
LIVING WITH
A DIAGNOSIS
OF LUNG CANCER
free to breathe
a partnership for lung cancer survival

We are Free to Breathe. We are a partnership of lung cancer survivors, advocates, researchers, healthcare providers and industry leaders.

We are united in the belief that every person with lung cancer deserves a cure.

For additional patient resources, please visit freetobreathe.org

TABLE OF CONTENTS

01 Introduction
02 What are Common Lung Cancer Questions?
05 What is Lung Cancer?
11 Who Will Treat My Lung Cancer?
14 How is Lung Cancer Treated?
27 How Can I Manage My Symptoms and Side Effects?
29 What Should I Know About Research and Clinical Trials?
32 How Can I Deal With My Lung Cancer Diagnosis?
34 Resources

INTRODUCTION

We hope this booklet will help prepare you for what lies ahead in your journey with lung cancer.

The first thing to know is there is reason for hope. Much progress is being made for people with lung cancer, with new treatments being developed and tested every day.

Of course, you may experience many strong emotions. This is part of the process of dealing with your diagnosis. But a key part of living with lung cancer is learning the facts. This booklet will give you an overview of your disease and treatment options. We encourage you to mark areas where you have specific questions and discuss them with your doctor.

FIND ADDITIONAL INFORMATION at freetobreathe.org

This booklet is not a substitute for the medical advice provided by your treatment team.

WHAT ARE COMMON LUNG CANCER QUESTIONS?

WHAT DOES MY LUNG CANCER DIAGNOSIS MEAN FOR ME?

After being told you have lung cancer, you may wonder what your **prognosis** (the likely outcome or course of your disease) will be – what this means for your future and your health. You may see estimates of how long a person may live after a particular type or stage of lung cancer is diagnosed and assume that this is what will happen to you. Don't think this way. Remember:

1. You are not a statistic. Statistics cannot predict what will happen to you. You are a unique individual and no one can predict exactly how your body will respond to your lung cancer. Lung cancer statistics estimate the average survival for all people with a specific type or stage of lung cancer. Remember that you are not "everyone else;" you are *not* among the cases that make up the statistics.
2. Lung cancer statistics are based on information from studies that were done from three to 10 years ago. Today's newer therapies have not been around long enough to affect the statistics, so your prognosis may be far more hopeful than the statistics suggest.

The chances of being cured of lung cancer depend mostly on the stage of lung cancer you have. Early-stage cancer is the easiest to treat and has the best chance of being cured. If the cancer has spread to other places in the body, the goal of treatment is to keep the cancer under control for as long as possible.

If you read or are told your cancer cannot be cured, remember that *incurable cancer does not always mean that the cancer can't be treated*. Newer treatments are helping some lung cancer patients live good, meaningful lives for years after their diagnosis.

WHAT ARE MY TREATMENT CHOICES?

Chemotherapy, radiation, surgery, and targeted therapies are the main treatment options for lung cancer. However, a number of factors can affect which treatments will be best for you, including your cancer's particular type and stage; location; and genetic or other molecular characteristics. Some promising new treatments may be available through clinical trials, so be sure to ask your doctor about these options. See pages 14-26 for more information on lung cancer treatments.

HOW LONG WILL MY TREATMENT LAST?

The length of your treatment will depend on the type and stage of lung cancer you have and how well you respond to treatment. Your treatment plan will be explained to you before therapy begins. If you have questions, be sure to ask them. You will be regularly checked on to see how your treatment is working, and to find any unexpected problems. If your cancer does not respond to the first treatment you receive, your doctor may discuss other treatment options with you.

HOW MUCH WILL TREATMENT COST? HOW DO I FIND OUT WHAT MY INSURANCE COVERS?

The costs of your lung cancer treatment will depend on the treatments you need and whether you get them at home, in a clinic or in a hospital.

For instance, most health insurance policies, including Medicare and Medicaid, cover the majority of the costs of getting chemotherapy. Targeted therapies are sometimes covered in a different way than other treatments, and they may require higher out-of-pocket costs; assistance programs are available to help pay for these treatments. Cancer centers and most hospitals have patient assistance departments that should be able to help you find out what your insurance will cover and whether you qualify for assistance. See pages 36-37 for more information about organizations that can help with money matters.

WHAT ARE TARGETED THERAPIES?

Targeted therapies are treatments uniquely tailored to the characteristics of your tumor. To determine these characteristics, your cancer care team may take a sample of your tumor and test it for changes or mutations that drive its growth. This process can be called molecular, biomarker, genetic or mutation testing. You should ask your doctor about whether such testing is appropriate for you. See pages 21-22 for a detailed explanation of targeted therapies and molecular tumor testing.

SHOULD I CONSIDER JOINING A CLINICAL TRIAL?

Clinical trials are research studies that measure how well new drugs, treatments or tests work, or help doctors learn more about cancer or other diseases. Many patients feel they get more attention, more care and more frequent check-ups if they participate in a clinical trial. Trials are generally available for every stage and type of lung cancer, although every individual may not be eligible for a given trial. See pages 29-31 for more information on clinical trials.

MORE INFORMATION can be found at freetobreathe.org

WHAT IS LUNG CANCER?

Only cancers that begin in the lungs are called "lung cancer." Sometimes cancer from other parts of the body may spread to the lungs, but it is not called lung cancer. For example, breast cancer that spreads to the lungs is still breast cancer and will be treated as breast cancer, not lung cancer. Lung cancer that spreads to the liver is treated as lung cancer, not liver cancer.

Cancer forms when cells multiply out of control. All of the normal cells in your body have very specific jobs and functions. For example, intestine cells absorb vitamins, minerals and other nutrients from our food; red blood cells carry oxygen throughout the body; and white blood cells fight infections. Normal cells stop growing and dividing when they get old. Normal cells also die if they are injured.

Cancer cells are different. They do not function normally, they keep dividing and multiplying, and they do not die when they grow old. They can also spread through the blood stream, or invade nearby **lymph nodes** (small collections of white blood cells scattered throughout the body) and spread through the lymph system. When cancer cells spread through any of these methods, they can **metastasize** (travel to other organs and form new tumors). Common lung cancer metastasis sites include the brain, bones and liver.

WHY DOES CANCER HAPPEN?

Every cell contains genes, which are the "brains" that tell the cell what to do. When a cell's genes are **mutated** (damaged or changed), cancer may develop. Some of these changes are **inherited** (passed down from parent to child), but others may occur due to exposure to certain toxins, such as cigarette smoke, radon and asbestos. When these mutations in the genes cause cells to multiply uncontrollably, a mass of cancer tissue, called a tumor, can develop.

