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SMALL CELL LUNG CANCER

A Treatment Guide for Patients and their Families

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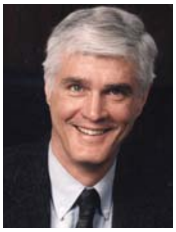

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Empower yourself by partnering with your health care team

Receiving a small cell lung cancer (SCLC) diagnosis may feel life-changing. It can be easy to feel lost in the complicated medical terms, new doctors and a changed vision of your future. But you are not alone. You will be surrounded by a multidisciplinary team of skilled health care professionals. They know it is difficult to process a SCLC diagnosis, and they are prepared to support and guide you so that you feel empowered to make the best treatment decisions for you.

You may have been diagnosed by your primary care physician or a local oncologist, but the first step to empowering yourself is knowing that you are the decision maker for your care. One of your first decisions will be to choose a treatment team. Look for these qualities:

- Accredited hospitals, cancer centers and doctors with expertise in treating SCLC.
- A doctor who is a good listener. Pick a doctor who will listen to your concerns so that you feel comfortable asking hard questions and making difficult decisions. You want to feel you can trust this person and that your interests are being considered.
- A doctor and/or care team who are compassionate and able to explain complex medical language so you can understand it. Knowledge is power, and understanding the choices you are facing is critical to making treatment decisions.

MEET YOUR HEALTH CARE TEAM

Become an active member of your health care team because you will be working closely with them. Think of your relationships with them as a collaboration. Learn all you can from them and the resources in this guide. Being informed will increase your confidence.

You may have several specialists on your team. Get to know them and find out how to contact them. They may include:

- Medical oncologists
- Surgical oncologists
- Radiation oncologists and radiologists
- Thoracic radiologists and surgeons
- Pulmonologists
- Oncology nurses
- Advanced practice providers (oncology nurse practitioners and physician assistants)
- Nurse navigators
- Case managers, social workers and patient advocates
- Rehabilitation specialists including physical, occupational and speech therapists
- Respiratory therapists
- Pharmacists
- Financial counselors
- Geriatric specialists

HOW THE LUNGS WORK

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 lobes, and the smaller left lung has two lobes (see *Anatomy of the Lungs*).

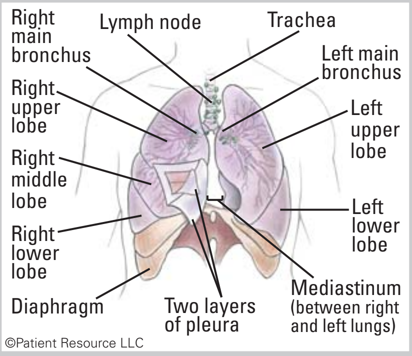
Your lungs expand and contract when you breathe, exchanging oxygen and carbon dioxide. When you inhale, your lungs fill with oxygen-rich air, which is delivered to red blood cells that then deliver the oxygen to the rest of your body. When you exhale, the carbon dioxide that is brought back to the lungs 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.

UNDERSTANDING LUNG CANCER

Lung cancer is more complicated than many people realize. There are different 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 cancer that may affect the lungs but are not considered lung cancer include mesothelioma and sarcoma of the lung. This guide focuses on SCLC.

SCLC is an uncommon form of lung cancer. It is named for its appearance under a microscope. Although it has traditionally been very challenging to treat, 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.

ANATOMY OF THE LUNGS



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Cancer develops when abnormal cells in the lining of the airways accumulate to form a tissue mass (primary tumor). 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. In advanced disease, lung cancer cells break away to form tumors (metastases) in the opposite lung and in distant sites such as the liver, brain or bones. Even though they are in other parts of the body, they are still considered lung cancer and are treated as such.

MOVING FORWARD

Many people feel they've lost control of their lives after they find out they have cancer. But there are several things you can control, and it's important to embrace them right from the beginning. For the most part, you can control what you eat and drink, how often you exercise and rest, and your attitude. If you have trouble eating or maintaining your weight, you can be referred to a dietitian. Other ideas to keep in mind include the following:

- Continue to set goals, plan special events and live your best life possible. Find the things that bring you joy and happiness.
- Be a student of the disease, and learn all you can about it.
- Stay hopeful. New therapies are available to treat SCLC, and research is looking for more options every day.
- Find support. ■

Find strength and support in the cancer community

Having support throughout treatment for small cell lung cancer (SCLC) makes a significant difference in your emotional and physical health. It can prevent feelings of being isolated, disconnected and lonely. Staying positive can impact your overall outlook, how well you accept your diagnosis and your willingness to stay on track with treatment. This makes finding support vitally important after diagnosis. Fortunately, there is a close-knit cancer community all around you that can help.

Welcome to the cancer community — one you never wanted to join, but it is full of support. This group of survivors, families, health care professionals and advocates may have walked in your shoes or are skilled at helping you navigate this new phase of your life. In their own ways, they can provide you with a wealth of information and support. Interact with them as much as you can, and learn from their experiences.

These supporters are passionate about helping you succeed. Read on to learn who is in this new circle of friends and professionals and how they can assist you. Keep in mind that although you didn't ask to be part of this community – your invitation came in the form of a cancer diagnosis – the health care professionals and advocates all made conscious decisions to help people whose lives are affected by cancer. They are here for you.

Support can come in a variety of forms, enabling you to choose what is most comfortable for you. Start by asking your health care team for recommendations.

CASE MANAGERS

Many hospitals and medical centers have case managers, also called patient advocates, to help you with questions and issues related to your cancer care (see *Case Management*, page 4). Managing a serious illness involves much coordination, such as filing insurance claims, paying medical bills and arranging for transportation. It is difficult to address these items when you are more concerned with understanding your diagnosis and making treatment decisions. 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.

Case managers can also help you find the support you may need in your community. For example, they may work to arrange supplemental oxygen or other necessary equipment, transportation or meals. If those resources are not available nearby, they will locate them at the state and national levels.

CAREGIVERS

A caregiver assists you with daily living tasks that you may not be able to perform for yourself, such as going to medical appointments, bathing, getting dressed and eating. You may also need help with other things, such as shopping, cooking meals and running errands.

Consider building a team of caregivers instead of relying on only one person. Start with your family and friends, but be prepared to go outside this inner circle into your community to find the assistance you need. Many cities have local volunteers who help others near where they live or work. You might also need to hire your caregivers. Hospitals and homecare agencies can provide skilled nursing care or arrange for someone to stay with you when family and friends cannot.

SUPPORT GROUPS

Whether they are online or in person, support groups offer you the chance to talk with others who are facing the same challenges and share knowledge about your cancer. Many advocacy groups offer peer-to-peer support through programs that match the patient with a person who has had a similar diagnosis. Being able to talk with someone who knows what you're going through is extremely helpful.

Ask your nurse navigator, case manager or patient advocate for a referral, and use the resources on page 16 in this guide.

