJCC Cancer Staging Manual, Eighth Edition (2017) published by Springer Science+Business Media. • Tissue biopsy. Some biopsies are performed with a needle, although sometimes part or all of the tumor must be removed surgically to determine a diagnosis.

Doctors may use a combined staging approach to stage small cell lung cancer (SCLC), referring to the Veterans Administration Lung Study Group (VALSG) staging system as well as the American Joint Committee on Cancer's (AJCC) TNM classification and staging system.

#### VA LUNG STUDY GROUP STAGING SYSTEM

The first staging system developed for SCLC is still the most widely used. The VALSG staging system divides SCLC into two stages: limited stage and extensive stage.

Limited-stage SCLC is confined to one part of the chest, in just one part of the lung and in nearby lymph nodes. Limited-stage cancers are considered to be Stages I to III of the American Joint Committee on Cancer (AJCC) TNM staging system.

Extensive-stage SCLC has spread to other TABLE 2 STAFEC OF LUNC CANCED

JIAULJ	UI LUNU U	ANULI	<u>1</u>
Stage	т	N	м
Occult carcinoma	TX	NO	M0
0	Tis	NO	MO
IA1	T1mi T1a	N0 N0	M0 M0
IA2	T1b	NO	MO
IA3	T1c	NO	MO
IB	T2a	NO	MO
IIA	T2b	NO	MO
IIB	T1a or T1b or T1c T2a or T2b T3	N1 N1 N0	M0 M0 M0
IIIA	T1a or T1b or T1c T2a or T2b T3 T4	N2 N2 N1 N0 or N1	M0 M0 M0 M0
IIIB	T1a or T1b or T1c T2a or T2b T3 T4	N3 N3 N2 N2	M0 M0 M0 M0
IIIC	T3 T4	N3 N3	M0 M0
IV	Any T	Any N	M1
IVA	Any T	Any N	M1a or M1b
IVB	Any T	Any N	M1c

parts of the body, such as the area between the lungs or other lung, or outside of the chest, such as to the brain or bone. It is considered to be Stage IV in the AJCC TNM staging system.

#### AJCC TNM STAGING SYSTEM

Some doctors also consult the TNM (tumor, node, metastasis) system, developed by the AJCC and the International Association for the Study of Lung Cancer, to classify and stage lung cancer (see Table 1).

The T category identifies the primary tumor's size and location. The N category indicates

whether lymph nodes show evidence of cancer cells. If so, the location of these lymph nodes is important because it shows how far the disease has progressed. The M category describes distant metastasis (spread), if any. Cancer can spread by growing into nearby tissue, or traveling through lymph vessels or blood vessels to other parts of the body. An M subcategory may be added based on the presence of tumor cells that can be detected only by using a microscope.

For illustration purposes, the tumors in Figure 1 are shown on one side of the lungs. They may, however, be present in any area of the lungs.

Staging combines the patient's T, N and M

status, then assigns a number (see Table 2).

- **Stage 0,** also known as in situ, is a precursor of an invasive cancer (not shown).
- Stages I and II are generally confined to the local area where the cancer is found, with or without adjacent lymph node involvement. They are treated as early stage and are considered potentially curable; therefore, every effort should be made to render a cure for these diagnoses.
- Stage III is considered locally advanced, still confined to the chest but having spread to regional lymph nodes outside the lung in the mediastinum.
- Stage IV is locally or regionally advanced disease that has spread to distant sites.



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#### 5

# Explore all therapeutic options with your doctor

**reatments for small cell lung cancer** (SCLC) are focused on managing the disease while extending life expectancy and improving quality of life. SCLC has historically had fewer treatment options than NSCLC, but that is beginning to change through research developments. New drug therapies and combinations of drug treatments are now available for both firstline and second-line use. Ongoing research is continuing to show some positive results for future treatments. As a result, a clinical trial may also be a good option for consideration.

Your treatment plan will be based on many factors:

- Whether you are newly diagnosed or are experiencing a recurrence
- The presence of symptoms
- The aggressiveness of the cancer
- · Your goals of treatment
- Your lung health and overall health

You may also want to seek a second opinion or advice from an SCLC specialist. A second opinion is a way to make sure your pathology, diagnosis and staging are accurate and that you are aware of all of your treatment options.

Many SCLC patients smoked and also have chronic obstructive pulmonary disease (COPD) in the non-cancer tissues of the lung, which may interfere with lung function and alter therapeutic options. A pulmonologist, who specializes in diseases of the lung, may assess your overall lung function at diagnosis. If you currently smoke, know that stopping will help your treatment be more effective (see *Stopping smoking at any time offers multiple benefits*, page 7).

#### TREATMENT TYPES

The goal is curative when using surgery or radiation therapy to treat limited-stage SCLC that is confined to the chest. Extensive-stage SCLC is treated to prevent progression and minimize symptoms. Ask questions and share your concerns with your multidisciplinary team so you feel informed about all your treatment options. For example, if firstline therapy fails, ask about the second-line therapies that are available.

Your doctor will monitor you regularly, and you will be responsible for communicating with your health care team and keeping follow-up appointments. Keep in mind that cancer treatment plans are commonly adjusted as the cancer or your response to treatment changes. Cancer treatment is a fluid process — patience is a good asset to have.

**Drug therapy** is systemic therapy that may be given through an IV into a vein or a port in your body. It may also be given as an injection (shot) or orally as a pill or liquid. Types of drug therapy used to treat SCLC include chemotherapy, immunotherapy and, in some neuroendocrine tumors of the lung, targeted therapy.

*Chemotherapy* is systemic drug therapy that kills rapidly multiplying cells throughout the body. Because of how quickly the disease can spread, chemotherapy is the primary treatment for all stages of SCLC. It is usually delivered in cycles, with treatment periods followed by recovery periods in an on-again, off-again manner. Treatment typically consists of a combination of two drugs for SCLC.

It may be given in pill form or as a solution injected or infused intravenously (IV). Injections and IV treatments may take place at your doctor's office or an outpatient cancer center. Additional fluids and medication may be given with IV chemotherapy to prevent side effects. Most often four to six cycles are given at three-week intervals.

As you learn about your diagnosis and treatment options, you will hear many terms you may be unfamiliar with. These explanations may help you feel more informed as you make the important decisions ahead.

**First-line therapy** is the first treatment used.

**COMMON** 

TERMS

TREATMENT

**Second-line therapy** is given when the first-line therapy does not work or is no longer effective.

**Standard of care** refers to the widely recommended treatments known for the type and stage of cancer you have.

**Progression of cancer** is growth of cancer to the degree that the growth can be detected by physical exam or scans such as CT, PET or MRI. **Recurrence** means cancer has returned or cancer cells have been detected again, usually after a period of time during which it could not be detected.

**Response to therapy** means that the cancer has reduced in size or lost its blood supply in a manner that can be measured by CT or MRI.