TYPES OF LUNG CANCER

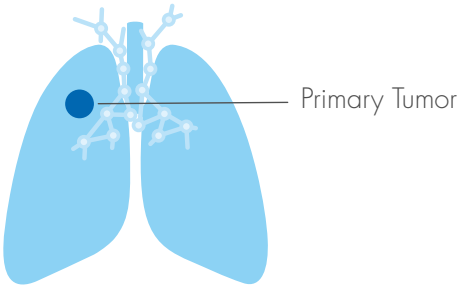
The two main types of lung cancer are: **small-cell lung cancer (SCLC)** and **non-small cell lung cancer (NSCLC).** NSCLC is further sub-typed as:

- Adenocarcinoma
- Squamous cell carcinoma
- Large cell carcinoma

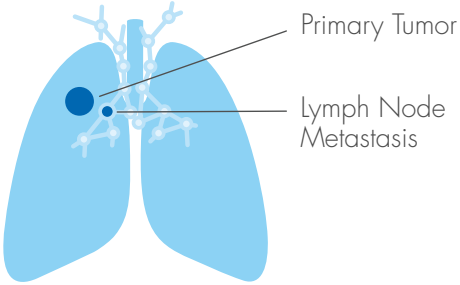
If you have NSCLC, it is important to know your subtype so that your medical team can develop the right treatment plan for you. The majority of lung cancers (about eight out of 10) are NSCLC, and most cases of NSCLC (about five out of 10) are adenocarcinoma. Small-cell lung cancers tend to grow and spread more rapidly and cause symptoms sooner than NSCLC. For these reasons, treatments for SCLC may differ from those for NSCLC (see pages 23-24 for more information on SCLC and NSCLC treatments).

WHAT IS STAGING, AND WHY IS IT IMPORTANT?

After your lung cancer is diagnosed, your doctors will determine the type of lung cancer you have and the stage of the disease. Staging is based on the tumor's size and whether it has spread to any lymph nodes in the area or to other organs.



STAGE I



STAGE II

STAGE I

A tumor up to 5 cm wide that has not spread to any lymph nodes or other organs is classified as stage I. These tumors are usually **resectable** (able to be removed surgically).

STAGE IA:

- 3 cm or smaller

STAGE IB:

- 3-5 cm wide in any direction

STAGE II

Stage II cancers are a little larger than stage I, may have spread to lymph nodes on the same side of the chest, and/or may have begun to invade other structures within the chest. These tumors are usually resectable.

STAGE IIA:

- 5-7 cm wide in any direction with no spread to lymph nodes OR
- less than 5 cm, but spread to lymph nodes on the same side of the chest

STAGE IIB:

- 7 cm or wider in any direction with no spread to lymph nodes OR
- 5-7 cm wide, but spread to lymph nodes on the same side of the chest OR
- beginning to invade structures within the chest OR
- more than one tumor in the same lobe of the lung

STAGE III

A tumor that has spread to lymph nodes beyond the same side of the chest, but does not appear to have spread to other organs outside the chest is classified as stage III. Often, stage III tumors are **unresectable** (unable to be removed surgically).

STAGE IIIA:

- spread to lymph nodes in the center of the chest

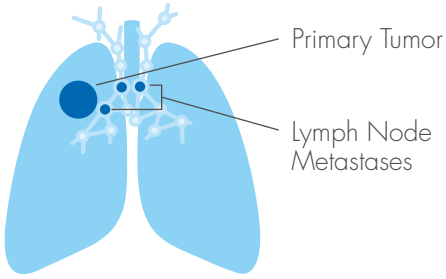
STAGE IIIB:

- spread to lymph nodes on the opposite side of the chest OR
- involves major structures, such as the heart or arteries

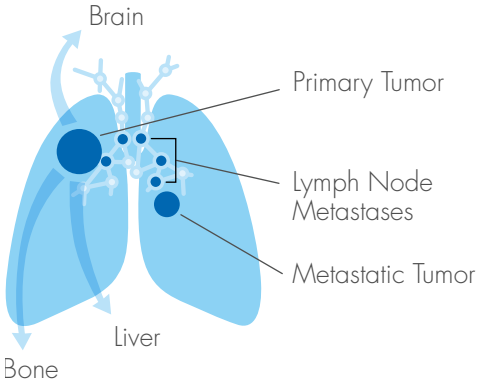
STAGE IV

Cancer accompanied by **pleural effusion** (a fluid build-up between the lungs and the chest wall) or that has **metastasized** (spread) to other parts of the body is classified as stage IV. Although stage IV cancers are difficult to cure, there are treatments available that may help you live longer and better.

REFER to pages 23-25 for detailed descriptions of treatments by cancer stage.

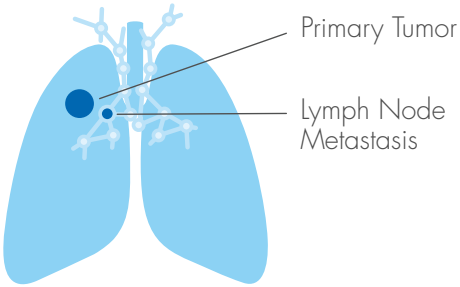


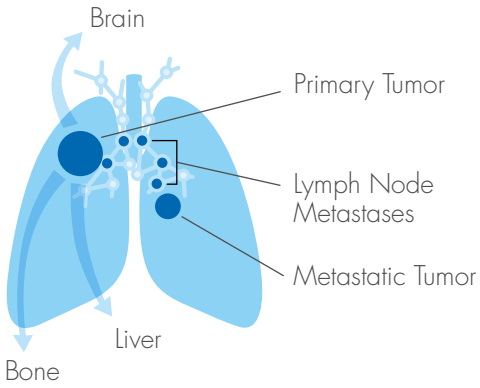
STAGE III



STAGE IV

Small-cell Lung Cancer (SCLC)





Limited-stage SCLC is cancer present in only one lung, which may have spread to surrounding lymph nodes. Treatment for limited-stage SCLC generally involves both chemotherapy and radiation therapy.

Extensive-stage SCLC is cancer that has spread to both lungs, lymph nodes far from the original cancer, or to other parts of the body. As with other advanced cancers, extensive-stage SCLC can be difficult to cure, but there are treatments available that may help you live better and longer.

REFER to pages 23-25 for detailed descriptions of treatments by cancer stage.

HOW WILL MY DOCTORS FIND OUT THE STAGE OF MY CANCER?

Your doctors will determine the stage of your cancer by using any combination of several procedures:

- **Computed tomography (CT)** scans are sophisticated x-rays that show the body in cross-sections. These cross-sections are very good at showing the location and size of tumors.

- **Positron emission tomography (PET)** scans can help determine where tumors are in the body. Because cancer cells grow faster than normal cells, they consume more sugar. When a small amount of special dye that contains sugar is injected into a vein, a PET machine is used to see where the sugar builds up.

