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Coping with Lung Cancer

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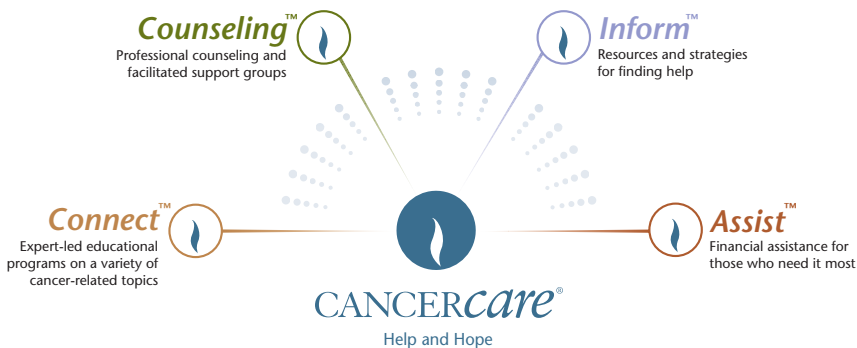
- Lung cancer basics
- Detection tools
- Treatment options
- Talking with your health care team



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Health care professionals interested in ordering bulk quantities of this booklet for their patients should contact publications@cancercare.org for more information.

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This patient booklet was originally made possible by a charitable contribution from AstraZeneca. Due to the great success of the original printing, a second printing was made possible by an educational grant from Genentech.

We now have many more treatments available for patients with advanced lung cancer.

Every day, researchers in medical centers throughout the world are making progress in preventing, detecting, and treating lung cancer. Yet the mysteries of lung cancer remain difficult to solve.

Lung cancer is the number one cause of cancer death in the United States among both men and women. We know that about 90 percent of all people with lung cancer have some history of smoking. The more you smoke, the greater your risk, although not all smokers develop lung cancer. Non-smokers can get lung cancer, too, from exposure to environmental **carcinogens** such as secondhand smoke, asbestos, or radon gas.

Since the lungs are large, tumors can grow in them for many years before they are detected. In fact, lung cancers can easily spread or **metastasize** outside the lungs without causing any symptoms. Many people who have symptoms assume they're suffering from a cold, bronchitis, or allergies.

Yet, emerging treatments and diagnostic tools—and a growing public awareness about the dangers of smoking—all offer promise for better outcomes. In this booklet we'll focus on what's new in the fight against lung cancer while stressing the importance of open communication with your family and health care providers. And we'll answer the questions you may have about coping with a disease that strikes 170,000 Americans each year.

Types of Lung Cancer

There are two major types of lung cancer:

Non-small cell lung cancer accounts for about 80 percent of lung cancers. Among them are these types of tumors:

- **Epidermoid carcinoma** (also called squamous cell carcinoma) forms in the lining of the **bronchial tubes**. This is the most prevalent type of lung cancer in men.
- **Adenocarcinoma** is found in the mucus glands of the lungs. This is the most common type of lung cancer in women and among people who have not smoked.

Bronchioalveolar carcinoma, which is a rare subset of adenocarcinoma, forms near the lungs' air sacs. Recent clinical research has shown that this type of cancer responds more effectively to the newer targeted therapies.

Signs and Symptoms

Lung cancer signs (things you or others can see) and symptoms (things you feel) generally don't appear until the cancer is quite advanced, because the lungs are such large organs. By the time a tumor has grown large enough to cause changes within the lungs, any or more of the following may be experienced:

- Difficulty or labored breathing
- Shortness of breath
- Wheezing
- Stridor (a harsh sound with each breath)
- Hoarseness
- Chronic fatigue
- Swelling of the neck and face
- Loss of appetite and loss of weight
- Persistent chest, shoulder, or back pain
- Repeated bouts of pneumonia or bronchitis
- Coughing up blood

- **Large-cell undifferentiated carcinomas** form near the surface (outer edges) of the lungs. They grow rapidly and often have spread by the time of diagnosis.