**Partial response** is a decrease in the size of a tumor, or in the extent of cancer in the body, in response to treatment. Systemic treatments travel throughout the body and are typically drug therapies, such as chemotherapy, targeted therapy and immunotherapy.

#### Maintenance therapy is

given to help keep cancer from coming back after it has disappeared following the initial therapy. It may include treatment with drugs, vaccines or antibodies that kill cancer cells, and it may be given for a long time.



**Measurable disease** indicates the amount of cancer that can be accurately measured in size. This information can be used to judge response to treatment.

Local treatments are directed to a specific organ or limited area of the body and include surgery and radiation therapy. In extensive-stage SCLC, chemotherapy is often combined with immunotherapy. Chemotherapy is also used for second-line treatment. If a recurrence occurs, depending on how quickly the cancer returns, the first chemotherapy combination may be used again in the second-line setting if there was a good and long lasting response to therapy. If there was not, other chemotherapies are approved to treat SCLC as second-line therapy, or a different combination of chemotherapies may be used.

*Chemoimmunotherapy* combines chemotherapy with immunotherapy. It is the preferred treatment for extensive-stage SCLC. Once the initial cycles are complete and testing shows no signs of cancer, you may continue on immunotherapy as continuation maintenance for up to one year.

*Chemoradiation*, also called chemoradiotherapy or concurrent chemoradiation, combines chemotherapy with radiation therapy. It makes cancer cells more sensitive to radiation, making it easier for the radiation therapy to kill them. Patients with limited-stage SCLC are usually treated with both chemotherapy and radiation therapy given concurrently for two of four chemotherapy cycles.

*Immunotherapy* stimulates the immune system to find and attack cancer. It most often is used in combination with chemotherapy (chemoimmunotherapy) as first-line therapy for extensive-stage SCLC. Its use with chemoradiation as initial therapy in limited-stage SCLC is being explored.

Immune checkpoint inhibitors are a type of immunotherapy approved to treat SCLC. Checkpoints keep the immune system "in check," preventing an attack on normal cells by using regulatory T-cells. When the correct proteins and cell receptors connect, a series of signals is sent to the immune system to slow down once an immune response is finished. Immune checkpoint inhibitors prevent the immune system from slowing down, allowing it to keep up its fight against the cancer.

**Radiation therapy,** also called radiotherapy, uses high-energy radiation to destroy cancer cells and shrink tumors. It is used to treat SCLC, prevent its spread to the brain and relieve symptoms. Radiation therapy is used for limited-stage SCLC that has not spread to the lymph nodes and that cannot be treated with surgery. It is often combined with chemotherapy in a treatment called chemoradiation.

If a complete or partial remission is seen after first-line treatment for limited-stage cancer, your doctor may offer prophylactic cranial irradiation to prevent the spread of SCLC to the brain. Before moving forward, talk with your doctor about the potential advantages and risks of this preventive approach for your specific situation.

*External-beam radiation therapy* (EBRT) is the most common form of radiation therapy used to treat SCLC. It delivers radiation from a machine outside the body. Types of EBRT include three-dimensional conformal radiation therapy (3D-CRT), stereotactic body radiotherapy (SBRT), intensity-modulated radiation therapy (IMRT) and volumetric arc-based therapy (VMAT), which delivers IMRT in an arc shape around the tumor.

Another type of radiation therapy that may be used is proton beam radiation therapy. It uses protons (tiny particles with a positive charge) to kill tumor cells. This type of treatment can reduce the amount

## Stopping smoking at any time offers multiple benefits

If you have just been diagnosed with lung cancer, regardless of whether you have been a long-term smoker or not, it's important to know that it is never too late to stop smoking and using other tobacco products. Your doctor will encourage you to quit so you can get the most out of your treatment. Studies show there are multiple benefits to quitting — some are immediate and others are long term. These benefits can also apply to loved ones who smoke.

The idea of quitting may feel intimidating or cause anxiety. That's understandable because nicotine is addictive and a hard habit to break. If you tried before and were unsuccessful, you may feel discouraged about trying again, but many resources are available that you may not have had access to in the past.

Ask your health care team about the options your treatment facility and community offer to help stop using tobacco. Other resources are available, such as smoking cessation programs, local support groups, call lines, text-based help and online assistance.

#### HOW STOPPING SMOKING WILL IMPROVE YOUR LIFE

**Immediate benefits** 

Breathe easier	Impr
Chemotherapy and radiation therapy may be more effective	treat Decr
Improved wound healing and faster	cond
recovery from surgery	Lowe
Reduced lung inflammation, which may help reduce the risk of cancer progression	
A boosted immune system that can fight disease and infections better	Few

#### Long-term benefits

Improved chances of survival after cancer treatment Decreased risk of secondary cancers and other

conditions linked to tobacco use

Lowered blood pressure and decreased heart rate, better blood circulation, increased lung function

Improved sense of smell and taste

Fewer illnesses such as colds and flu, lower rates of bronchitis and pneumonia

The following resources are available to help you or loved ones be proactive about quitting tobacco products and improving lung health.

American Cancer Society: www.cancer.org, 800-227-2345

American Lung Association Lung Helpline and Tobacco Quitline: 800-586-4872

BecomeAnEx: www.becomeanex.org

CDC Tobacco Quitline: 1-800-QUIT-NOW; 800-784-8669

National Cancer Institute LiveHelp: livehelp.cancer.gov/app/chat/chat\_ launch

National Cancer Institute Smoking: Quitline: 877-44U-QUIT; 877-448-7848

Nicotine Anonymous: nicotine-anonymous.org

North American Quitline Consortium: naquitline.org

**Smokefree.gov:** smokefree.gov, 800-784-8669

**SmokefreeTXT:** smokefree.gov/toolstips/text-programs, text QUIT to 47848 of radiation damage to healthy tissue near a tumor.

**Surgery** is not commonly used for treating SCLC and is typically reserved for very earlystage disease. In this case, chemotherapy is administered after the surgery. However, surgery may be used more often for neuroendocrine tumors of the lung. A board-certified thoracic surgeon experienced in lung cancer should determine whether this type of tumor can be removed successfully. The procedure selected will depend on how much of your lung is affected, tumor size and location, and your overall health.

**Clinical trials** may offer the opportunity to try an innovative treatment that is testing drug therapies or types of surgery or radiation therapy before they are widely available. Some trials are even underway to find improved methods to quit smoking (see *Clinical Trials*, page 9).

#### TREATING A RECURRENCE

Even with successful treatment, SCLC often returns. This is called a recurrence. Should this happen, your doctor may run more diagnostic tests to determine the next treatment option. This is a good time to discuss any questions about the second-line treatments available. Second-line therapies include other types of chemotherapy. If the cancer has progressed, immunotherapy may be added if you have not previously received it.