- **Bronchoscopy** is a procedure in which a doctor puts a camera down the airway to look for tumors and possibly perform a **biopsy** (removal of a sample of the tumor or lymph nodes) using a needle.

- **Endobronchial ultrasound (EBUS)** is a newer, more specialized type of bronchoscopy that uses sound waves to create an image of the tumor and nearby tissues to help the doctor decide what area to biopsy.

- **Navigational bronchoscopy** uses CT scans, computer software, and special very small devices to guide the bronchoscopy procedure. This form of bronchoscopy may be used when a tumor exists in the smallest parts of the airways, or to help doctors better find the right spot to take a standard biopsy.

- **Bone scans** create pictures of the bones. A special dye is injected into a vein, and a camera is used to see the dye. This tells doctors how healthy the bones are and whether they have any tumors in them.

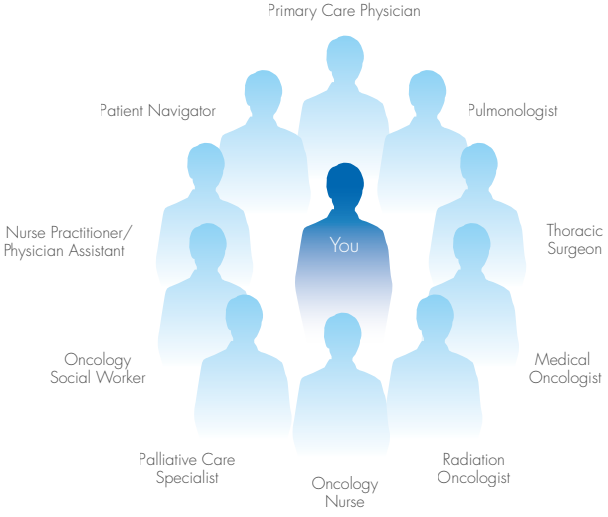
- **Magnetic resonance imaging (MRI)** uses magnetic fields to produce detailed images of the body. MRI is particularly useful for finding abnormal growths in the brain.

MORE INFORMATION can be found at freetobreathe.org

WHO WILL TREAT MY LUNG CANCER?

As a partner in your own care, choosing the right cancer care team, beginning with your **oncologist** (a doctor who is a cancer specialist), is the first step. Many other doctors, nurses and specialists will likely also be involved in your care, and understanding their roles will help as you decide how to proceed with your care.

It is very important that you feel comfortable talking to members of your cancer care team. You have the right to ask questions, discuss your treatment options, and openly express your concerns, emotions and wishes.



YOUR CANCER CARE TEAM

Your treatment options will depend on the type and stage of your disease. Your cancer care team will develop a detailed treatment plan for you, taking into consideration your cancer as well as your other health needs.

A variety of specialists may be included in your cancer care team:

A **medical oncologist** will prescribe the drugs, such as chemotherapy, targeted therapy agents and supportive care treatments that are needed to help treat your cancer and manage your symptoms.

A **thoracic oncologist** specializes in treating lung cancer patients.

A **radiation oncologist** uses concentrated x-rays to eliminate cancer cells. Radiation and medical oncologists often work together to determine and carry out treatment plans.

A **thoracic surgeon** has special training to remove or operate on lung cancer tumors. If there is not a thoracic surgeon available in your area, ask which nearby surgeon performs the most lung cancer surgeries.

Palliative care specialists may provide care and support as you and your loved ones face the challenges of living with cancer. These doctors and nurses can help you sort through information to make medical decisions; assist with making plans for living well during and after your cancer treatment; or prescribe treatments to control pain, issues with breathing, or other uncomfortable symptoms. These specialists can also help you and your loved ones find the emotional and spiritual support you may need.

Nurse practitioners and **physician assistants** are specially trained to provide you with medical care ranging from preventive care and physical exams to ordering tests and prescribing certain medications. They work with your doctors to check on your overall health and how you are responding to your treatment(s). They can help you manage the symptoms of your cancer and any side effects of your treatments.

MORE INFORMATION can be found at freetobreathe.org

Oncology nurses are specially trained in the care of cancer patients. Working with your doctors, they will carefully check your progress as partners in your journey with lung cancer. Oncology nurses may also give you the drugs your doctors prescribe. If you are part of a clinical trial testing a new treatment, research nurses will help check on you and take any concerns or questions to your doctor. They also help collect information needed for the clinical trial.

Oncology social workers provide counseling and support. They often work with oncology nurses and palliative care specialists to address your specific needs and connect you with useful resources in addition to medical treatment. For example, a social worker may help you and your family find a place to stay during treatment if your cancer center is far from home. A social worker might also help you with payment or other financial issues that you may face as a result of your cancer.

Patient navigators help coordinate care with the many different people on your team. They may help ensure that your tests get ordered or appointments scheduled, work with your insurance on any questions that come up or help you find emotional, financial or other support services. Nurses, nurse practitioners, social workers or others may act as patient navigators. Your patient navigator is often your key contact when you have questions or problems.

Depending on your needs, other specialists could be part of your cancer team. A **nutritionist** can discuss foods and supplements that will help keep you healthy while you are in treatment. A **psychologist** can help you and your family deal with the emotions surrounding your cancer diagnosis and treatment. Your lung cancer care may be coordinated by a **case manager**, and a **respiratory therapist** or **pulmonologist** can help if you have trouble breathing. Even though you will be seeing specialists for your cancer treatment, you will still need regular medical care from someone overseeing your general health. Your **primary care physician (PCP)** should be kept informed about your condition and updated about your cancer treatment. For the best care, your oncologist and PCP should work together as a team. This communication is usually done with written reports sent to your PCP after you visit your cancer care team.

HOW IS LUNG CANCER TREATED?

Your treatment options will be based on your cancer's particular type and stage, location, molecular characteristics, and your overall health. The most common treatments for lung cancer are surgery, radiation therapy and chemotherapy. Some patients may be prescribed targeted therapy, which includes drugs that "target" cancer cells. New treatment options are also being tested in clinical trials. If you are interested in learning more about clinical trials, talk with your doctor about the possibility of participating in one (see pages 29-31 for more information on clinical trials).

SURGERY

Surgery, or having an operation, is the physical removal of the cancer tumor and any nearby lymph nodes that may contain cancerous cells. Ideally, a **thoracic surgeon**, an expert in lung cancer surgery, should perform this operation. If you need surgery, find a surgical center that performs a lot of lung cancer surgeries. Don't be afraid to ask whether your recommended surgeon is a thoracic surgeon and how many lung cancer surgeries he or she does. Surgeons performing one or more lung cancer surgeries per week are recommended.