Small cell lung cancer accounts for 20 percent of all lung cancers. Although the cells are small, they multiply quickly and form large tumors that can spread throughout the body. Smoking is almost always the cause of small cell lung cancer.

The Stages of Lung Cancer

One of the most important questions to ask your doctor is, “What stage is my cancer?” The stage helps determine your treatment, taking into account the size of the tumor and whether the cancer has spread. Because early-stage non-small cell lung cancer (stages I and II) is so hard to detect, most people are diagnosed at stages III and IV.

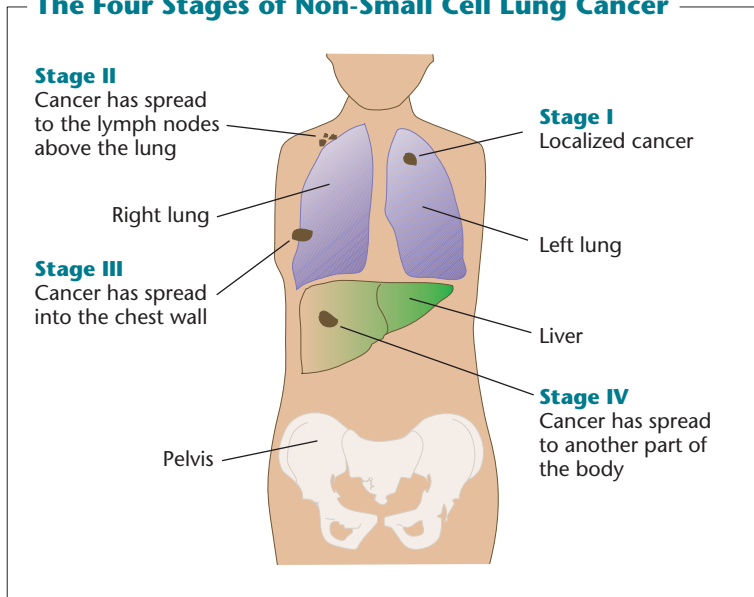
STAGE I

The cancer is located only in the lungs and has not spread. This is the least advanced stage. Treatment recommended for stage I lung cancer is surgical removal of the tumor, which is successful for most patients. While that’s very encouraging, unfortunately, most people are not diagnosed at this stage, since the symptoms are often not pronounced enough to signal cancer.

STAGE II

The cancer has spread to the nearby **lymph nodes** found in the chest near the lungs. Lymph nodes are small, bean-shaped structures that act as filtering stations to remove waste and fluids and help fight infection. When invaded by cancer cells, lymph nodes are a point from which tumors can spread throughout the body. Depending on the size of the nodes found on a **CAT scan**, your doctor may recommend an additional test, called a **mediastinoscopy**. This test is a minor operation to perform a biopsy on the lymph nodes in the chest. A mediastinoscopy can determine whether the nodes actually have cancer in them or are enlarged only because of inflammation associated with the cancer.

The Four Stages of Non-Small Cell Lung Cancer



If this procedure shows no traces of cancer in the lymph nodes, the treatment recommendation would most likely be surgery on the main tumor followed by radiation and/or chemotherapy for the lymph nodes.

STAGE III

Cancer is found in the lymph nodes in the middle of the chest adjacent to the lungs. Stage III lung cancer has two subtypes:

- If the cancer has spread to the lymph nodes on the same side of the chest as where the cancer started, it is called stage III-A. Most doctors recommend beginning treatment for stage III-A with chemotherapy or a combination of anti-cancer drugs and radiation. Then, depending on how well the treatment has worked, they may remove the remaining tumor with surgery. This combination of chemotherapy with surgery or radiation offers the best possibilities for cure.
- If the cancer has spread to lymph nodes on the opposite side of the chest, it is called stage III-B. Most doctors do not

recommend surgery for this stage. A combination of chemotherapy and radiation usually offers the greatest benefit.

STAGE IV

Stage IV is the most advanced stage of lung cancer. This is when the cancer has spread to a distant part of the body—the liver, bones, brain, or other organs. For stage IV, most doctors agree that chemotherapy is the most effective treatment. Often, different combinations of chemotherapy drugs will be tested, to see which is the most effective for a particular individual.