YOUR INNER CIRCLE

Draw strength from the relationships you already have. Now is the time to reach out to your family, spiritual community, neighbors or any other group that gives you comfort.

MENTAL HEALTH PROFESSIONALS

Cancer can affect you emotionally as well as physically. Taking care of your emotional well-being will help you better cope with cancer-related issues, including managing physical side effects. Supportive care services can connect you with resources to help you work through your feelings. You can begin by asking your medical team for referrals or recommendations. Consider contacting advocacy and non-profit support groups.

GO2 FOR LUNG CANCER

One-on-one support, educational materials, guidance on treatment and clinical trial information, referrals and more are available from GO2 for Lung Cancer. Following are some of their valuable services:

- Lung Cancer HelpLine at 800-298-2436 or support@go2.org
- Small Cell Lung Cancer program provides vital support, education, community connection and updates on the latest treatment advances
- Phone Buddy, a peer-to-peer support program
- GO2 for Lung Cancer LungMatch program, an on-demand treatment navigation and clinical trial matching resource
- No-cost educational materials
- Glossary or lung cancer-related terms
- Questions to ask your health care team
- A video library
- Online support resources

Your new community will always be there for you. With so many resources, you should never have to go through this alone. ■

Understand how treatment plans are made

People who receive a cancer diagnosis are often asked about their stage. Though it is sometimes thought of as an indicator of how advanced the cancer is, it is much more. The staging process allows your medical team to learn more about your specific diagnosis and, in turn, provide you with a prognosis (outlook) and a treatment plan.

Your doctor collaborates with other medical professionals to learn about your cancer. They review the results of your physical examination, lab and imaging tests, and biopsies. They evaluate 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. The final step is for the doctor to stage your cancer using one or a combination of two staging systems.

The **Veterans Administration Lung Study Group (VALSG)** created the first staging system for SCLC. It separates SCLC into 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.
- ***Extensive-stage SCLC*** has spread to other parts of the body, such as the area between the lungs or the opposite lung, or outside of the chest, such as to the brain or bone.

In the **American Joint Committee on Cancer's (AJCC)** and **International Association for the Study of Lung Cancer's** TNM classification and staging system, 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, that can be detected only by using a microscope.

Your T, N and M status are combined and assigned a number:

- Stages I and II are generally confined to the local area where the cancer is found, with or without nearby 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 (area between the lungs).
- Stage IV is locally or regionally advanced disease that has spread to distant sites.

Some doctors combine the staging systems to enhance diagnosis and treatment planning.

- Limited-stage is considered to be Stages I to III of the AJCC TNM staging system, but Stage I SCLC is not common.
- Extensive-stage is considered to be Stage IV in the AJCC TNM staging system.

Sample AJCC staging illustrations in Figure 1 (page 5) show tumors on one side of the lungs. However, tumors may be present in any area of the lungs. These examples are not meant to represent the amount or placement of your tumors. View staging tables online at PatientResource.com/SCLC_staging. ■

WORDS TO KNOW

- **Contralateral:** on the opposite side as the primary tumor
- **Hilar lymph nodes**: in the lungs, in the region where the bronchi, arteries, veins and nerves enter and exit the lungs
- **Ipsilateral:** on the same side as the primary tumor
- **Mediastinal lymph nodes:** between the lungs, in the part of the chest that lies between the sternum and the spinal column

Case managers offer assistance

From finding a specialist and treatment center to understanding health insurance coverage and payment options, knowing where to begin after receiving a small cell lung cancer (SCLC) diagnosis can feel overwhelming. Adding a case manager to your care team as soon as possible can help you address these and other practical issues while you and your family focus on what matters most — your health.

Case management is typically a free resource designed to help manage the real-world issues related to a serious illness. These issues are considered barriers to care because they prevent you from receiving the best care and services available.

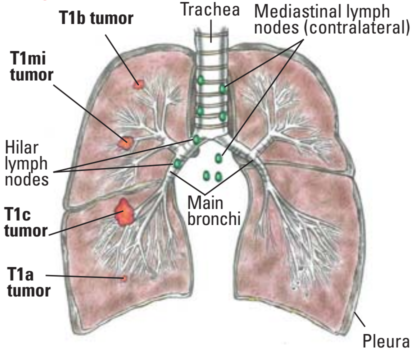
You can benefit from a case manager in many ways. For example, you may ask for their help accessing clinical trials or speeding up referrals to palliative care services. Financial considerations are some of the most common concerns with cancer care. Their help may relieve the stress that often accompanies financial matters and may even reduce the cost of your care. Case managers are experienced in navigating the health insurance world and can take that responsibility off your shoulders.

Ask your health care team to connect you with a case manager. If one is not available, ask for a referral. Reach out to your health insurance company, medical or mental health office, doctor's office or advocacy group, or use the resources in the back of this guide. Though they may not be called social workers, registered nurses, nurse navigators or other health care professionals, case managers use their extensive experience to advocate for you and your family. Choosing to have a case manager can feel empowering. ■

FIGURE 1

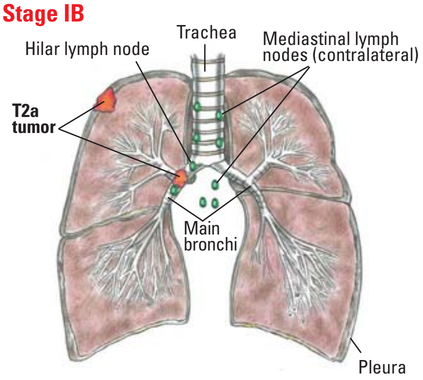
AJCC NINTH EDITION ILLUSTRATED STAGES OF LUNG CANCER*

Stages IA1, IA2, IA3



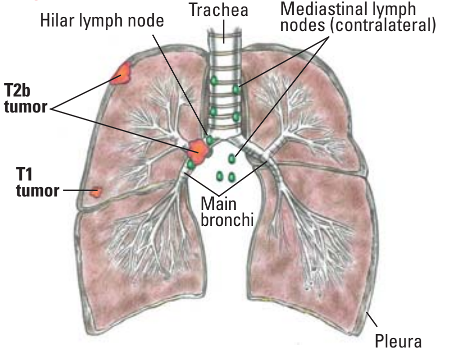
The tumor may range in size from less than 1 cm to not more than 3 cm. Lymph nodes are negative for cancer.

Stage IB



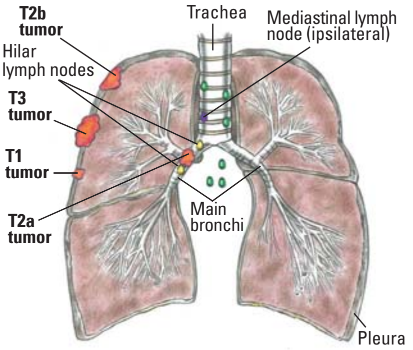
The tumor may be more than 3 cm but not more than 4 cm or may have invaded the outer layer of the lung, the other lung or part of the bronchus; or has collapsed part of the lung or caused inflammation of lung tissues. Lymph nodes are negative for cancer.