MORE INFORMATION can be found at freetobreathe.org

Whether you can be treated with surgery depends on:

- The type and stage of your cancer (see pages 7-9). Surgery is generally not recommended if the cancer has spread to other organs (stage IV NSCLC) or for SCLC.
- The location and size of your tumor. If the surgeon cannot safely remove your tumor, the disease is called inoperable, or unresectable, and surgery may not be an option (stage IIIB and some stage IIIA NSCLC).
- If you are otherwise healthy enough to have surgery. If you have heart or lung disease in addition to lung cancer, you may not be able to withstand surgery.

If you have lung cancer surgery through the traditional, opened-chest approach, it usually takes six to eight weeks to fully recover. Depending on the size and location of your tumor, you may be able to have lung surgery by **video-assisted thoracic surgery (VATS)**. This type of surgery is less invasive because it uses smaller openings and a video camera to guide the surgeon. This procedure results in less injury to your bones and muscles, and a shorter recovery time. Some centers also use robotics during VATS. Recovery time will vary depending on your particular surgery, your general health and how well you heal.

MYTH-BUSTER: CANCER SURGERY

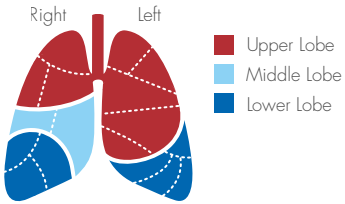
You may hear that cancer can spread if it is exposed to air during surgery, but this is not true. Some people may get this idea if the doctor finds more cancer during the surgery than was previously expected. Although doctors can usually get a very good idea of the extent and location of cancer from scans and tests, these methods are not perfect. Occasionally, a surgeon will find more cancer than expected. In these cases, the cancer was already there, but it wasn't seen on previous scans or tests. Delaying or refusing surgery because of this myth could make it significantly harder for your cancer care team to treat your cancer.

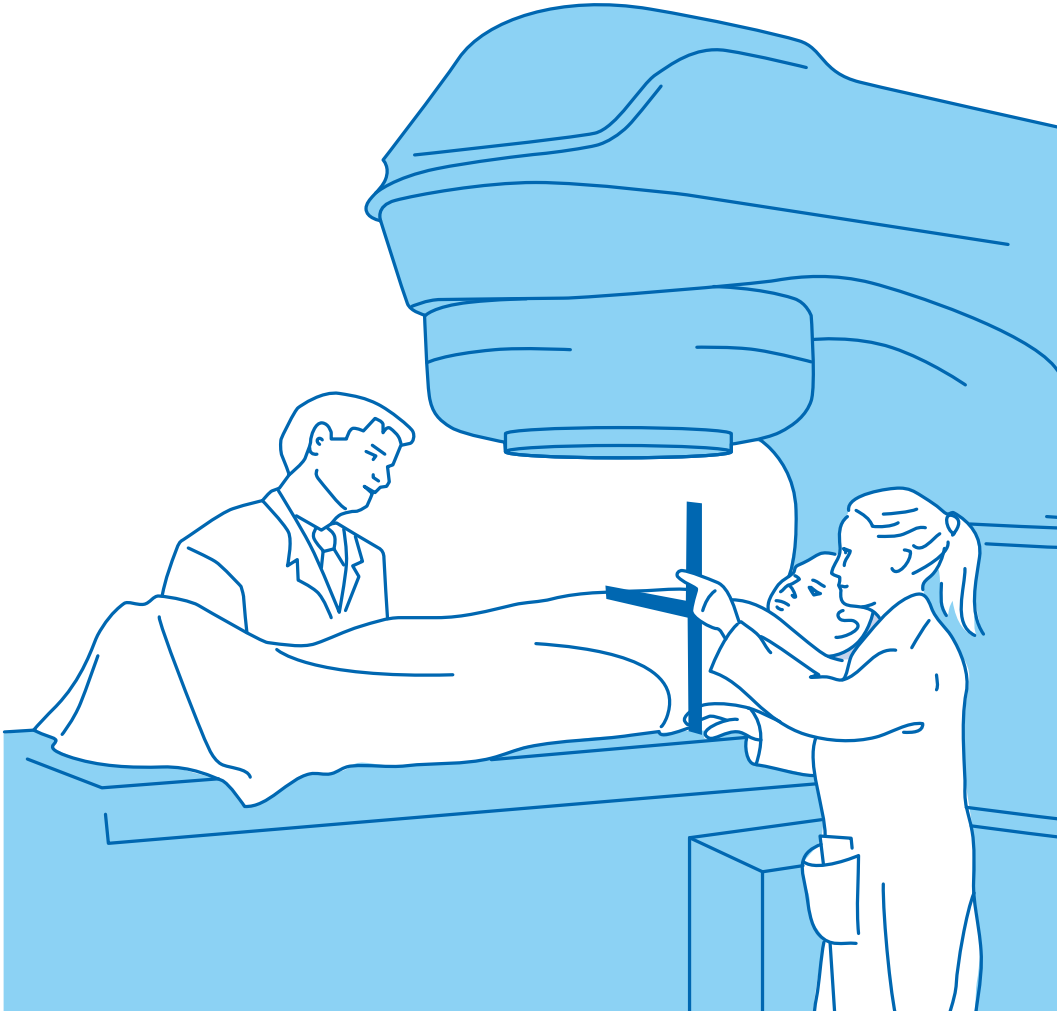
TYPES OF SURGERY:

- **Wedge resection**: In this procedure, the surgeon removes a small wedge-shaped section of the lung containing the tumor and a small amount of healthy tissue around the cancer. This procedure allows you to maintain a majority of your lung function.
- **Segmentectomy**: This procedure involves removal of one or more **segments** (regions supplied by distinct blood and air supply routes) of the lung that is affected by the lung cancer. Typically, more lung tissue and lymph nodes are removed in a segmentectomy than in a wedge resection, but less than a lobectomy.
- **Lobectomy**: This procedure involves removing the entire **lobe** (portion) of the lung affected by lung cancer. The right lung has three lobes, and the left lung has two, so having a lobectomy allows you to maintain most of your lung function.
- **Pneumonectomy**: In this procedure, the surgeon completely removes the lung with cancer. This must be done when the tumor is located in the lung's largest airway or very near the trachea, or when the cancer affects more than one lobe of the lung. This procedure can significantly reduce lung function, but most people find they can get back to nearly normal activities with physical and respiratory therapy.

If you have surgery, your surgeon will likely also remove some lymph nodes to check them for cancer cells. This will help your doctors determine if your cancer could have spread elsewhere in your body. If cancer cells are found in the lymph nodes, chemotherapy and/or targeted therapy may be recommended after your surgery.