Small cell lung cancer is divided into two stages:

- **Limited stage** In this form, cancer is found in one lung, the tissues between the lungs, and in nearby lymph nodes only.
- **Extensive stage** Here, cancer has spread outside of the lung in which it began or to other parts of the body.

Detection Tools

Unlike mammography for breast cancer or colonoscopy for colon cancer, there is no widely accepted screening tool for early-stage lung cancer. Unfortunately, X-rays generally find only larger tumors, when the disease is in its advanced stages. But another imaging technique can now detect tiny cancer nodules (tumors) as small as 5 millimeters—less than a ¼ inch—in size. Called **computed tomography** (or a CAT scan), the technique is being tested in clinical trials in the National Lung Screen Trial and the Early Lung Cancer Action Program.

Recently, the US Food and Drug Administration (FDA) approved another device—the laser-induced fluorescence endoscopy (LIFE) imaging system—for detecting spots in the lungs that may become cancerous. This approach is currently being used by researchers to help identify **angiogenic squamous dysplasia**, a rare cell condition associated with lung cancer at its very earliest stages.

Magnetic resonance imaging (or MRIs) also shows the lungs, lymph nodes, or other parts of the body with much greater

What to Ask Before Taking Part in a Clinical Trial

- How is this experimental treatment different from the standard treatment for my cancer?
- Will I be eligible for the trial? (Bear in mind that being accepted or turned down has nothing to do with whether you will get better or not. It simply means that the characteristics of your cancer or your general health do or do not match what scientists need for this particular research.)
- What are the potential side effects?
- What steps will be taken for any pain relief?
- Will the treatment limit me physically or affect day-to-day life?
- What does it mean to sign a statement of “informed consent”?
- How long will the treatment take?
- Will I need to travel to another facility, city, or state?
- Will the project’s sponsor cover the cost of the new drugs? Will my insurance cover the doctor and hospital fees associated with the trial? Will there be other costs for travel, hotels, and meals? (Note that many health plans do not cover experimental treatments.)
- Can I bring a family member with me during treatment?
- I know I can stop participating in a trial at any time. If that happens, what’s next?

Finally, it is important to be as clear as possible with yourself about what you expect from the clinical trial. It is impossible to say in advance how effectively a given treatment will work—experimental or otherwise—so there will always be uncertainty. Discuss these issues with your family, support network, and health care team.

precision than X-rays. Other studies now underway examine markers in the blood for early detection of lung cancer. People at high risk may want to consider taking part in clinical trials.

Treatment Options

As with most cancers, surgery, radiation, chemotherapy, and

now targeted therapy—alone or in combination—are used to treat lung cancer. Depending on the stage of lung cancer, treatment choices are available. For patients with lung tumors that can be surgically removed, there is evidence that additional chemotherapy, known as **adjuvant chemotherapy**, is of benefit. For people with stage III cancer, doctors may recommend a combination of anti-cancer drugs, possibly radiation to shrink the tumor, and then surgery to remove what remains of the tumor.

For patients with stage IV disease, doctors have helped patients live longer and/or manage symptoms by combining cisplatin (Platinol) or carboplatin (Paraplatin) with other drugs, such as paclitaxel (Taxol), docetaxel (Taxotere), gemcitabine (Gemzar), vinorelbine (Navelbine), or irinotecan (Camptosar). Some patients experience side effects such as fatigue, low blood counts, thinning or brittle hair, nausea, mouth sores, or loss of appetite.

TARGETED TREATMENTS

Medical scientists now have a better understanding of cell growth and survival and how normal cells differ from lung cancer cells. This information has provided the opportunity to “target” or block cellular functions. These targeted treatments usually cause fewer side effects than traditional chemotherapy. For example, **epidermal growth factor receptor** (EGFR)—the reason behind many cancers—can be blocked with drugs such as gefitinib (Iressa) or erlotinib (Tarceva). Erlotinib can improve symptoms and survival in patients whose disease has not been controlled by chemotherapy. More and more information is becoming available, including genetic profiling, that enables doctors to determine which patients are likely to benefit from EGFR inhibitors.