In rare cases, non-small cell lung cancer (NSCLC) cells can transform into SCLC. Known as transformed small cell lung cancer (tSCLC), it most often occurs in NSCLC that has the *EGFR* biomarker and usu-

### Maximize drug treatment benefits

► Taking medication on time every time is referred to as medication adherence, and it applies to every type of treatment, including taking oral therapies at home and receiving intravenous treatments at your doctor's office or cancer clinic. Taking your medication correctly is important because it can influence the effectiveness of the treatment and the management of side effects.

Most therapies are designed to maintain a specific level of medication in your system for a certain time based on your symptoms, overall health and other factors. If your medications are not taken exactly as prescribed, the consequences can lead to unnecessary or unrelieved side effects, physician visits, hospitalizations and even cancer progression.

For SCLC, most systemic treatments are given intravenously at an office or clinic. Keeping your schedule of treatment appointments is important for achieving the best outcome.

Medication adherence also applies to taking medications that help manage treatment side effects. People who are being treated for SCLC are often prescribed anti-nausea medications, white blood cell growth factors and drugs to combat myelosuppression, which is a decrease of red blood cells, white blood cells and platelets. Download a medication journal to keep track of your medications at PatientResource.com/Medication\_Journal.

Following are suggestions to help you take medications on time:

- Ask your pharmacist to explain how to take your medications and discuss possible drug interactions.
- If the dosing schedule is complicated or you are also managing additional medications for other conditions, ask the pharmacist or your doctor whether it can be simplified so medications can be taken at the same time of day or around meals.
- Keep a treatment diary. Track each treatment, including missed doses or appointments, and detail any side effects. If you miss a dose or appointment, let your health care team know so they can determine whether you should make it up immediately or wait until your next scheduled time.
- Set up reminders for taking your medications and scheduling refills. A reminder can be an alarm on your clock or phone. Some pharmacies offer automatic refill programs.
- Try weekly pill organizers to keep track of and organize your medications.
- Find out whether you can order a 90-day prescription to lessen trips to the pharmacy, or ask whether the pharmacy offers home delivery so you don't have to go out if you aren't feeling well.

#### COMMON DRUG THERAPIES FOR SCLC PATIENTS

These therapies may be used alone or in combination. For some possible combination therapies your doctor might suggest, go to PatientResource.com/SCLC\_Treatment

- atezolizumab (Tecentriq)
- carboplatin (Paraplatin)
- cisplatin (Platinol)
- doxorubicin (Adriamycin)
- durvalumab (Imfinzi)
- etoposide (Etopophos)
- irinotecan (Camptosar)
- Iurbinectedin (Zepzelca)
- ► topotecan (Hycamtin)
- trilaciclib (Cosela)

As of 8/11/23

ally contains both NSCLC and SCLC cells. Treatments may consist of combined therapies used to treat both NSCLC and SCLC.

#### **ON THE HORIZON**

Scientists have recently discovered that SCLC has several subtypes that respond differently to chemotherapy and immunotherapy. One subtype (SCLC-I) tends to respond more to immunotherapy. More research is needed to understand how treatment affects each of these subtypes.

Research in clinical trials holds promise for new treatments to come. Several novel medications, including a new type of immunotherapy, are currently in trials and could be approved in the future. Novel antibodies targeting a receptor called DLL3, which is frequently expressed in SCLC, has shown promising results in clinical trials. Other research is studying chimeric antigen receptor (CAR) T-cell therapy, another type of immunotherapy. In this treatment, a patient's T-cells are taken and a gene for a special receptor is added to the T-cells to bind to a certain protein on the cancer cells. These CARs are grown in a laboratory and given back to the patient by infusion.

#### JOIN THE LUNG CANCER REGISTRY

The Lung Cancer Registry is a database of patient information that is donated by patients or by a loved one of someone who faced lung cancer. It is a direct way to improve the future of lung cancer treatment by simply sharing insights and experiences.

Participants provide data by answering questions from a home computer or mobile device about the patient, their medical history and diagnosis, treatment, outcomes and quality of life. They decide how the information will be used and whether they want to be contacted by Registry staff. No medical visits are required, and no biopsies or specimens are needed. It is free to join. To get involved, go to www.lungcancerregistry.org.

# Advancements in science bring hope and options

**linical trials may become** part of your treatment plan, so it is important to learn about them. These research studies contribute to medical knowledge related to treatment, diagnosis and prevention of diseases or conditions. Ultimately the goal of a clinical trial is to provide you and the entire cancer community longer, healthier lives. Understanding the different types, their potential impact on your treatment plan and the broader benefits of such research can help you decide whether a clinical trial is right for you.

A clinical trial is a research study that investigates new or emerging treatments for a disease and compares these treatments to established protocols to determine their effectiveness, safety or new usage. The results of these studies can make a positive difference in future cancer care in a variety of ways. Currently several treatment strategies for small cell lung cancer (SCLC) are being studied in clinical trials. These include drug therapies in the first- and second-line settings, radiation therapy and combination therapies.

Choosing to participate in a clinical trial may provide you options when your diagnosis has few or no approved therapies or your cancer has become resistant to your current treatment. In addition, you will have the opportunity to be monitored by both the specialists managing your trial and your cancer treatment team. Although most trials involve some risks, they may not be greater than the risks related to standard-of-care treatments or disease progression.

Volunteers of all ages, genders, locations, races and ethnicities, weights, sexual orientations and socioeconomic groups help researchers understand how a variety of people react to certain interventions. This diverse pool of volunteers also helps determine how a strategy works in people who are at higher risk for certain conditions such as heart disease and diabetes.

#### THE TYPES OF TRIALS

The following types of clinical trials explore treatment and non-treatment strategies.

Therapeutic treatment trials evaluate one or more interventions, such as drug therapies, medical devices and new or revised approaches to surgery or radiation therapy. Recently, a great deal of focus has been on identifying therapies that treat cancers with specific biomarkers. For SCLC, detecting certain biomarkers can indicate whether a cancer will be more receptive to certain therapies, such as immunotherapy. Research is also ongoing to find new treatments for cancers that do not exhibit a biomarker.

Designed to evaluate one or more ways to identify or diagnose a particular disease or condition, **disease prevention and patient screening trials** also find ways to prevent the initial development or recurrence of a disease or condition. These can include medicines, vaccines or lifestyle changes, among other approaches.

**Diagnostic tools and procedures trials** are conducted to examine new and improved methods for identifying a condition or the risk factors for that condition.

Researchers use **genetic risk factor studies** to learn more about the genetic disorders and disease-related mutations that cause various types of cancer.