Lung Lobes and Segments
(segments defined by dotted lines)





Radiation therapy (also sometimes referred to as radiotherapy, x-ray therapy, or irradiation) is the use of x-rays or other high-energy beams to damage cancer cells and stop them from growing or multiplying. Because radiation also affects normal cells, this therapy is aimed at the cancer tumor. Like surgery, radiation is a local form of therapy and not a **systemic** (whole-body) treatment like chemotherapy or targeted therapy. High **doses** (amounts) of radiation are given when the tumor is confined to one area of the body, with the hope that it will kill all of the tumor cells in that area. This might involve daily doses of radiation for six weeks or longer.

If the cancer has spread from the lungs to other parts of the body, radiation may be given in smaller doses to relieve symptoms in affected areas, such as the brain or bones. Radiation given for periods ranging from one day to four weeks can kill enough cancer cells to bring relief from symptoms such as pain, breathing difficulties and headaches. A very focused form of radiation therapy, called **radiosurgery**, is sometimes offered if the cancer has spread to the brain or bones.

SPECIALIZED RADIATION THERAPY

Your radiation oncologist may recommend a special type of treatment called **Stereotactic Body Radiation Therapy (SBRT) or Stereotactic Ablative Radiotherapy (SABR)**; these terms mean the same thing. SBRT/SABR uses radiation from multiple angles, which allows higher doses of radiation to be precisely focused on the tumor, avoiding healthy tissue. SBRT/SABR can be used to treat lung tumors that cannot be surgically removed because they are too large or in a difficult location, as well as for small tumors in people who cannot have traditional surgery due to other health conditions. SBRT/SABR can be performed with many different types of machines, and different options may be presented to you depending on the machines available at a given treatment location.

Other advances in radiation therapy are being developed and may be available after the printing of this booklet.

MORE UP-TO-DATE INFORMATION can be found at freetobreathe.org

CHEMOTHERAPY

Chemotherapy drugs are used to kill cancer cells. Unlike surgery and radiation, which are used to treat local disease, chemotherapy is systemic; it can affect cancer cells throughout the body. A number of different chemotherapy drugs are used for lung cancer, including (at the time of this booklet's publication):

- cisplatin
- carboplatin
- docetaxel (Taxotere®)
- etoposide (VP16, Vepesid®)
- gemcitabine (Gemzar®)
- nab-paclitaxel (Abraxane®)
- paclitaxel (Taxol®)
- pemetrexed (Alimta®)

Generally, one platinum-containing agent (cisplatin or carboplatin) is combined with a non-platinum drug. Additional or different combinations of therapies may be prescribed by your doctor depending on her/his expert opinion on what is likely to work best for you. Still more drugs are in development, which may be available after the printing of this booklet.

These drugs are administered through the veins (intravenously or IV) or taken orally as pills. Usually, chemotherapy drugs are given for four to six "cycles." Generally, each cycle is a treatment followed by about a three-week rest period. For example, if you are prescribed four cycles, it usually means you will receive the chemotherapy drugs four times – each dose given about three weeks apart – for a total of 12 weeks of therapy. However, depending on your particular cancer and overall health, your doctors may recommend a different schedule for your treatment.

Many people are concerned about the side effects of chemotherapy. It is important to know that different types of cancers are treated with different types of chemotherapy, and that chemotherapy has changed a lot over the years. If someone tells you what they or a friend went through, remember that your cancer and your treatment – and therefore your experience – may be very different. See pages 27 and 28 for some possible side effects of chemotherapy and other treatments, and ways to manage these symptoms.

FOR YOUNG PEOPLE WITH LUNG CANCER

Most lung cancer patients are over age 60. However, a large number of young people, even those under 40, get lung cancer. If preserving your ability to have children is important to you, be sure to talk with your doctor about your options before you start treatment.

TARGETED THERAPY

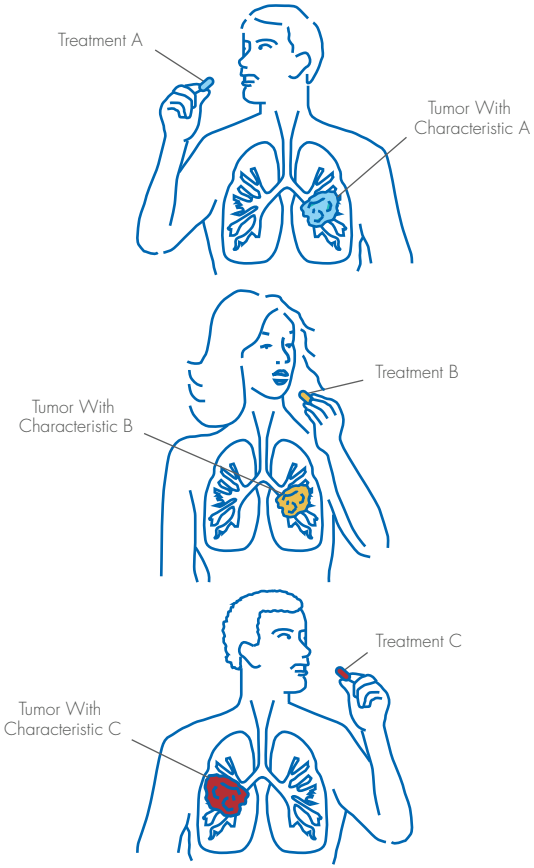
Over the past decade, scientists have made many discoveries about what makes cancer cells multiply out of control. They have discovered a number of ways that cancer cells are different from normal cells, and are developing drugs that "target" these differences in cancer cells. Although there are many types of targeted therapies, all are designed to target cancer cells and stop or limit the growth and spread of cancer.

For example, normal cells make chemicals called **growth factors**, which attach to proteins called receptors on that same or nearby cells – like a baseball fitting into a catcher's glove. This leads to a chemical reaction inside the cell, which causes the cell to grow and multiply. In cancer cells, too many growth factors may be present, or the receptor may be mutated so that it "thinks" the growth factor is attached when it really isn't. This situation causes cells to inappropriately multiply. In patients whose tumors have these mutations, blocking the receptors with drugs, like afatinib (Gilotrif®), crizotinib (Xalkori®) and erlotinib (Tarceva®), can stop the cancer from growing or spreading.

Some other types of targeted therapy drugs, like bevacizumab (Avastin®), can stop **angiogenesis**, (a process where the tumor makes new blood vessels). Blocking the ability of a tumor to make blood vessels can prevent it from getting the oxygen and nutrients it needs to grow.

Some of these treatments work best for people whose tumors have specific molecular characteristics or genetic mutations, so testing the tumor tissue for these characteristics is very important. Many more drugs are being tested in clinical trials to determine if they will help people with NSCLC and SCLC, and even more drugs are in other stages of development. **Molecular tumor testing** is often required in order to check whether you are eligible for targeted therapies and clinical trials.