The blocking of new blood vessels from forming, called **anti-angiogenesis**, is another form of targeted treatment, and, when combined with chemotherapy, can improve survival. Bevacizumab (Avastin) when combined with chemotherapy has been shown to improve survival in patients with certain types

of non-small cell lung cancer such as adenocarcinoma. The main concern with this treatment is the side effect of increased bleeding, particularly the coughing of blood.

Talking with Your Health Care Team

Learning you have lung cancer—and that it's likely at an advanced stage—may be a shock that's almost unbearable to handle alone. You may not know what questions to ask your doctor, nurse, social worker, or other members of your health care team. You may find it difficult to gather and absorb all the new information. These tips should help you approach your care in a more systematic, step-by-step way.

WHEN YOU SEE YOUR DOCTOR...

- Before the visit, write down any questions you might have.
- Bring a relative or a friend with you who can later help you reflect on the visit. Have that person take notes.
- Consider bringing a tape recorder with you as well.
- Don't be afraid to ask your doctor to slow down, explain words you don't understand, or repeat information.



ASK YOUR DOCTOR OR OTHER MEMBER OF YOUR HEALTH CARE TEAM TO DESCRIBE...

- What you might anticipate during the upcoming weeks and months
- Your treatment options
- Possible treatment side effects
- How you might participate in clinical trials

BE SURE TO TELL YOUR DOCTOR...

- **How you deal with life in general** Knowing that will help him or her design a treatment plan that's right for you. For example, do you want to be involved with all decision making? Do you want to know about all treatment options, including experimental treatments?
- **Your pain symptoms** Keep a journal of your symptoms and be specific. Is the pain jabbing? Like pins and needles? Or is it burning? What time of day or night is the pain worse or better? What triggers the pain? Doctors match the type of pain with specific medication and may prescribe physical therapy, acupuncture, or other complementary medicine alternatives.

Connecting with Your Support System

Some people openly discuss their fears with their loved ones. Others keep their feelings inside, wanting to protect their friends and family members from any sort of burden. That only serves to isolate you from those you love and need the most during a very difficult time. Don't put your life on hold. Share



how you're feeling about your cancer. Find ways to spend time with your family. If you're on a three-week chemotherapy cycle, for example, consider taking some time off from work and vacationing between cycles.

No one wants to think negatively, but should you lack the capacity to make decisions, a living will or health care proxy will allow someone else to make health care decisions for you. The best time to bring up the topic with your family is at the beginning of your care, so that you can document your wishes and then put the subject aside. Most treatment centers will provide you with advanced care planning materials.

Consider joining a support group People want acceptance and hope whatever the stage of their disease. Support groups can help by providing education, companionship, coping skills, and personal empowerment. People in cancer support groups find common ground in discussing depression, fatigue, and the side effects of treatment.

Some lifelong smokers blame themselves or believe that society blames them for their disease. The guilt can be so debilitating that some people give up on treatment. Others with lung cancer who never smoked, or stopped years ago, need to vent their shock and anger. Whether it's a support group or family counseling, it's important to talk through your feelings so you can focus on getting well.

Advocating for Yourself

Many people feel more in control when they educate themselves about their disease. The downside of gathering information is that you may learn of a poor prognosis. Take into account that any statistics you read are based on averages. As support group leaders often say to members, "Statistics don't know you."

Make sure your sources are reliable. At CancerCare, we provide free professional help to people with all cancers through counseling, education, information, referral, and direct financial assistance. We offer free telephone and online support groups, facilitated by professional oncology social workers, for people with cancer and for caregivers. Other groups, such as the Alliance for Lung Cancer Advocacy, Support, and Education (ALCASE), match patients or their family members with those who have had similar experiences through a phone buddy system. ALCASE also offers support and information through a toll-free lung cancer hotline.

For contact information and other resources, see page 16.