Stage IIA



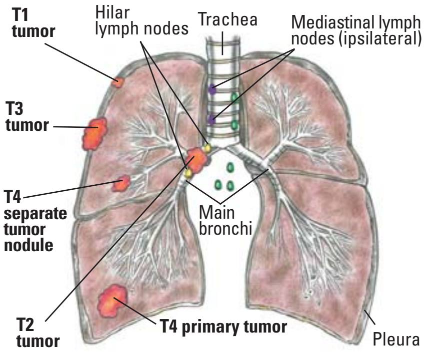
The tumor may be less than 3 cm but not more than 5 cm or may have invaded the outer layer of the lung, the other lung or part of the bronchus; or has collapsed part of the lung or caused inflammation of lung tissues. Lymph nodes may be positive for cancer.

Stage IIB



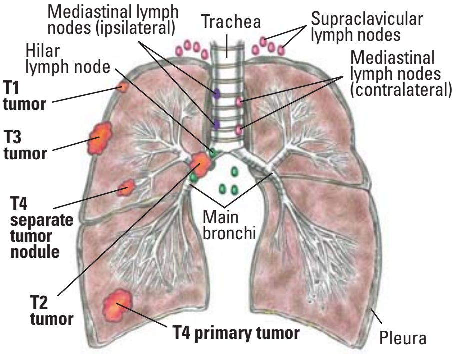
The tumor may be less than 3 cm but not more than 7 cm or may have invaded the outer or inner layer of the lung, the chest wall, lining around the heart, nearby nerves or veins, the other lung, or part of the bronchus; or has collapsed part of the lung or caused inflammation of lung tissues. Lymph nodes may be positive for cancer.

Stage IIIA



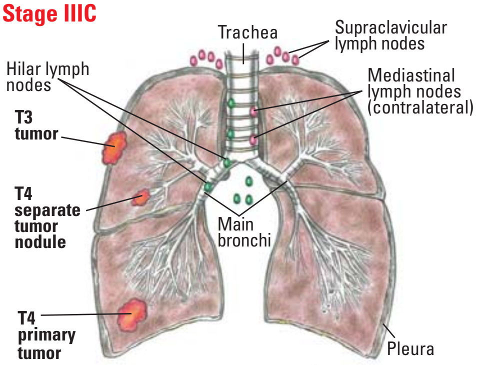
The tumor may be any size or may have invaded the outer or inner layer of the lung, the chest wall, lining around the heart, nearby nerves or veins, the other lung, part of the bronchus or nearby structures in the mediastinum; or has collapsed part of the lung, and caused inflammation of lung tissues or has a separate tumor on the same side as the primary tumor. One or more lymph nodes on the same side as the tumor may be positive for cancer.

Stage IIIB



The tumor may be any size or may have invaded the outer or inner layer of the lung, the chest wall, lining around the heart, nearby nerves or veins, the other lung, part of the bronchus or nearby structures in the mediastinum or spinal area; or has collapsed part of the lung or caused inflammation of lung tissue, or has a separate tumor on the same side as the primary tumor. One or more lymph nodes on the same side or opposite side of the tumor may be positive for cancer.

Stage IIIC



The tumor is larger than 5 cm or may have spread to the outer layer of the lung, chest wall, lining around the heart, nearby nerves or veins, nearby structures in the mediastinum or a separate tumor may have developed on the same side as the primary tumor. Lymph nodes on the same side or opposite side of the tumor are positive for cancer.

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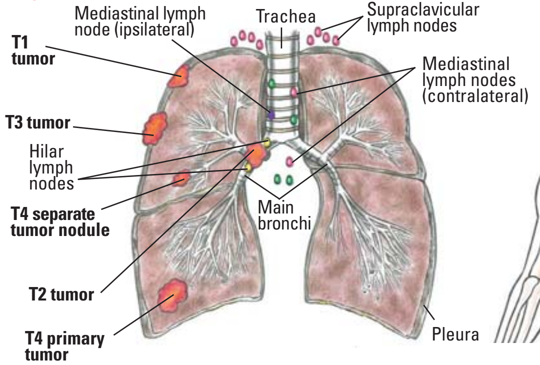
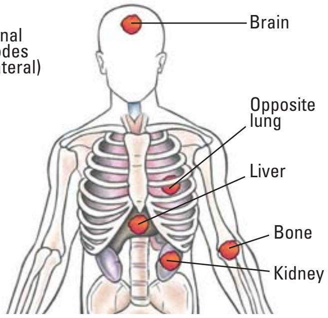
Stages IVA, IVB



The tumor may be any size, lymph nodes may be positive for cancer, or a separate tumor may have developed in the opposite lobe, and has spread to distant sites in the body, including organs and bones.

Metastasis



Lymph Nodes Key

- 🟩 – Unaffected nodes
- 🟨 – Positive hilar nodes
- 🟪 – Positive ipsilateral mediastinal nodes
- 🟥 – Positive contralateral mediastinal nodes and supraclavicular nodes

**The illustrations above are examples of what possible tumors may look like for the stage of disease shown.*

Be prepared to participate in treatment decision making

Having an open and honest conversation with your doctor will be important as you begin making decisions with your health care team about the best treatment for you and your desired quality of life. Your treatment plan will be based on whether you are newly diagnosed or are experiencing a recurrence, the symptoms you have, how aggressive the cancer is, the stage of the cancer, your goals for treatment as well as your ability to travel for treatment, if necessary, and your overall health.

This is also a good time to discuss the risks and benefits of specific treatments and procedures. Share any concerns you have with your care team and ask about potential side effects, both physical and emotional that you may experience (see *Supportive Care*, page 10).

While you are making decisions about which path forward is the best for you, this may be a good time to seek a second opinion or advice from a small cell lung cancer (SCLC) specialist. You are encouraged to get another opinion from a doctor who is experienced in treating SCLC. Getting a second opinion is also a way to discover whether your pathology, diagnosis and staging are accurate.

TYPES OF TREATMENT

Your doctor will develop your treatment plan starting with stage (see *Staging*, page 4). Limited-stage SCLC, which includes Stages I to III, is typically treated with chemotherapy, radiation therapy and/or immunotherapy to cure the cancer. Extensive-stage SCLC, which is Stage IV, is treated to prevent progression and minimize symptoms.

As you discuss your options with your doctor, keep in mind that it is common for the first therapy given to stop working at some point. Before you begin treatment, talk to your doctor about maintenance therapy, which will be an important part of your overall treatment plan. In some cases, you may receive second-line therapy as well. The goal of maintenance therapy is to delay a recurrence. It is very common to have to adjust a care plan. Knowing this in advance, and being patient when changes are necessary, is a good strategy to have.

Drug therapy is a type of treatment given intravenously (IV) into a vein or port in your body, as an injection (shot), under the skin (subcutaneously) or orally as a pill or liquid. 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. Following are the types of drug therapy that may be used to treat SCLC.