Lifestyle and behavioral changes trials are designed to explore and measure ways to

#### CLINICAL TRIALS RESOURCES

- Cancer Support Community: www.cancersupportcommunity.org/find-clinical-trial, 888-793-9355
- Center for Information & Study on Clinical Research Participation: www.searchclinicaltrials.org
- ClinicalTrials.gov: www.clinicaltrials.gov
- ► GO<sub>2</sub> for Lung Cancer LungMATCH: 800-298-2436
- Lazarex Cancer Foundation: www.lazarex.org, 877-866-9523
- LUNGevity Clinical Trial Finder: clinicaltrials.lungevity.org
- National Cancer Institute: www.cancer.gov/clinicaltrials
- ► NCI Cancer Information Service: 800-422-6237
- WCG CenterWatch: www.centerwatch.com, 866-219-3440

#### SMOKING CESSATION CLINICAL TRIALS FOR YOUR LOVED <u>ONES</u>

If your friends or family smoke or use tobacco products, your experience may encourage them to think about stopping. Habits involving nicotine can be hard to break — especially on their own. The most successful approach combines medications, counseling and support, which they may find by participating in a smoking cessation clinical trial.

Along with reducing the risk of lung and other types of cancer, long-term advantages of these potentially lifestylechanging studies include decreased risk of other conditions related to tobacco use, lowered blood pressure, decreased heart rate and improved sense of smell and taste. Use the resources on this page to learn more about this proactive step toward better health.

make people more comfortable as they manage a chronic condition. Some test the effect lifestyle changes have on lowering the risk of cancer and on current cancer treatments. Others incorporate measures to improve quality of life.

#### SEARCHING FOR A CLINICAL TRIAL

First, consult with your medical team to identify the trials they recommend. After gathering your diagnosis and treatment information, you can search for SCLC trials online or by phone. Further customize your search by including information such as age, desired location or previous treatments.

Once you have found a trial that interests you, call the clinical trial team to gather information. Then, discuss it with your doctor and loved ones.

You may undergo testing to see whether you meet the eligibility requirements. In addition, you must review and sign the Informed Consent form, a safety measure designed to protect participants throughout the clinical trial. The Informed Consent document generally includes the trial's goals, modality (method of treatment), potential risks and benefits, costs, safeguards, and other information. Keep in mind that even after signing the form and beginning the trial, you may leave the trial at any time and for any reason. ■

# Plan ahead for the best quality of life during treatment

**oday, more medications are available** to make it easier to prevent and manage the effects of cancer and its treatment effectively and with a better quality of life. Your health care team will draw from a range of supportive care services to address these physical and emotional challenges associated with cancer. Your family members, caregivers and others close to you can also benefit from this support.

Supportive care, also referred to as palliative care, is designed to help anyone with a serious or life-threatening illness. It is available from the time you receive your diagnosis through survivorship. Palliative care is often confused with hospice care, which is reserved for end of life. Think of the purpose of palliative care as "quality-of-life preservation or restoration."

As an approach to comfort care and symptom management, supportive care addresses the physical, emotional, practical, spiritual, financial and family-related challenges associated with cancer. Many people use it to manage physical side effects, which includes medications for pain, cough suppression and breathing assistance; opening closed airways; appetite stimulants; nutritional supplements to reduce weight loss; and reducing nausea, anxiety, depression, constipation, fatigue and sleep problems. Other resources available include assistance with fitness, mental health and physical/occupational therapy.

#### **PHYSICAL SIDE EFFECTS**

Although most cancer treatments have physical side effects, some may be managed or even prevented (see Table 1). Others, however, may be severe. It is also important to receive, discuss and sign a written consent form for any treatment, and to talk with your medical team before treatment begins about the side effects to expect and what to do if they occur. Keep in mind that although it is helpful to talk with others who have had similar diagnoses and treatments, how your body reacts may be different. Stay in close contact with your medical team so they can address your needs promptly and safely. It may also be helpful to keep track of your symptoms. Download a side effect tracker at PatientResource.com/Tracker.

**Potentially severe side effects** can occur with certain treatments. Though they are

uncommon, ask your doctor whether you are at risk from the therapies in your treatment plan, how to identify the symptoms and when to seek emergency care. Report symptoms immediately so they can be treated right away. Some potentially severe side effects include the following:

Immune-related adverse events (irAEs) are

associated with certain immunotherapy drugs. They can occur if the immune system becomes overstimulated by treatment and causes inflammation in one or more organs or systems in the body (see Table 2). Some irAEs can develop rapidly, becoming severe and even life-threatening without swift medical attention.

Some irAEs can be detected early during routine laboratory and imaging tests even before you can feel symptoms, which makes it crucial to stay on schedule with all medical appointments. Contact your medical team if symptoms arise between appointments, and remain alert to the possibility of irAEs for up to two years after completing immunotherapy.

# SOME COMMON PHYSICAL SIDE EFFECTS

Side Effects*	Symptoms
Bone loss and pain	Weakened bone caused by the cancer or treatment
Breathing problems	Shortness of breath (dyspnea) with or without cough (may be caused by anemia, a lower-than-normal red blood cell count), upper respiratory infections
Bruising and bleeding	May be caused by thrombocytopenia, a lower-than-normal number of platelets in the blood
Chemo brain (cognitive dysfunction)	Brain fog, confusion and/or memory problems
Constipation	Difficulty passing stools or having less frequent bowel movements compared to usual bowel habits
Decreased appetite	Eating less than usual, feeling full after minimal eating, not feeling hungry
Diarrhea	Frequent loose or watery bowel movements that are commonly an inconvenience but can become serious if left untreated
Edema	Swelling caused by excess fluid in body tissues
Fatigue	Tiredness that is much stronger and harder to relieve than the fatigue a healthy person has (may also be caused by anemia, a lower-than-normal red blood cell count)
Fever	Raised body temperature that could signal an infection
Hair loss (alopecia)	Hair loss on the head, face and/or body
Mouth sores (oral mucositis)	Tiny sores begin in the mouth lining and become red, burn-like or ulcer-like sores; can make it difficult to eat, drink or swallow.
Myelosuppression	Decrease of red blood cells, white blood cells and platelets that may cause fatigue, dizziness and shortness of breath
Nausea and vomiting	The feeling of needing to throw up and/or throwing up
Neuropathy	Numbness, pain, burning sensations and tingling, usually in the hands or feet at first
Neutropenia/ leukopenia	Low white blood cell count that increases the risk of infection
Pain	Musculoskeletal pain and aches that occur in the muscles, bones, tendons, ligaments or nerves
Skin reactions	Rash, redness and irritation or dry, flaky or peeling skin that may itch
Taste changes	Cells in the mouth that are damaged by treatments sometimes may cause food to taste different (for example, giving it a metallic taste)

<sup>\*</sup>Side effects listed in alphabetical order. Talk with your doctor about what to expect.

Infection can occur as a result of a low white blood cell count (neutropenia/leukopenia) or other factors. Contact your doctor immediately – do not wait until the next day – if you have any of these symptoms: oral temperature over 100.4°F, chills or sweating; body aches, chills and fatigue with or without fever; coughing, shortness of breath or painful breathing; abdominal pain; sore throat; mouth sores; painful, swollen or reddened skin; pus or drainage from an open cut or sore; pain or burning during urination; pain or sores around the anus; or vaginal discharge or itching.