Matching Targeted Therapies to a Tumor's Molecular Characteristics



MOLECULAR TUMOR TESTING

Scientists continue to learn more and more about the molecular changes and genetic mutations that "drive" cancer growth. Molecular tumor testing is key to understanding the changes that are present in your tumor, which can help your cancer care team decide which treatments are most likely to work for your specific cancer. If your doctors have enough tissue from your initial biopsy, this tissue can be tested. If not, you may need to undergo a second biopsy or minor surgery to obtain enough tissue for a molecular tumor test.

If your doctor doesn't recommend tumor testing, it is okay for you to ask, "Why not?" Testing may not be appropriate in all cases, but it is best for you to know as much as you can about your disease so you and your doctors can be full partners in your care.

ALTERNATIVE THERAPIES

After a lung cancer diagnosis, you may hear about "alternative therapies," such as herbal remedies, dietary supplements, massage therapy, acupuncture or chiropractic treatments. While some of these therapies may be helpful in managing pain or side effects of treatment, they are never a substitute or replacement for proven medical treatments prescribed by the specialists on your cancer care team. Additionally, some of these alternatives may harm you; they may cause problems with the treatment you are receiving, or keep it from working. Always talk with your cancer specialists before starting any alternative therapy plan.

IF YOU SMOKE

If you smoke, it is important to work with your treatment team to quit smoking. Quitting smoking will help you breathe easier, put less stress on your heart and lungs and help your treatments work better. Studies have shown that quitting smoking helps you live longer, even once you have lung cancer. Talk with your oncology social worker, case manager, or psychologist to find out about programs to help you develop a plan and quit smoking. This plan may include counseling and medications designed to make quitting easier. It is not too late to quit.

To create a quit plan today, call 1.800.QUIT.NOW or visit becomeanex.org.

NON-SMALL CELL LUNG CANCER (NSCLC) TREATMENTS BY STAGE

Because new treatments are rapidly becoming available, please visit freetobreathe.org for the most up-to-date information.

STAGE I

The ideal treatment for **stage I** NSCLC is surgery. New research is helping doctors predict which stage I NSCLC patients will need chemotherapy before or after their surgery and which will not.

STAGE II

The optimal treatment for **stage II** NSCLC is surgery preceded and/or followed by chemotherapy.

STAGE III

For **stage IIIA** NSCLC cancer, chemotherapy with radiation therapy, or chemotherapy with surgery are the standard treatments. Research is under way to help doctors decide the best timing for these different treatments. Your treatment team will develop a plan based on your needs and their best experience in fighting this disease. **Stage IIIB** cancer is usually treated with chemotherapy and radiation therapy. Surgery is generally not recommended, but may be considered in specific cases.

STAGE IV

Because **stage IV** cancer has spread to other parts of the body, surgery is not usually recommended. Chemotherapy is used because it fights the cancer throughout the body. Targeted therapy may be prescribed in addition to—or instead of—chemotherapy, depending on the type, size and location of the tumors, and whether you are on medications for other health conditions. If the cancer has spread to your bones, you may be given medication, such as denosumab (Xgeva®) or zolendronic acid (Zometa®), to help strengthen your bones. Radiation may be used to shrink tumors that are causing symptoms.

Continuing a drug or using a different drug after the initial course of chemotherapy, often called maintenance therapy, can help treat the cancer and may prevent it from spreading. However, not every person can manage the side effects of these drugs so soon after initial treatment. Your treatment team will work with you to decide whether **maintenance therapy** is right for you.

RECURRENT NSCLC

If your cancer at first responded to one type of therapy, but then progressed, your cancer is called **recurrent**. In these cases, other chemotherapy or targeted therapy drugs may be recommended. Many people experience great improvement with additional treatment, even after their cancer has recurred.

SMALL CELL LUNG CANCER (SCLC) TREATMENTS BY STAGE

LIMITED-STAGE

Limited-stage SCLC is typically treated with radiation to the chest and chemotherapy. **Prophylactic cranial irradiation (PCI)**, radiation to the whole brain, may also be offered. The brain is a common site for cancer to come back in patients with SCLC because chemotherapy does not treat cancer that has spread to the brain as effectively as it treats cancer in other parts of the body. PCI is recommended for SCLC patients whose cancer appears to be in **remission** (no current sign of cancer) as a result of treatment. It is important to discuss PCI with your oncologist.

EXTENSIVE-STAGE

Individuals with extensive-stage SCLC are treated with chemotherapy. Should remission occur, PCI will also be considered for most patients.

PERSONALIZED CANCER CARE PLAN

You may wish to work with your doctor and/or nurse to develop a **personalized cancer care plan**, which acts as a one-stop reference for information relating to your treatment and care. This plan will include your initial treatment plan, which is a list of your cancer treatments; other medicines or therapies you will need to help your

GETTING A SECOND OPINION

Understanding all of your treatment options before beginning therapy can help you feel confident that you are making the best decisions you can. Getting a second opinion is one way to gain this confidence. The additional experts you consult may tell you the same thing as your original cancer care team, or they may suggest new options or clinical trials that you may want to consider. Consider going to a National Cancer Institute–designated Comprehensive Cancer Center (cancercenters.cancer.gov/cancer_centers) or other major medical center to seek a second opinion. These centers are ideally suited to provide you with the treatment you need.

PALLIATIVE CARE: START EARLY

Some care you receive may not be designed to treat your cancer, but will address possible symptoms caused by your cancer or treatments, and any psychological, social or spiritual concerns you may have. This care is called **palliative care**. In addition to improving how patients with advanced cancer feel, palliative care has recently been found to lengthen patients' lives; it is not only for "end of life." If you have advanced-stage cancer and you are not referred to a palliative care specialist soon after your diagnosis, ask to see one.

treatments work best; possible side effects; and symptoms to watch for. Once your initial treatment is complete, you may wish to update your care plan with information on any medicines you are continuing to take, any ongoing medical issues that need to be addressed and when to return for check-ups. A basic outline for a personalized care plan includes the following:

- Treatment provided
- Treatment purpose (cancer treatment, bone strengthener, ease breathing, etc.)
- When to take (daily, weekly, specific dates)
- How to take (after meals, before bed, with water, etc.)
- When and where you need to go for treatments
- Reactions to look out for
- Follow-up needed
- Follow-up date(s)

Your cancer care team may have a more detailed version to share with you. If you are not given a personalized cancer care plan, you can download one to fill out with your treatment team at freetobreathe.org/care-plan

ONGOING CARE

Once your treatment is over, it is important that you receive regular follow-up care. Visit your doctor as prescribed to monitor for any return of the cancer. The American Society of Clinical Oncology recommends that you have follow-up appointments with your oncologist every three months during the first two years after treatment, every six months during years three through five, and yearly after that. You should feel free to schedule more frequent appointments if you are experiencing symptoms that worry you, or if you have other healthcare concerns. Ask your oncologist what symptoms you should be on the lookout for. If symptoms occur, report them promptly.