Chemotherapy, which kills rapidly multiplying cells, is the primary treatment for all stages of SCLC because of how quickly the disease can spread. It may be given alone or in combination with surgery, radiation therapy or immunotherapy. For limited-stage SCLC, chemotherapy may be combined with radiation therapy to the chest. In extensive-stage SCLC, chemotherapy may be combined with immunotherapy. Chemotherapy is also used for second-line and maintenance treatment. Most often chemotherapy is given at three-week intervals for four to six cycles. This therapy is used to destroy cancer cells, prevent progression or slow the cancer's growth.

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 maintenance.

UNDERSTANDING THE TREATMENT ORDER FOR PEOPLE WITH SCLC

Knowing the order in which treatments are given is important. You will likely hear the following terms.

- **Front-line therapy,** sometimes called initial or first-line therapy, is the first treatment given for a disease. It is often part of a standard set of treatments, such as chemotherapy and radiation therapy. If it does not cure the disease or causes severe side effects, other treatment may be added or used.
- **Maintenance therapy** can be given after first-line therapy. It is given to help keep cancer from coming back after it has disappeared following therapy.
- **Second-line therapy** is treatment given when initial treatment or initial treatment plus maintenance therapy does not work or stops working.

It is important for you to realize there are treatment options past the first line. Some people mistakenly believe that if the first treatment fails or stops working, they have no other options. However, recent advances in treatment now offer several second-line options.

It is a good idea to discuss your full treatment plan with your doctor before treatment even begins. If your doctor does not bring it up, ask them what options may be available if the cancer were to return after the first treatment.

This treatment is typically given intravenously, but one drug has been approved to be given beneath the skin (subcutaneously).

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 (Stage II or Stage III) are usually treated with both chemotherapy and radiation therapy given concurrently for two of four chemotherapy cycles.

Immunotherapy stimulates your immune system to find and attack cancer. Most often it is used in combination with chemotherapy (chemoimmunotherapy) as first-line therapy for extensive-stage SCLC. It may also be combined with chemoradiation. It may also be used for limited-stage SCLC after chemotherapy.

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. Immune checkpoint inhibitors prevent the immune system from slowing down, allowing it to keep up its fight against the cancer.

Another type of immunotherapy uses a bispecific T-cell engager to attack the cancer from two angles. A laboratory-made molecule is connected to a T-cell, which is part of the immune system, and to the cancer cell. When the T-cell and cancer cell are linked, it triggers the T-cell to attack and destroy the cancer cell. It may be used as a second-line treatment for extensive-stage SCLC after chemotherapy and the cancer has returned.

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 cannot be treated with surgery. It is often combined with chemotherapy. It is also approved for extensive-stage SCLC.

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

(continued on page 8)

Research shows more reasons to quit smoking

It is common to think that quitting smoking is pointless because you've already received a small cell lung cancer (SCLC) diagnosis. That is simply not true. If you currently smoke, consider quitting. It is beneficial at any time regardless of how long you smoked or whether you were a mild to moderate or heavy smoker. Many SCLC patients who have smoked may 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 be included on your team to assess your overall lung function.

Research has shown that stopping will help make your treatment be more effective along with other multiple benefits. Quitting at or around the time of a lung cancer diagnosis is associated with improved overall survival, is also associated with delaying the cancer's return or worsening of the disease, and improves overall quality of life and symptoms. It may also improve survival regardless of whether you receive chemotherapy or radiation therapy.

It is well known that nicotine is addictive and breaking the habit is hard. Many resources are available to help. Some options include smoking cessation programs, intensive counseling, local support groups, call lines, text-based help and online assistance. Research has shown the most successful method of quitting combines intensive counseling with cessation medications. Ask your health care team about the options your treatment facility and community offer to help you or your loved ones quit tobacco products.

SOME BENEFITS ARE IMMEDIATE AND OTHERS ARE LONG TERM

Immediate benefits
Breathe easier
Chemotherapy and radiation therapy may be more effective
Recover faster from surgery and heal wounds more easily
Reduced lung inflammation, which may help reduce the risk of cancer progression
Less stress on the immune system so it can fight disease and infections better

Long-term benefits
Improved sense of smell and taste
Improved chances of survival after cancer
Lowered blood pressure and decreased heart rate, better blood circulation, increased lung function
Decreased risk of secondary cancers and other conditions linked to tobacco use
Fewer illnesses, such as colds and flu, lower rates of bronchitis and pneumonia

The following resources are available to help you or your 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/tools-tips/text-programs, text QUIT to 47848

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 of radiation damage to healthy tissue near a tumor.

Surgery is not commonly used for treating SCLC and is typically reserved for very early-stage disease (Stage I), which is uncommon. In this case, chemotherapy is administered after the surgery. A board-certified thoracic surgeon, who has special training in operating on organs inside the chest and is experienced in lung cancer surgery, 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 are research studies that may offer the opportunity to try an innovative treatment being tested, such as drug therapies, 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). Patients with SCLC that returns after first-line therapy may be considered for a clinical trial.

Treatment advances for SCLC have been slow. Joining a clinical trial may be a valuable option. All of the treatments available to treat cancer today are a result of someone participating in a clinical trial and contributing to the future of cancer care.

Several new drugs and drug combinations are being tested in clinical trials. The newest chapter in SCLC treatment includes antibody drug conjugates (ADCs) and PARP inhibitors as well as other novel therapies. An ADC is a type of monoclonal antibody (mAb) that binds to specific proteins or receptors found on certain types of cells, including cancer cells. The linked chemotherapy drug enters these cells and kills them without harming other cells. PARP inhibitors are a type of targeted therapy that blocks an enzyme in cells called PARP, which helps repair DNA when it becomes damaged. Blocking PARP may help keep cancer cells from repairing their damaged DNA, causing them to die.

UNDERSTANDING RECURRENCE

Recurrence happens when some tiny cancer cells remain in your body after treatment. Over time, these cells divide and grow into cancer again. It may come back in your lungs or a different part of your body, such as the brain, opposite lung, bone or liver.

SCLC is an aggressive form of cancer that usually responds well initially to treatment with chemoradiation therapy. But after a period of time, the cancer develops resistance to chemotherapy and returns. This is called a recurrence, and it is common in SCLC patients. Should this happen, your doctor may run more diagnostic tests to determine the next treatment option.

Being aware that the cancer may return after your initial therapy is important. Treatment options after first-line therapy failure will depend on how soon the recurrence happens after treatment ended as well as whether the cancer is limited-stage or extensive-stage.