Infusion-related reactions most frequently occur with drug therapies that are given intravenously (IV) through a vein in your arm or through a port, usually soon after exposure to the drug. Reactions are generally mild, such as itching, rash or fever. Other symptoms, such as shaking, chills, low blood pressure, dizziness, throat tightness, skin rash or flushing, breathing difficulties and irregular heartbeat, can be serious or even fatal without medical intervention.

#### **EMOTIONAL SIDE EFFECTS**

TABLE 2

Cancer affects more than just the body. It can upset your overall well-being. Be kind to yourself. Know that everything you feel is normal, and it is healthy and necessary to recognize and learn how to manage your emotions.

Support is available online and from inperson support groups, advocacy organizations, counselors, psychologists, psychiatrists and other specialists. Some organizations offer one-on-one buddy programs that pair you with another person who has SCLC. It can be very satisfying to share your feelings with people who can relate because they have been through something similar.

Following are some of the common emotions you may experience and suggestions for ways to feel better. However, it is critical to notify your health care team if you are unable to follow treatment due to extreme emotional distress; have excessive crying or continued feelings of hopelessness or despair; are unusually angry or irritable; are withdrawing and isolating yourself from family and friends; or feeling worthless. Get immediate medical attention for thoughts of death or suicide.

Anxiety can begin as soon as you receive your diagnosis and may ebb and flow. Dyspnea (shortness of breath) can worsen anxiety and even cause panic. Moderate to severe anxiety is often treated with medication, therapy or a combination of both. Share your feelings with a trusted friend or by journaling. Explore relaxation techniques, such as meditation, muscle relaxation, yoga or guided imagery.

**Depression** is a psychological reaction to your situation as a whole. Certain ongoing treatments, such as chemotherapy, can cause or contribute to depression. Don't avoid talking to your doctor about it because you think depression is just part of having cancer — it isn't. Talk with a member of your health care team if you feel hopeless, helpless or numb. If these feelings last more than a few days or if you have thoughts of death or of suicide, seek medical attention immediately.

**Doubt** about the meaning of life and your purpose may arise. Some people find strength in support from family, friends, the community or spirituality. It may also help to open up to a counselor or support group.

**Fear** about the treatment, side effects and your prognosis is common. Relying on supplemental oxygen can also be unsettling. Make sure you and your caregiver know how to operate the equipment. Have extra oxygen tanks on hand so you never run out. Making plans may become difficult because every ache and pain triggers a concern. Surround yourself with a medical team you trust and a solid support system, and do your best to take it one day at a time.

Guilt may occur if you feel you've been a burden to loved ones or if you wonder why you survived when others with similar conditions didn't. You may feel the burden of the stigma that often accompanies a lung cancer diagnosis if you used tobacco. Rely on the strength and support of non-judgmental close friends and family members, and consider talking with a therapist about these feelings.

Scanxiety is a word that describes the anxiety that can happen when you are awaiting results from imaging scans, laboratory tests or examinations you have as part of your treatment or follow-up plan. Scanxiety can be extremely stressful, and it may help to find ways to manage it. Set expectations with your medical team so you can know when to expect results instead of being left waiting and wondering. Keep your mind occupied with things you enjoy, such as reading, exercising, social activities or meditation. Staying busy gives you less time to worry.

#### **OTHER SUPPORT SERVICES**

Supportive care extends beyond physical and emotional issues. It includes the practical and family-related challenges that accompany cancer. This support also may include financial counseling, help with lifestyle decisions and spiritual guidance. If you need assistance and can't find it, talk with a member of your health care team. They are skilled and compassionate and can refer you to resources that will help. ■

#### IMMUNE-RELATED ADVERSE EVENTS (IRAEs) Body System\* irAE Symptoms & Signs

Body System*	irAE	Symptoms & Signs
Cardiovascular	Myocarditis	Chest pain, shortness of breath, leg swelling, rapid heartbeat, changes in EKG reading, impaired heart pumping function
Endocrine	Endocrinopathies	Hyperthyroidism, hypothyroidism, diabetes, extreme fatigue, persistent or unusual headaches, visual changes, alteration in mood, changes in menstrual cycle
Gastrointestinal	Colitis	Diarrhea with or without bleeding, abdominal pain or cramping, bowel perforation
Liver	Hepatitis	Yellow/orange-colored skin or eyes (jaundice), nausea, abdominal pain, fatigue, fever, poor appetite
Nervous system	Neuropathies	Numbness, tingling, pain, a burning sensation or loss of feeling in the hands or feet, sensory overload, sensory deprivation
Neurologic	Encephalitis	Confusion, hallucinations, seizures, changes in mood or behavior, neck stiffness, extreme sensitivity to light
Pulmonary (lungs)	Pneumonitis	Chest pain, shortness of breath, unexplained cough or fever
Renal (kidneys)	Nephritis	Decreased urine output, blood in urine, swollen ankles, loss of appetite
Skin	Dermatitis	Rash, skin changes, itching, blisters, painful sores

\*Body systems listed in alphabetical order. Talk to your doctor about what to expect.

# Healthy choices are key in survivorship planning

urvivorship is defined in different ways. Some people identify as a survivor at diagnosis; others consider themselves survivors once primary treatment has ended or as they start maintenance therapy. However you define it, it is important to have a conversation with your doctor about having a survivorship care plan. This plan is designed to keep track of all pertinent information about your care and may include your medical history, ongoing medications, a treatment summary and more.

Sometimes it may feel like cancer is making all the rules, but there is one way you can exert some much-needed control. Take an active role in your survivorship care plan by choosing to lead a healthy lifestyle. Draw on the support of your family, friends, health care team and trusted resources to help you move forward and make a positive impact during treatment. Ask your doctor for a plan or start one on your own (see Lung Cancer Survivorship Care Plan, page 16).

#### NUTRITION

Research shows that good nutrition during cancer treatment offers a better chance at recovery. However, getting the nutrients and fluids your body needs to heal can be challenging. Working with a dietitian to help tailor a nutrition plan soon after diagnosis can get you started on the right track.

Appetite loss is common during cancer treatment. It can be caused by fatigue, stress, depression, pain and treatment side effects, such as nausea, constipation and changes in how food smells and tastes. The weight you may lose is not just weight you feel you can stand to lose; it is also loss of muscle mass,

so it is important to ensure you are eating the calories and nutrients your body needs. As you go through treatment, your body needs more nutrients and calories to withstand the treatment. It will be important to keep your strength up, and high protein foods may help.