HOW CAN I MANAGE MY SYMPTOMS AND SIDE EFFECTS?

You may experience symptoms from your cancer or from your cancer treatments. In most cases, these symptoms can be controlled with medications, exercises or other therapies to help you feel better and continue with your daily life. Remember:

- Take care of yourself. Eat well, drink plenty of water, exercise when you are able, and get enough rest, both at night and during the day.
- Ask to see a pulmonologist or respiratory therapist if you feel short of breath.
- Don't be afraid to take pain medications. Although many people may fear getting addicted to or "hooked" on pain medications, research has shown addiction is unlikely when these medications are used appropriately.
- Ask your doctor for help if you experience long-term depression or sleeplessness. Living with any serious illness can cause mental exhaustion. It is normal to be worried, fearful, sad, or anxious. It is okay to ask for counseling or other help to deal with these feelings.
- Your cancer or your treatment may affect your ability to be intimate with your spouse or significant other. Talk about this with your partner, and take time to just be together. If necessary, talk to your doctor or a counselor.

MANAGEMENT OF COMMON SYMPTOMS

Ask your oncology nurse, nurse practitioner, physician assistant or doctor to talk with you about how these or other methods may help you manage symptoms of your cancer or side effects of your treatments.

POSSIBLE SYMPTOM OR SIDE EFFECT	RECOMMENDATIONS
Pain	Take pain medications as prescribed.
	Both long-acting and short-acting pain medications are available. To be most effective, long-acting pain medications need to be taken before you feel the pain. Short-acting medications can be used at other times.
Shortness of breath	Use inhalers or other medications to open up airways or reduce swelling.
	Use portable oxygen.
Severe sore throat	Take pain or other medications before eating or as prescribed.
	Eat soft, cool foods; avoid citrus and acidic foods, and carbonated or caffeinated drinks.
Skin rash/redness/peeling/itching	Moisturize skin before, during and after therapy as recommended.
	Wear loose-fitting clothes.
	Stay out of the sun.
	Use hydrocortisone or antibiotic creams and/or oral antibiotics as prescribed.
Fatigue/tiredness	Be kind to yourself. Rest when you need to and don't take on additional activities.
	Eat a healthy diet to ensure proper nutrition.
	Have your red blood cell levels checked. If they are very low, you may need a transfusion.
	Keep a regular exercise routine. Even light walking can help.
Nausea/vomiting	Take anti-nausea medications as prescribed. These are usually most effective when taken before, during and after therapy.
	Eat small meals throughout the day.
Hair loss	Plan for hair loss by getting a hair cut, wigs, hats or scarves.
Weaker immune system	Wash your hands often and avoid being around people who are sick.
Numbness or tingling of hands/feet	Avoid snug socks and shoes.
	Exercise if you are able, including walking and other light activities.
	Dress appropriately, especially for cold weather.
Diarrhea	Drink plenty of non-caffeinated fluids.
	Take anti-diarrhea medications as prescribed.
Constipation	Take stool softeners or laxatives as prescribed.
	Eat fruits, vegetables and other high-fiber foods and drink plenty of fluids.

WHAT SHOULD I KNOW ABOUT RESEARCH AND CLINICAL TRIALS?

When you are diagnosed with lung cancer, you and your doctor should discuss whether or not a clinical trial is a good treatment option for you. If you are interested in taking part in a clinical trial and your doctor does not discuss this option with you, ask if there may be opportunities for you to participate.

WHAT IS A CLINICAL TRIAL?

Clinical trials are medical research studies that test the safety and effectiveness of promising approaches to disease prevention, diagnosis, treatment and care.

Cancer clinical trials that test treatments might involve the use of drugs, radiation therapy, surgery or other treatment methods. Treatments are only brought to clinical trials after significant prior research shows promise. These trials are carefully conducted by doctors to ensure that patients receive the best possible treatment and care.

Some people may think they should consider a clinical trial only after they've exhausted standard treatment options. However, many trials are designed to test treatments for patients with newly diagnosed or early-stage lung cancer. Progress in treatments cannot happen without clinical trials, and many patients find that clinical trials offer them excellent treatment options and care.

POTENTIAL BENEFITS OF CLINICAL TRIALS

- Many patients find they get more attention, care and frequent check-ups when they participate in clinical trials.
- All patients participating in cancer clinical trials receive the best cancer treatment currently known for their type and stage of cancer.
- Many newer treatments are only available through clinical trials.
- By taking an active role in their care, clinical trial participants often feel empowered.
- When you participate in a clinical trial, you'll be investing in the future of cancer therapy for those who are diagnosed after you.

IMPORTANT ISSUES TO KEEP IN MIND

- Your clinical trial options will be based on your particular type and stage of lung cancer and your overall health. To determine which clinical trials are appropriate for you, talk to your doctor.
- If **placebos** (non-active pills, injections, etc.) are used, patients usually receive them in addition to standard, proven treatments. Placebos may also be used when testing a new treatment for a particular type and stage of disease for which no standard treatments are available.
- All clinical trial participants are volunteers who can stop at any time they choose.
- If you are given an experimental treatment as part of a clinical trial, there may be unexpected side effects.
- An experimental treatment in a clinical trial may not be effective.
- If you volunteer for a clinical trial, you may have additional office visits, tests, or procedures.

MORE INFORMATION can be found at freetobreathe.org

- Your insurance company and/or the trial itself will pay for your care in a clinical trial. Your doctor's office should be able to help you contact your insurance company before you start a clinical trial, and deal with any insurance issues.
- All clinical trials are reviewed and followed by outside experts to make sure the patients' health and wellbeing are looked after.

LOCATING CLINICAL TRIALS

You can find listings of clinical trials specific to your condition and area of the country. Ask your doctor for referrals and check the EmergingMed Lung Cancer Clinical Trial Matching Service at emergingmed.com/networks/freetobreathe or 1.800.698.0931

MORE INFORMATION about clinical trials is available at freetobreathe.org/clinical-trials

STORIES OF STRENGTH

To learn about other lung cancer patients' experiences with clinical trials, please see our video, *Stories of Strength: Making the Decision to Enter a Lung Cancer Clinical Trial*. You can watch this video at freetobreathe.org/clinical-trials-video

HOW CAN I DEAL WITH MY LUNG CANCER DIAGNOSIS?

There isn't one best or easiest way to live with a diagnosis of lung cancer. Here are some suggestions for ways you can live well and take positive steps to deal with your diagnosis and treatment:

ADVOCATE FOR YOURSELF

Talk with your doctors and nurses. Ask questions. Ask them to repeat things you don't understand. Repeat back to them what you think you heard and ask them to confirm that you understand. Be active in your care and choices. Use a notebook to keep track of questions you have and information about your health and disease, such as your latest test results, medical reports and notes. Bring a family member or friend with you to all appointments so you can confirm the information you hear from your doctors.