Catching a recurrence as soon as possible will help your doctor determine the next best treatment for you. A recurrence may be caught through routine follow-up screening with scans or bloodwork. Or, you may experience symptoms that you should share with your health care team right away, including:

- A cough that doesn't go away
- Chest pain
- Shortness of breath
- Lung infections, such as bronchitis and pneumonia
- Blood when you cough
- Pain
- Fatigue
- Skin issues
- Fever
- Unexplained weight loss

SOME 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)
- atezolizumab and hyaluronidase-tqjs (Tecentriq Hybreza)
- carboplatin (Paraplatin)
- cisplatin (Platinol)
- doxorubicin (Adriamycin)
- durvalumab (Imfinzi)
- etoposide (Etopophos)
- irinotecan (Camptosar)
- lurbinectedin (Zepzelca)
- tarlatamab-dlle (Imdelltra)
- topotecan (Hycamtin)

As of 6/30/25

Get immediate help for sudden or serious symptoms, such as high fever, severe pain or difficulty breathing.

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

JOIN THE LUNG CANCER REGISTRY

The Lung Cancer Registry is a database of patient information that is donated by patients or by loved ones of people 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. ■

Explore the potential benefits of a clinical trial

Because small cell lung cancer (SCLC) is aggressive and can progress rapidly, the inclusion of a clinical trial in your care plan may make a significant difference in your life. Clinical trials may be designed for early detection or to improve therapy. At any time during diagnosis and treatment, these research studies may offer more options for people with SCLC. Before making treatment decisions, it is important to learn what clinical trials are and how they may help.

Clinical trials are research studies conducted by a specialized team that is focused on finding cancer early or finding new and improved ways to treat cancer. There are different types of clinical trials with different goals that explore treatment and non-treatment strategies, such as disease prevention, patient screening, diagnostic tools and procedures, and others look at genetic risk factors and lifestyle/behavioral changes. Not all trials are treatment trials.

If you choose to learn more, keep in mind that your participation would not only contribute to the future of cancer care, it may offer access to treatments that would not be available otherwise. Also, it is good to know that doctors understand that people can experience the same disease differently because each patient is biologically and genetically unique. It is vital that new medications are tested in clinical trials in which participants reflect real-world populations to get a clear understanding of the drugs' safety and efficacy. Volunteers of all ages, genders, locations, races and ethnicities, weights, sexual orientations and socioeconomic groups are needed.

GET THE FACTS

Although most of the advances made in treating all types of cancer today were once therapies or procedures that were developed, tested and evaluated through the clinical trials process to gain approval from the U.S. Food and Drug Administration (FDA), many people do not know much about them. And, what they do know is not always accurate. Read on to learn the truth behind some of the most common myths about clinical trials.

MYTH: Clinical trials are a last-ditch effort.

FACT: Although this is a very common belief, it is not true. Depending on your diagnosis, a clinical trial may be an option right after diagnosis or at another time in the future. It may be your best option when your diagnosis has few or no approved therapies or if your cancer has become resistant to your current therapy.

MYTH: It is too risky to try a clinical trial instead of a proven treatment.

FACT: Like all approved cancer treatments, the therapies used in clinical trials come with risks. But it is important to know that clinical trials are designed with strict safety measures in place that were established and are enforced by the U.S. Food and Drug Administration. Though many trials are focused on developing new treatments, the majority of cancer clinical trials include therapies that are already approved, sometimes alone and sometimes in combination with new therapies.

MYTH: I can't participate if I don't live near a city with a large cancer center.

FACT: Clinical trials take place in nationally known cancer centers in major cities, in university medical centers, regional hospitals and even oncologists' offices. Advances in technology have enabled some trials to incorporate telehealth to reduce travel for appointments and certain checkups.

MYTH: Quitting a clinical trial is not possible.

FACT: Once you sign the Informed Consent form and begin the trial, you are not locked in. You may leave the trial at any time and for any reason.

TAKING THE NEXT STEP

Let your doctor know that you are open to clinical trials. While your health care team is looking for some that may fit into your treatment plan, you can search online, too. To get started, use the resources on this page and do the following:

1. Gather your cancer diagnosis and treatment information.
2. Search by your small cell lung cancer diagnosis.
3. Enter your age, preferred location, distance you will travel, etc., to narrow your search.
4. Review the list of trials. If you find one, contact the clinical trial team listed for more information.
5. Discuss what you've learned with your health care team and your loved ones.

When you and your doctor determine a specific trial is an option, move forward with testing to see whether you are eligible. Every clinical trial has certain criteria you must meet to participate. If you meet the criteria, thoroughly review the provided Informed Consent document. It explains the purpose of the trial and lists all the specifics, from therapies being used and expected side effects to the number of appointments and financial responsibilities.

If you have questions, reach out to the clinical trial team who will be responsible for monitoring your care while you are part of the trial. It is crucial that you are comfortable moving forward. ■

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
- **GO2 for Lung Cancer LungMATCH:** www.go2.org/resources-and-support/general-support/lungmatch/, 800-298-2436
- **Lazarex Cancer Foundation:** www.lazarex.org, 877-866-9523
- **LUNGevity Clinical Trial Finder:** www.lungevity.org
- **National Cancer Institute:** www.cancer.gov/clinicaltrials
- **NCI Cancer Information Service:** 800-422-6237
- **WCG CenterWatch:** www.centerwatch.com, 866-219-3440

Feeling better is a team effort

Nearly every type of cancer treatment has side effects, and these are often concerning for people being treated for small cell lung cancer (SCLC). Fortunately, you do not have to face them alone. As a result of ongoing scientific advances, your health care team is able to offer new and better ways to manage these physical and emotional effects through a set of services known as supportive care.

Some side effects are a minor annoyance, and others could be life-threatening without immediate attention (see Table 1). The symptoms and how you react to them are based on your body and the type of treatment you receive. The key is to have a plan so you know what to watch for, what to do if they happen, what is considered urgent, and when and how to inform your health care team.

Having the right mindset is important. Do not be afraid to report your symptoms. You may worry that telling your doctor about side effects means you have failed the treatment and will be taken off the drug you are on or that the dosage will be reduced. Sometimes a change in treatment or an adjustment in dosage is exactly what you need, and it can offer you a lot of relief without sacrificing the effectiveness of the treatment. Only your doctor can make that decision.

You may hesitate to "bother" your medical team with something that you think is not that important or serious enough to contact them. You are not bothering them, and side effect management is important. The goal is for you to have the best overall care available, and that includes relieving symptoms so you have a better quality of life. The sooner you contact your medical team, the sooner they can help.

Be prepared by doing the following:

- Talk with the team before treatment begins about the side effects to expect.
- Identify whom you should contact and how (phone, text, email or portal) if they occur.
- Provide as much information as you can to your health care team. Download and print a side effect tracker to help you keep track of when symptoms occur (PatientResource.com/tracker).

POTENTIALLY SEVERE SIDE EFFECTS

Ask your doctor whether the therapies in your treatment plan may have potentially severe side effects. If so, learn when to seek emergency care. Report symptoms immediately. Some potentially severe side effects are outlined below.