Staying hydrated during treatment for SCLC is crucial. Sipping water can remedy a dry mouth, thin the mucus in your throat and feel soothing after coughing. Some treatments, such as radiation therapy, can increase your risk of dehydration, which can cause nausea, fatigue, dizziness and headaches. Side effects of certain drug therapies, such as diarrhea or vomiting, can also cause dehydration. Drinking water can help reduce that risk. However, if diarrhea is severe, you may not be able to absorb plain water, and your doctor may recommend a specialized oral rehydration solution. Talk to your doctor or dietitian for more information.

#### EXERCISE

As surprising as it may sound, exercising while you have SCLC is possible - and encouraged. The type of exercise you can do now may be different than what you are used to, but the rewards will be the same: more energy, decreased fatigue and improved mood. Feeling better overall also positions you to better manage treatment-related side effects.

Your exercise plan should be focused on avoiding inactivity and simply getting moving. Try not to be completely sedentary. In-

#### EXERCISES FOR PEOPLE WITH SMALL CELL LUNG CANCER

**Breathing exercises** Exercises such as diaphragmatic breathing can strengthen muscles that improve endurance and regulate your breathing when you are short of breath.

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Light stretching on a regular basis can help expand your chest cavity and lung capacity. It can also increase your range of motion and flexibility.



# <u> PAYOUR HEALTH CARE TEAM</u>

Medical oncologists treat cancer with drug therapy and other medications.

Surgical oncologists operate to remove cancer tumors and have special training in performing biopsies.

**Oncology nurses** provide inpatient or outpatient care in a cancer treatment facility.

Pulmonologists are doctors who have special training in diagnosing and treating diseases of the lungs.

Thoracic radiologists are experts at imaging the chest. Thoracic surgeons operate in the chest.

**Respiratory therapists** are health professionals trained to evaluate and treat people who have breathing problems or other lung disorders.

Radiation oncologists treat cancer using radiation therapy.

**Nurse navigators/patient** navigators serve as guides throughout the continuum of care, from diagnosis through treatment and follow-up. They may also be patient advocates, helping identify barriers to treatment such as the need for transportation or help with copays and deductibles, and accessing resources to resolve such barriers.

**From diagnosis through survivorship, these and other health** care professionals may be involved in your care.

**Palliative care specialists** work to provide physical and emotional relief for cancer symptoms and treatment-related side effects.

#### **Rehabilitation specialists,**

including physical, occupational and speech therapists, help restore movement and build physical strength after cancer treatment.

Nutritionists/dietitians help meet nutritional challenges that arise during and after treatment.

**Oncology pharmacists** have special training in how to design, administer, monitor and adjust chemotherapy for cancer patients.

Pharmacists have special training in preparing and dispensing prescription drugs. They are an excellent resource for learning about the use and storage of medications, and the possible side effects and interactions with your current prescriptions and over-the-counter therapies.

#### **Case managers/social workers**

assist you and your family if you need psychosocial (emotional) care or assistance, or require resources outside of medical care or advance directive planning.

Geriatric specialists are physicians who focus on the health care of elderly people.

stead, set a goal to get back to the activity level you had before diagnosis. Your health care team can help tailor a daily activity plan for you that may include the following.

**Breathing exercises.** Performing these regularly can strengthen chest and abdominal muscles used for breathing and help you breathe easier by reducing shortness of breath (dyspnea).

**Stretching.** Warming up is always smart before activity. It increases blood flow and oxygen to the muscles and, in turn, increases your lung capacity. It also extends your flexibility and range of motion, and reduces stiffness.

Aerobic exercise. This is any activity that gets your heart pumping, such as dancing, swimming and biking. If those activities seem too aggressive, keep in mind that you can also get these cardiovascular benefits from walking. Being active can also help prevent and relieve constipation. **Strength training.** This activity can strengthen muscles weakened by treatment and regain muscle mass. Strength training may help improve your balance and posture and increase your bone strength, which is especially important if cancer has metastasized to your bones. It may be nice for family and friends to want to do things for you but continuing daily tasks such as cooking and light chores can help prevent some muscle loss.

#### **SLEEP HYGIENE**

Your regular sleep pattern may be interrupted. Often, disrupted sleep can be attributed to pain and the physical and mental challenges caused by cancer, treatment or side effects.

Try to get 7 to 9 hours of sleep per night. Start a habit of going to bed at the same time and waking up at the same time. Wind down before bed. That includes shutting down your screens, such as your TV and phone, because blue light activates your brain and can keep you from falling asleep. Turn on relaxing music. Avoid snacking, drinking caffeine and exercising too late into the evening. Talk with your doctor about additional ways to get enough rest if you have trouble maintaining a good sleep schedule.

#### SEXUAL HEALTH

Cancer and its treatment may affect how you feel about yourself and your body and how you relate intimately to your partner. Lack of desire is the most common sexuality issue among both men and women with cancer. Untreated side effects can reduce the interest in sex, libido and feelings of desirability. Talk with your doctor before treatment begins to find out what to expect in terms of sexuality issues and when it is safe to resume sexual activity after treatment.

#### **TOBACCO USE**

If you currently smoke or use tobacco products, it is important to stop and to avoid smoky environments. See *Stopping smoking at any time offers multiple benefits*, page 7, for more information and resources. ■

Get involved with the Lung Cancer Community to help bring more awareness to SCLC ▶ World Lung Cancer Day is always on August 1 ▶ November is Lung Cancer Awareness Month

### FOR THE CAREGIVER

# **Embrace this role that is rewarding and practical**

acing lung cancer is worrisome and stressful for both you as caregiver and your loved one who now needs your assistance. Caregiving can be a rewarding experience but requires patience, empathy and good listening skills. Your loved one may have concerns you haven't thought of and they will need your help with managing them along with what you may consider the "expected" responsibilities now facing you. These may include attending medical appointments, shopping for and preparing meals, and taking care of other household tasks. Remember during this time to take care of yourself. Consider joining a support group of other caregivers to have people to talk with. Ask the navigator or case manager for a referral to such a group. The practical tasks are many and discussed here, but the emotional ones that can be helped through a support group may be even more important.

Get the "OK" to receive medical information. Be sure you are authorized to communicate with the health care team, access medical information, renew prescriptions and more. If you are unsure about the forms you may need to sign, ask a member of the health care team.

Meet the health care team. Introduce yourself to the doctors, nurse navigator, pharmacist, case manager and others. Determine the best ways and times to contact them. Building strong relationships will make it easier to communicate openly and honestly with them.

**Give and track medication.** Medication must be taken at the right dose and at the right time for the treatment to be most effective (see *Maximize drug treatment benefits*, page 8). This may include anti-anxiety medicines, as those may be needed to calm the panic that can accompany the struggle to breathe or while awaiting test results.

**Organize paperwork.** Set up a system to manage bills, insurance papers, research, medical forms, etc. Also work with your loved one to prepare an Advance Directive, Living Will, Will and Power of Attorney.