DON'T LET ANYONE STEAL YOUR HOPE

Even the experts don't understand everything about lung cancer, especially concerning how each person will respond to treatment. Ignore the statistics. They tell you nothing about what is going to happen to you. Find doctors who share your hope for survival and are willing to fight alongside you.

LET FAMILY AND FRIENDS HELP

When your cancer was diagnosed, your family and other loved ones likely began their own personal journeys with lung cancer. They are dealing with their own sadness, fears and worries. One way for them to handle their feelings is to try to take care of you. If possible, allow them to help you. It is part of their healing process as well as yours.

When it comes to family and friends, be sure to:

- Surround yourself with positive and encouraging people.
- Take someone along to doctor visits to help listen or take notes.
- Accept offers for help. When people ask, "What can I do?", it is because they truly want to "do" something. Allow them the pleasure and privilege of helping you. They can cook for you, bring you flowers, play cards, or do whatever you can think of that will help you with your lung cancer journey. (See pages 35-36 for resources to help coordinate meals, rides, etc.)
- Continue with the community activities you can, such as book clubs, community groups, etc., to keep your life as "normal" as possible, and let your friends know what you are going through. Sharing information, involving friends in your life, and spreading awareness can help you on your journey with lung cancer.

FIND A SUPPORT GROUP

Support groups offer a chance to talk with others going through situations similar to yours, yet some people are not comfortable seeking out support groups because they feel guilty about a lung cancer diagnosis. If you have smoked and you feel it is your own "fault" that you got lung cancer, a support group may be an especially important and helpful step in your lung cancer journey. Remember that *no one deserves lung cancer,* and everyone deserves appropriate treatment. Even if there is no support group near you, multiple resources are available online and via telephone. (See page 35 for more information about support groups and services.)

You may go to your first support group meetings seeking encouragement and hope for yourself, only to find that you have the power to give that same encouragement and hope to someone else. Many kinds of support are available, and some can also help your family and loved ones who are affected by your illness. Many people continue to find comfort from support groups even after their treatment has ended.

MORE INFORMATION can be found at freetobreathe.org

RESOURCES

LUNG CANCER INFORMATION

FREE TO BREATHE (freetobreathe.org; 608.833.7905)

Free to Breathe is dedicated to improving lung cancer patients' lives, funding research and bringing the lung cancer community together in the spirit of hope through a variety of programs.

Free to Breathe offers a suite of educational and informational resources for patients and their loved ones, covering important topics, including::

- **Finding an Oncologist**
- **Clinical Trials**
- **Molecular Tumor Testing**
- **Research Updates**

Download our **Personalized Care Plan**, which will help you track treatments, appointments and other aspects of your care, at freetobreathe.org/care-plan.

CANCER.NET (cancer.net/cancer-types/lung-cancer; 571.483.1780 or 888.651.3038)

This website, sponsored by the American Society of Clinical Oncology, provides expert information to help patients and families make informed healthcare decisions.

GLOBAL RESOURCE FOR ADVANCING CANCER EDUCATION (GRACE) (cancergrace.org/lung)

This organization is dedicated to improving care for cancer patients. Through online information resources, they provide education on current and emerging cancer management options in order to empower patients, caregivers and health professionals to become direct partners in cancer care.

NATIONAL CANCER INSTITUTE:
LUNG CANCER
(cancer.gov/cancertopics/types/lung;
800.422.6237)

This website, sponsored by the federal government, describes lung cancer, its causes and treatments. It also provides information on clinical trials and research relating to lung cancer as well as a glossary of cancer terms.

SUPPORT GROUPS

CANCERCARE
(lungcancer.org; cancercare.org;
800.813.4673)

This organization provides free, professional support services for anyone affected by cancer. Lung cancer support groups are available in person, online, and by telephone. Trained oncology social workers answer every call, providing counseling, education, financial assistance, and practical help.

THE CANCER SUPPORT COMMUNITY
(cancersupportcommunity.org;
202.659.709 or 888.793.9355)

This organization, created through a merger of Gilda's Club and The Wellness Community, provides professional programs for emotional support, education and hope for people affected by cancer at no charge. General cancer support groups are available at Cancer Support Community centers around the country, and some centers also have lung cancer-specific support groups.

OTHER SUPPORT SERVICES

A number of websites allow patients and family members to share information on health updates, receive encouragement from friends and request specific assistance:

CAREPAGES
(carepages.com)

CARING BRIDGE
(caringbridge.org)

LOTSA HELPING HANDS
(lotsahelpinghands.com)

MyLifeLine
(mylifeline.org)

FINANCIAL ASSISTANCE

PATIENT ADVOCATE FOUNDATION
(patientadvocate.org; 800.532.5274)

This organization provides mediation and arbitration services to patients to remove obstacles to healthcare. They address issues including medical debt crisis, insurance access issues and employment issues for patients with chronic, debilitating and life-threatening illnesses.

CANCERCARE CO-PAYMENT ASSISTANCE FOUNDATION
(cancercarecopay.org; 212.601.9750 or 866.552.6729)

This organization addresses the needs of individuals who cannot afford their insurance co-payments to cover the cost of medications for treating cancer.

CANCER LEGAL RESOURCE CENTER
(disabilityrightslegalcenter.org/about/cancerlegalresource.cfm; 1.800.843.2572)

This organization provides free information and resources on cancer-related legal issues to cancer survivors, caregivers, healthcare professionals, employers and others coping with cancer.

PARTNERSHIP FOR PRESCRIPTION ASSISTANCE
(pparx.org; 888.477.2669)

This organization helps qualifying patients without prescription drug coverage get the medicines they need for free or nearly free. This service offers a single point of access to more than 475 public and private programs.

PATIENT ACCESS NETWORK FOUNDATION
(panfoundation.org; 866.316.7263)

This organization provides assistance to underinsured patients for their out-of-pocket expenses for life-saving medications.

UNITED WAY
(unitedway.org)

This organization leads and supports a network of nearly 1,800 community-based organizations. Local United Ways can help with basic living expenses, including rent, mortgage, utility payments and food.

If your doctor recommends a particular drug that you have trouble paying for, contact the drug company that makes it. Most drug companies have programs to help patients get the drugs they need when insurance, co-pays or other money matters get in the way. Your nurse, social worker or patient navigator can help.

QUESTIONS FOR MY DOCTOR

NOTES

We're always seeking ways to improve our resources for patients and families.

If you have feedback on this booklet or any other patient resources from Free to Breathe, please write to info@freetobreathe.org, or call 608.833.7905.


we are
FREE TO BREATHE