Cytokine release syndrome (CRS) is a severe immune reaction in which the body releases too many cytokines into the blood too quickly. This is called a cytokine storm, and it may also occur after treatment with some types of immunotherapy. Signs and symptoms include a fever of 100.4°F or higher, inflammation (redness and swelling), shortness of breath and severe fatigue and nausea. Sometimes, a cytokine storm may be severe or life-threatening and lead to multiple organ failure. Without swift medical treatment, CRS can be fatal.

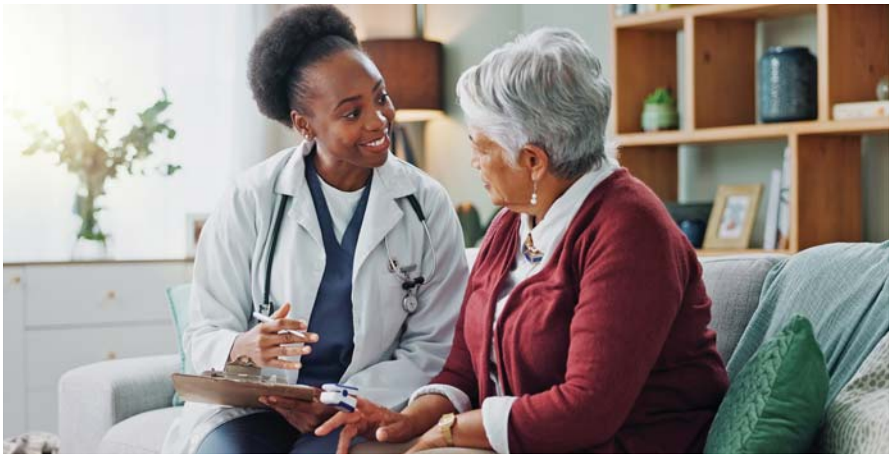
Immune Effector Cell-associated Neurotoxicity Syndrome (ICANS) is a clinical and neuropsychiatric syndrome that can occur in the days to weeks following treatment with certain types of immunotherapy. ICANS affects a person's nervous system. Symptoms include confusion; behavioral changes; inability to speak or understand speech; attention, thinking and memory problems; muscle weakness, muscle jerks and twitching; headaches; and seizures.

TABLE 1

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 less frequent bowel movements compared to your 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 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	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 cause food to taste different (for example, giving it a metallic taste)

**Side effects listed in alphabetical order. Talk with your doctor about what to expect.*



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 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.

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. They may even occur on the first day of treatment. Reactions are generally mild, but can be serious or even fatal without medical intervention. ■

TABLE 2

IMMUNE-RELATED ADVERSE EVENTS (IRAEs)

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, fever, shortness of breath, unexplained cough
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.*

MANAGING EMOTIONS

FIND YOUR SUPPORT

Coming to terms with a small cell lung cancer (SCLC) diagnosis is tough. You can expect to feel everything from anger and sadness to fear and anxiety. Finding trusted sources of support is crucial. At the same time, this diagnosis is emotionally difficult for your loved ones. Fortunately, help for everyone is available.

Start by exploring the lung cancer community (see *Finding Community*, page 3). It is a tight-knit group that is dedicated to helping anyone whose life is touched by lung cancer. Advocacy and support groups, such as GO2 for Lung Cancer, offer a variety of programs both online and in person. One-on-one counseling and buddy programs are also offered. Talking with people who have been in similar situations can help you work through your feelings.

Look for sessions for caregivers and loved ones that they can attend independently. These can be especially helpful because they may be afraid to share their feelings in front of their loved one facing cancer. An opportunity to open up with others in similar situations can be a comforting outlet and help them learn ways to better manage their fears.

Following are other suggestions for managing your emotions:

- Express your feelings. Don't keep them bottled up.
- Find ways to relax, such as meditation, yoga, walking, guided imagery, reading, journaling or spending time in nature.
- Be physically active if you can. Even a 10-minute walk is a mood lifter.
- Remind yourself that not every day has to be upbeat. It is okay to have bad days.
- Do something every day that brings you a little bit of joy.

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***

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: ☐ YES ☐ NO

TYPE *(chemotherapy, immunotherapy, molecular therapy, targeted therapy)*	DRUG	HOW GIVEN	DOSE	HOW OFTEN	START AND/OR END DATES

RADIATION THERAPY: ☐ YES ☐ NO

TYPE *(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:

- ☐ Anemia *(low red blood cell count)*
- ☐ Changes in appetite
- ☐ Cognitive dysfunction *("chemo brain")*
- ☐ Depression
- ☐ Fatigue
- ☐ Heart issues
- ☐ Lymphedema *(fluid buildup and swelling)*
- ☐ Neuropathy *(tingling, numbness or pain in hands/feet)*
- ☐ Neutropenia *(low white blood cell count)*
- ☐ Pain
- ☐ Sexual difficulties
- ☐ Skin problems
- ☐ Stress or anxiety
- ☐ Weight gain or loss

☐ Other: ______________________

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

SURVIVOR GIVES BACK BY SHARING SUPPORT AND POSITIVITY

Until Mike Knecht was diagnosed with Stage IIIA small cell lung cancer (SCLC) at 65, he had never seen the inside of an emergency room. Despite the shock, he faced treatment with determination and a positive attitude. A good family friend who has ties to the cancer community led him to GO2 for Lung Cancer, which offered empowering information and programs. He now volunteers as a phone buddy at GO2 for Lung Cancer to give back and support others with SCLC.

Mike Knecht and his wife Lois

While I was on vacation in California with my wife and daughter, I hiked to the top of a hill. I struggled to breathe and was very fatigued, which was not normal for me. After returning home, my wife became alarmed when I could barely get out of bed and into a chair. She knew something was terribly wrong and insisted we go to the emergency room immediately.

Initial bloodwork revealed I was low on sodium. I also had an X-ray to rule out pneumonia, and it showed something on my lung. The doctor was very concerned and stressed to us that I needed to see a specialist right away. He called ahead to a larger hospital across the street and told them to expect me. Even though he didn't say it, I thought I had cancer.

When I arrived, several medical professionals were waiting for me. They were very concerned about my low sodium level and wanted it to be higher before they could do a biopsy. I spent a week in intensive care while they worked to get my sodium levels up. I decided to face the future with a positive attitude. I willed myself to get better.

Once my sodium was at an acceptable level, I had the biopsy, which determined I had Stage IIIA small cell lung cancer (SCLC). The doctors considered it treatable, and they called an oncologist who had a bed waiting for me at a cancer hospital that was 45 minutes away. I was admitted immediately so I could start treatment right away.

The first chemotherapy treatment started that night. However, it was short lived because I had an allergic reaction. A nurse who wasn't even part of my ward happened to be walking by my room and discovered that I wasn't breathing. Days after I recovered, I asked this nurse, who had 22 years of experience, if she could turn around so I could see her wings. She saved my life that day, and I am truly grateful.