**Encourage any form of activity.** Exercise can help reduce fatigue and improve emotional well-being, and it does not have to be strenuous. Also, avoid "over-helping." It is important to let your loved one maintain independence.

Learn to operate breathing accessories. Your loved one may use an incentive spirometer, supplemental oxygen or another type of equipment. Learn how these tools should be used and how to operate a backup oxygen tank in case of a power outage.

# Using support resources may improve care and outcomes

**anaging a cancer diagnosis** and undergoing treatment can feel overwhelming. One valuable resource that may benefit you during this journey is case management — an often free program that helps manage the practical issues and problems associated with cancer. Case managers advocate, communicate, educate, organize and empower you to improve your care and outcome.

Case management is sometimes very specific and short term, confined to a period of time or to a certain issue, or it may be a longterm engagement based on your particular needs. Your case manager will complete an assessment to identify your needs and help develop individual goals and plans. From screening and assessment to care coordination and discharge planning, these personal advocates work to ensure you receive quality services.

Your case manager may be a social worker, trained financial counselor, nurse or some combination of these areas of expertise. They can work for hospitals, insurance companies and even primary care physician offices. Depending on your situation, you may have more than one case manager to help you overcome various financial, logistical and other barriers to care.

#### **COORDINATING CARE**

Managing a serious illness involves much coordination, such as filing insurance claims, paying medical bills and arranging for transportation. Although it may be difficult to focus on these items when you are concerned about your diagnosis and treatment, they often become critical. Your case manager can facilitate these responsibilities, reducing your anxiety so that you can focus on your health. In addition, a case manager can help alleviate stress on your family and caregivers so that they can better support your well-being. Case managers often collaborate with health care professionals and non-medical personnel, developing a comprehensive management plan and coordinating care among different health providers. They may provide information about clinical trials or work to resolve issues with symptom management.

Not only can they help you better understand your disease and treatment options, they may secure access to therapies, therapeutic agents and medical supplies. Also, they help ensure treating physicians are fully informed about other treatments you are receiving.

#### **FINANCIAL CONCERNS**

It's an added complication to think about the expenses associated with managing SCLC treatment. A case manager can connect you with financial experts who are skilled in planning for and managing the cost of cancer care. They can also assist with insurance enrollment, communication and benefits. This may include recommendations on how and when to make medical bill payments, clarification about insurance Explanation of Benefits (EOB) forms, and steps to get uncovered treatment approved. You are encouraged not to dismiss potential treatment options until you have looked into the financial resources that are available, even if you are uninsured or underinsured. In addition, your advocate can clarify Medicare Parts A, B, C and D, so you know the rules and pro-



cedures to follow and what is covered. If you are denied and wish to issue an appeal, your case manager can guide you in this process.

#### MANAGING RESOURCES

Because they are familiar with available local resources, case managers can help you find the support you may need in your community or, if those resources are not available nearby, at the state and national level. For example, they may work to arrange supplemental oxygen or other necessary equipment, transportation or meals. In addition, they may suggest ways to help improve safety in the home. If you need to travel for treatment, a case manager can connect you with organizations that may provide transportation resources and lodging for individuals affected by cancer and their families. If you are employed, your treatment may require you to change your work schedule or request accommodations to help you continue to successfully perform your job. By providing information about workplace protections and disability benefits, these advocates empower you through knowledge.

Case management sometimes offers indispensable services surrounding end-of-life needs. If you choose to be at home at this time, a case manager may be available to arrange for door-to-door transportation from the medical facility to your home and ensure a hospice company, necessary equipment and a nurse are on site before you arrive. The goal is to help you feel secure and comfortable, surrounded by people who care.

#### **GETTING STARTED**

Ideally, a case manager will contact you after a hospital admission or diagnosis. However, if that does not happen or if your health care team does not offer case management services, you can ask for a referral or call your insurance company or primary care physician's office. You may also choose to hire the services of a private case manager.

Your needs will change as time goes on. Keep in mind that even if you do not work with a case manager immediately after receiving your diagnosis, you can decide to explore case management services at any time.

# Support and financial resources available for you

#### **CAREGIVERS & SUPPORT**

BeholdBeGold	www.beholdbegold.org
Cactus Cancer Society	
CanCare	www.cancare.org, 713-461-0028
CANCER101	www.cancer101.org, 646-638-2202
Cancer and Careers	www.cancerandcareers.org, 646-929-8032
Cancer <i>Care</i>	www.cancercare.org, 800-813-4673
Cancer Connection	www.cancer-connection.org, 413-586-1642
Cancer Hope Network	www.cancerhopenetwork.org, 877-467-3638
Cancer Really Sucks!	www.cancerreallysucks.org
Cancer Support Community	www.cancersupportcommunity.org, 888-793-9355
Cancer Support Community Helpline	
Cancer Support Services	www.cancersupportservices.org, 877-593-4212
Cancer Survivors Network	csn.cancer.org, 800-227-2345
Caregiver Action Network	www.caregiveraction.org, 855-227-3640
CaringBridge	www.caringbridge.org, 651-789-2300
Center to Advance Palliative Care	
Cleaning for a Reason	www.cleaningforareason.org
Connect Thru Cancer	www.connectthrucancer.org, 610-436-5555
Cooking with Cancer	www.cookingwithcancer.org, 205-978-3570
Family Caregiver Alliance	www.caregiver.org, 800-445-8106
Friend for Life Cancer Support Network	www.friend4life.org, 866-374-3634
The Gathering Place	www.touchedbycancer.org, 216-595-9546
GO2 for Lung Cancer	www.go2.org, 800-298-2436
Guide Posts of Strength, Inc.	
Imerman Angels	www.imermanangels.org, 866-463-7626
Livestrong Foundation	www.livestrong.org, 855-220-7777
Living Hope Cancer Foundation	www.getupandlive.org
Lotsa Helping Hands	www.lotsahelpinghands.com
LUNGevity Caregiver Resource Center	www.lungevity.org/caregiver, 844-360-5864
MyLifeLine	www.mylifeline.org, 888-793-9355
National LGBT Cancer Project	www.lgbtcancer.org, 917-301-1913
National Transitions of Care Coalitions	ntocc.org/consumers
Patient Empowerment Network	www.powerfulpatients.org, 833-213-6657
SHARE Caregiver Circlewww.share	cancersupport.org/caregivers-support, 844-275-7427
Stronghold Ministry	www.mystronghold.org, 877-230-7674
Triage Cancer	www.triagecancer.org, 424-258-4628
Walk With Sally	www.walkwithsally.org, 310-322-3900
Well Spouse Association	
WeSPARK Cancer Support Center	
Wigs & Wishes	www.wigsandwishes.org, 856-582-6600

#### **CHEMOTHERAPY**

Chemo Angels	www.chemoangels.com
ChemoExperts	www.chemoexperts.com
The Chemotherapy Foundation	www.chemotherapyfoundation.org, 212-213-9292