Later that night, after being prepped for a different chemotherapy drug, I broke out in hives. They stopped that medication and gave me medicine to relieve the hives. The pharmacist suspected both reactions were due to the solvent given before the chemotherapy. He made a special solvent for me, and I was then able to tolerate the chemotherapy. We then added radiation therapy, which I opted to do twice a day for 15 days. Fortunately, I did not have any side effects from either.

After finishing both chemotherapy and radiation therapy, my doctor talked with me about having additional radiation therapy to my brain to prevent metastasis. After consulting a friend and one of my daughters, who has medical experience, I chose to have it.

For the next five months, I felt good. But after travelling at Thanksgiving, I had the same symptom of not being able to drag myself out of bed. A trip to the hospital showed my sodium level was dropping. A PET and CT revealed my cancer had come back.

Despite the cancer returning, I was optimistic because my doctor said I now qualified for immunotherapy. The treatment worked on the cancer but caused body aches and a loss of feeling and strength in my hands. My doctor prescribed physical therapy, which helped me regain strength in my hands.

Although I kept a positive attitude, even after the recurrence, I didn't know how hard my wife took the news. It brought a new level of stress and anxiety that was difficult for her to manage. She reached out to a therapist, and it has helped her. It made me realize that cancer doesn't just affect the person who has it.

Support was vital throughout treatment. Family, church associates and friends have sent cards and called to check on me. I found GO2 for Lung Cancer through a family friend who has ties in the cancer community. Their website has a wealth of information, and they paired me with a phone buddy for more support. After I finished treatment, I became a phone buddy for others, too. It is rewarding to help others, especially people with SCLC.

After my most recent scan, my doctor said my cancer was considered stable. I know it's possible for my SCLC to progress, but my doctor assures me that if it does, we have more treatment options to try. Because of that, I've never been without hope. ■

Empower Yourself in 3 Steps

1. Reach out to GO2 for Lung Cancer for valuable information and support.
2. Do what you have to do to keep a good attitude.
3. When first diagnosed, adopt a positive mentality or as I think of it, a rallying cry. I adopted a slogan that guides me: "Enjoy every sandwich!"

Strive for balance through life’s changes

Focusing on survivorship requires a certain mindset. Although your day-to-day schedule will be filled with medical appointments, treatments and other illness-related commitments, it is important to realize that small cell lung cancer (SCLC) does not have to consume your whole life. You can still live a happy and rich life. It just takes a plan.

Cancer survivorship means different things to different people. Some people consider themselves survivors right after diagnosis; to others, it is after they finish primary treatment or begin maintenance therapy. Regardless of how you define it, you are encouraged to talk about it with your doctor. Together, you will develop a plan that will serve as a roadmap for the future.

A survivorship plan starts with your medical information. It is a comprehensive record of your medical history, diagnosis and treatment plan, including ongoing medications. It is also a schedule of follow-up appointments, which are essential for monitoring treatment effectiveness and staying alert to the possible spread of cancer or onset of other health issues.

The rest of the plan identifies other priorities that will help you lead a healthy, well-balanced lifestyle.

DAILY ACTIVITIES

The things you are used to doing every day, such as cooking, folding laundry or walking to the mailbox, may suddenly be more difficult. Continue to do them but take breaks when you feel your energy waning. Talk with an occupational therapist on your health care team about smarter ways to accomplish your daily activities. Give yourself some grace. Remember that you do not have to do everything exactly how you did it before, or all on your own. Accept help from friends who offer, and ask for help when you need it.

EXERCISE

Although you may not have the lung capacity or the energy you used to, being active is still extremely important. It gives you more energy, reduces fatigue and helps relieve constipation. And, it is a general mood-lifter. Knowing that the type of exercise you can do now may be different than what you used to do, set goals you can work up to:

1. Avoid inactivity. Get moving, whether it is walking to the mailbox or around the house.
2. Perform breathing exercises regularly (see Figure 1). They can strengthen chest and abdominal muscles used for breathing and reduce shortness of breath (dyspnea).
3. Warm up before exercising. Stretching 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.
4. Regain muscle mass. Strength training can fortify muscles weakened by treatment and improve your balance and posture. It can also increase your bone strength, which is especially important if cancer has metastasized to your bones.
5. Get your heart pumping. Aerobic exercise, such as dancing, swimming and biking, offers great cardiovascular benefits.

FIGURE 1

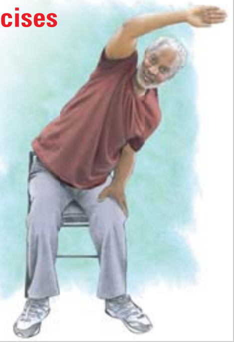
EXERCISES FOR PEOPLE WITH SMALL CELL LUNG CANCER

Breathing exercises

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

Stretching exercises

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.



BREATHING AIDS

You may need additional oxygen when you feel short of breath or while you are exerting yourself. Make sure your caregiver understands how to use your oxygen equipment and how to hook up a supplemental tank, especially in case of a power outage. Your doctor may also provide you with an incentive spirometer or another type of equipment to strengthen your lung capacity.

SLEEP HYGIENE

Your body needs proper rest to tolerate treatment and to heal. It is common, however, to occasionally have trouble falling and staying asleep or be excessively sleepy. The following may help prevent ongoing sleep issues:

- Set a routine for sleeping and waking.
- Go to bed at the same time and wake up at the same time daily.
- Limit daytime napping to 20 to 30 minutes, and avoid napping in the late afternoon or early evening.
- Avoid exercising within two hours of bedtime.
- Limit caffeine and alcohol too close to bedtime. Keep in mind that although alcohol may make you sleepy at first, it may disrupt your sleep.
- Drink warm milk or herbal tea.
- Only use your bed for sleeping, not for watching television, using your computer, talking on the phone, reading or eating.
- Create a restful bedroom. Turn off or dim the lights, eliminate noise, set a comfortable temperature and keep your bedding and pillows clean.

If your sleep issues continue for more than a few days, tell your health care team so they can help you manage them right away. Also, talk with them before taking over-the-counter sleep aids to ensure they don’t interact with your medications.

SPIRITUALITY

Having faith can help you manage the emotions and struggles that accompany a serious illness. Where you find your faith is up to you. It may stem from religion, spirituality or anything that brings you joy. Yoga, meditation, journaling or other forms of creative expression are all ways to find comfort. Keep looking until you find something that brings you peace.

TRAVEL

If vacationing is a big part of your life, keep it up. Whether you take a weekend trip or spend a few weeks away, traveling offers many physical and emotional benefits. You just have to plan well:

1. Make your plans around your medical appointments and treatments.
2. Prepare for possibly needing medical care while you are away. Take a copy of your Survivorship Plan, as it has all the details of your medical status and your health care team's contact information.
3. Organize activities that match your energy level. Take a cane or walker and oxygen to make it easier on you.
4. If you plan to fly, contact the airline before you go about how to properly travel with oxygen.

SEXUAL HEALTH

Cancer and its treatment can affect how you feel about yourself sexually. Talk with your doctor early to find out what to expect in terms of sexuality issues, from potential side effects to your ability to have an active sex life. Talking with your partner, a therapist or a trusted friend may help you work through any challenges.

TOBACCO USE

Even after a SCLC diagnosis, you will benefit from stopping smoking and using any form of tobacco. Quitting is challenging, and it is easier when you have support. Refer to the resources on page 7 or ask a member of your health care team to help you. Counseling makes it easier to stay away from tobacco.

NUTRITION

Maintaining your weight is essential for keeping up your energy and making your treatment most effective. The different and sometimes metallic way food tastes and not having much of an appetite can make it challenging. Meet with the nutritionist on your health care team. Together, you can develop a meal plan that includes foods you like along with nutrients you need. Check into meal delivery services that promote nutritious and easy-to-make meals. And make sure you are drinking 8 to 10 glasses of water a day to prevent dehydration, which can worsen some side effect symptoms.

SUPPORT

Surrounding yourself with people you can rely on, confide in and, most importantly, who understand what you are going through will help you immeasurably. Use the resources in the back of this guide to connect with the lung cancer community and learn from the wisdom of others who have been touched by lung cancer. Many offer online, phone or in-person support options, so you can find one that is most comfortable for you.

If your doctor does not bring up a survivorship plan first, ask about it. In the meantime, you can make a copy of the *Survivorship Care Plan* on page 12 and fill out as much as you can on your own. ■

FOR THE CAREGIVER

Prepare for the instrumental role of caregiver

Helping a loved one who has a small cell lung cancer (SCLC) diagnosis will be a challenge, but it also could be one of the most rewarding things you will ever do. From helping with day-to-day activities to being a source of comfort, providing this valuable help will require strength, patience and flexibility. You will benefit from sharing your feelings with another person other than your loved one who has cancer. Talking to other caregivers through online forums or in-person support groups can be educational and comforting.

Your responsibilities, which may change daily, will generally include the following.

Meet the health care team. You will be a key point of contact for your loved one, so it is essential that you are authorized to talk to the doctor, nurse navigator and case manager as well as access medical information, renew prescriptions and more.

Manage the household. From shopping and cleaning the house to managing a calendar of appointments and providing transportation, this is an area where you can delegate. Friends often want to help but don't know how. When they offer, accept and be specific.

Track medications and symptoms. You will be responsible for ensuring all medications, from drug therapy to breathing treatments, are taken the way the doctor intended. Use the tools available, such as medication reminders and a medication tracking form. Download and print a Medication Tracking form at PatientResource.com/Medication_Journal.

Prepare important paperwork. All of us, whether or not we are facing a serious illness, should have an Advance Directive, Living Will, Will or Trust, and Powers of Attorney. If you do not already have an attorney, ask your case manager to connect you with one who can create these important documents for you.

Spend time with loved ones. Have them over for dinner, a walk or a visit. If you can, take a vacation and make lasting memories. Every day matters.

Learn to operate breathing accessories. Have extra supplies on hand. Try to never run out of equipment that helps your loved one breathe.

Encourage support. Social media has enabled people to offer thoughts and prayers easily. Those mean a lot, but sometimes actions mean more than words. Do what you can to help your loved one, and encourage friends and family members to do the same.

Practice self-care. To be an effective caregiver, you must take care of yourself. That includes making and keeping your preventive health care appointments, following a healthy diet, exercising, sleeping enough and making time for things that make you happy. ■

Support and financial resources available for you

CAREGIVERS & SUPPORT

BeholdBeGold	www.beholdbegold.org
Cactus Cancer Society	www.cactuscancer.org
CanCare	www.cancare.org, 713-461-0028
CANCER101	www.cancer101.org, 646-638-2202
Cancer and Careers	www.cancerandcareers.org, 646-929-8032
Cancer*Care*	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	888-793-9355
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	www.capc.org, 347-835-0658
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.	www.cancergps.org, 336-883-4483
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 Circle	www.sharecancersupport.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	www.wellspouse.org, 732-577-8899
WeSPARK Cancer Support Center	www.wespark.org, 818-906-3022
Wigs & Wishes	www.wigsandwishes.org, 856-582-6600

EMOTIONAL HEALTH

American Psychosocial Oncology Society Helpline	866-276-7443

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*Care*	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	www.ssa.gov
Social Security Disability Resource Center	www.ssdrc.com

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	www.go2.org
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

PATIENT GUIDELINES

National Comprehensive Cancer Network	www.nccn.org/guidelines

REIMBURSEMENT & PATIENT ASSISTANCE PROGRAMS

Amgen Safety Net Foundation	www.amgensafetynetfoundation.com, 888-401-4931
Amgen SupportPlus	www.amgensupportplus.com/patient/imdelltra, 866-264-2778
AstraZeneca Access 360	myaccess360.com/patient, 844-275-2360
AstraZeneca Prescription Savings Program (AZ&ME)	azandmeapp.com, 800-292-6363
AstraZeneca US Patient Support	azpatientsupport.com, 800-236-9933
Bristol-Myers Squibb Access Support	bmscopay.com, 800-861-0048
Bristol-Myers Squibb Patient Assistance Foundation	bmspaf.org, 800-736-0003
Genentech Access Solutions	genentech-access.com/patient, 877-436-3683
Genentech Oncology Co-pay Assistance Program	copayassistancenow.com, 855-692-6729
Genentech Patient Foundation	gene.com/patients/patient-foundation, 888-941-3331
Hycamtin Patient Assistance Now Oncology	www.patient.novartisoncology.com/financial-assistance/pano, 800-282-7630
Imfinzi Access 360	myaccess360.com/patient/imfinzi-durvalumab, 844-275-2360
JazzCares	jazzcares.com, 833-533-5299
Novartis Patient Assistance Foundation	pap.novartis.com, 800-277-2254
Pfizer Oncology Together	www.pfizeroncologytogether.com/patient, 877-744-5675
Tecentriq Access Solutions	genentech-access.com/patient/brands/tecentriq, 877-436-3683
Zepzelca JazzCares	www.zepzelca.com/jazz-cares-financial-assistance, 833-533-5299

Mind Over Matter

Having support while you or a loved one is facing lung cancer is invaluable. One of the biggest challenges can be facing the emotions that a lung cancer diagnosis brings up.

GO2 for Lung Cancer now offers a 5-week virtual support program called Mind Over Matter. This interactive series helps small groups of participants learn tips, tools and other coping skills to support them while managing a lung cancer diagnosis. It is designed to fill in the gaps in support services. It is not therapy and does not provide medical advice. Classes are held weekly on Zoom, and they provide themes for each week.

The program is open to all lung cancer patients and their caregivers.

To join, scan this QR code to fill out a survey. GO2 will reach out to you directly for registration into the next available group.

Questions?
Email smchale@go2.org.

GO2 FOR LUNG CANCER

For more resources, go to PatientResource.com

SMALL CELL LUNG CANCER

NOTHING SMALL ABOUT IT

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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