#### **FINANCIAL ASSISTANCE**

Accessia Health	accessiahealth.org, 800-366-7741
American Cancer Society (Hope Lodge)	www.cancer.org/hopelodge, 800-227-2345
Bringing Hope Home	www.bringinghopehome.org
Cancer <i>Care</i>	www.cancercare.org/financial
Cancer Financial Assistance Coalition	www.cancerfac.org
HealthWell Foundation	www.healthwellfoundation.org
Medicare.gov	www.medicare.gov
Medicine Assistance Tool	www.medicineassistancetool.org
National Cancer Assistance Foundation	www.natcaf.org, 866-413-5789
NCOA   BenefitsCheckUp	www.benefitscheckup.org
NeedyMeds	www.needymeds.org
Patient Access Network Foundation	www.panfoundation.org
Patient Advocate Foundation	www.patientadvocate.org
RxAssist	www.rxassist.org
RxHope	www.rxhope.com
Social Security Administration	
Social Security Disability Resource Center	www.ssdrc.com

State Health Insurance Assistance Program	www.shiphelp.org
Stupid Cancer	www.stupidcancer.org, 212-619-1040
Triage Cancer	www.triagecancer.org

#### **IMMUNOTHERAPY**

Cancer Research Institute	www.cancerresearch.org/patients,	800-992-2623
Cancer Support Community	www.cancersupportcommunity.org,	888-793-9355
Society for Immunotherapy of Cancer	www.sitcancer.org,	414-271-2456

#### LUNG CANCER

A Breath of Hope Lung Foundation	abreathofhope.org
American Lung Association	www.lung.org
Caring Ambassadors Lung Cancer Program	www.lungcancercap.org
Free ME from Lung Cancer	www.freemefromlungcancer.org
GO2 for Lung Cancer	
International Association for the Study of Lung Cancer.	www.iaslc.org
Lung Cancer Action Network	www.lungcan.org
Lung Cancer Foundation of America	www.lcfamerica.org
Lung Cancer Registry	www.lungcancerregistry.org
Lung Cancer Research Foundation	www.lungcancerresearchfoundation.org
LUNGevity Foundation	www.lungevity.org

#### **MENTAL HEALTH SERVICES**

American Psychosocial Oncolog	y Society Helpline	
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#### **REIMBURSEMENT & PATIENT ASSISTANCE PROGRAMS**

AbbVie Savings Card
abbvie.com/patients/patient-support/patient-assistance/savings-card, 800-222-6885
Amgen Safety Net Foundation www.amgensafetynetfoundation.com, 888-762-6436
Amgen SupportPlus www.amgensupportplus.com/patient, 866-264-2778
Astellas Pharma Support Solutions astellaspharmasupportsolutions.com/patient, 800-477-6472
AstraZeneca Access 360 myaccess360.com/patient, 844-275-2360
AstraZeneca Patient Savings Programs For Specialty Products
astrazenecaspecialtysavings.com, 844-275-2360
AstraZeneca Prescription Savings Program (AZ&ME)azandmeapp.com, 800-292-6363
Bayer US Patient Assistance Foundationpatientassistance.bayer.us, 866-228-7723
BI Cares Patient Assistance Program
www.boehringer-ingelheim.us/our-responsibility/patient-assistance-program, 800-556-8317
Bristol-Myers Squibb Access Support
bmsaccesssupport.bmscustomerconnect.com/patient, 800-861-0048
Bristol-Myers Squibb Patient Assistance Foundation
Loseia G I to Une Patient Support Programwww.coseia.com/patient/support, 833-418-bbb3
EMD Serono
C1 Therepoulties
G1 Therapeutics
Genericecti Access Solucions
Genericech Uncology Co-pay Assistance ProgramCopayassistancenow.com/patients, 855-692-6729
Genericed Patient Foundation
Hycamtin Patient Assistance Now Uncology
Imfinzi Access 260 myaccess260 com/nationt/imfinzi.dun/alumab 8//-275-2260
Inninizi Access 300
Janssen Garer aut
Jazz Cales
Lilly Carea Equidation Patient Assistance Program
Lilly Cales Foundation Fatient Assistance Flogram
Liny Oncology Support Center
Merck Access Program
Merck Patient Assistance Programmerckneips.com, 800-727-5400
myAbbvie Assist
Prizer Uncology logether www.prizeroncologytogether.com/patient, 8//-/44-56/5
Iakeda Uncology Lo-Pay Assistance Programwww.takedaoncologycopay.com
lakeda Uncology HereZAssist www.hereZassist.com, 844-817-6468, option 2
Iecentriq Access Solutions
Zepzelca JazzCares

► For more resources, go to PatientResource.com

# LUNG CANCER SURVIVORSHIP CARE PLAN

**Use this to document important information** regarding your medical care. Make copies and update it as your condition changes. NOTE: This is not meant to replace your permanent medical records.

#### **YOUR DIAGNOSIS**

LUNG CANCER / SUBTYPE / LOCATION	
STAGE / GRADE	
DIAGNOSIS DATE (YEAR)	
FAMILY HISTORY OF CANCER 🗖 YES 🗖 NO	
GENETIC MARKERS OR BIOMARKERS (if any)	

#### YOUR TREATMENT RECORD

DRUG	THERAPY:	<b>YES</b>	🗖 NO	
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<b>TYPE</b> (chemotherapy, immunotherapy, molecular therapy, targeted therapy)	DRUG	HOW GIVEN	DOSE	HOW OFTEN	START AND/OR END DATES

#### RADIATION THERAPY: YES NO

<b>TYPE</b> (brachytherapy, external-beam radiation therapy, proton therapy, systemic radiation therapy)	BODY AREA TREATED	HOW OFTEN	START AND/OR END DATES

#### SURGERY: 🗆 YES 🛛 NO

TYPE OF PROCEDURE	BODY AREA TREATED	DATE		

#### YOUR TREATMENT TEAM

NAME	TITLE	CONTACT INFORMATION

#### Symptoms or late effects that have continued or occurred after the end of treatment:

Depression

Anemia (low red blood cell count)

Changes in appetite

Cognitive dysfunction ("chemo brain")

Fatigue
 Heart issues
 Lymphedema (fluid buildup and swelling)

Neuropathy (tingling, numbress or pain in hands/feet)

Neutropenia (low white blood cell count)
 Pain

Sexual difficulties
 Skin problems

Stress or anxiety

U Weight gain or loss

Other:

For additional copies of this form, go to PatientResource.com/LungSurvivorPlan



Nothing Small About It is designed to provide information, support and encouragement for people navigating a small cell lung cancer (SCLC) diagnosis.



# To learn more visit NothingSmallAboutIt.com.

Nothing Small About It is an online program from Jazz Pharmaceuticals developed with consultation from CancerCare, GO2 For Lung Cancer, Lung Cancer Foundation of America and LUNGevity Foundation.

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