Once you're armed with information, realize that you are the consumer. Be assertive. You have the right to select the medical services that are right for you.

Frequently Asked Questions

Q What's the best way to deal with chemotherapy-related nerve pain (**neuropathy**)?

A Neuropathic pain results from nerve damage. It can lead to a burning sensation, a feeling of “pins and needles,” or numbness. Fairly common, neuropathy may resolve over time. To make treatment more effective, it's important to alert your doctor or nurse *immediately* about the pain you are having. A number of medications offer relief from a burning or prickly sensation. These drugs are prescribed “off label” because they were designed to treat other medical conditions, such as depression or epilepsy. It's harder to treat the type of neuropathy in which there is no feeling, only numbness. Physical therapy or massage may help.

Q I have non-small cell lung cancer. My surgical oncologist wants to perform a **lobectomy** and remove the lymph nodes in my chest. He said they would hope for a “negative margin.” Please explain.

A A pathologist will examine that part of the lung that your surgeon has removed. A “negative margin” means there are no traces of disease in the healthy tissue surrounding the tumor.

Q My mother has mixed small cell and large cell lung cancer. Her doctor said her small cell staging was “limited.” What does that mean?

A The term “limited” usually refers to an isolated area of early-stage small-cell lung cancer that can respond very well to treatment. Because of that it is associated with longer survival.

Q I've tried Iressa and another oral drug as part of a research program. Neither seems to work. Why?

A Unfortunately, not all drugs shown to be helpful in clinical trials work on all individuals. Researchers have discovered that only a small percentage of patients treated with gefitinib (Iressa) respond to this new targeted therapy. Patients who benefit most have a rare form of lung cancer called bronchioalveolar carcinoma, a type of non-small cell lung cancer usually not associated with smoking.

Q I already have lung cancer. Why should I bother to quit smoking now?

A It's never too late to quit. You'll still benefit from:

- Fewer treatment complications
- Lower chance of the tumor coming back after treatment
- Lower risk of having a second lung tumor
- Better chance of surviving

Q I just finished my second round of chemotherapy, and I'm exhausted. Even washing the dishes is an effort. Is this normal?

A Yes. One of the most common causes of fatigue is chemotherapy treatment. Chemotherapy can lower the number of red cells in your blood, which carry oxygen throughout your body and give you energy. Your medical team can provide you with helpful information to improve fatigue or prescribe medications to treat any physical conditions (such as anemia due to chemotherapy) that might be the cause of it.

Glossary

adenocarcinoma A type of non-small cell lung cancer found in the mucus glands of the lungs. This is the most common type of lung cancer in women and in people who have never smoked.

adjuvant chemotherapy The use of anti-cancer drugs after surgery to prevent the return of a tumor that has been removed surgically.

angiogenic squamous dysplasia A rare, benign cell condition associated with lung cancer in its earliest stages.

anti-angiogenesis Stopping the growth of blood vessels that feed tumors. “Angio” comes from the Greek word for vessel, and “genesis” refers to creation of blood vessels.

bronchial tubes Branches of the windpipe through which air passes to and from the lungs.

bronchioalveolar carcinoma A rare subset of adenocarcinoma which forms near the lungs’ air sacs.

carcinogen A cancer-causing substance, such as secondhand smoke, asbestos, or radon gas.

CAT scan or computed tomography An imaging test in which X-rays are taken from different angles to produce cross-sectional pictures of internal organs. A CAT scan can detect tumors as small as 5 millimeters (less than ¼ inch) in diameter.

epidermal growth factor receptor (EGFR) Promotes cell growth. The more receptors on a cell, the more it grows and divides. Drugs such as gefitinib (Iressa) and erlotinib (Tarceva) work by blocking growth factor receptors.

epidermoid carcinoma (also called squamous cell carcinoma) A type of non-small cell lung cancer found near the bronchus, the area of the windpipe (trachea) that divides into tubes. Usually linked to smoking.

large-cell undifferentiated carcinoma A type of non-small cell lung cancer that forms near the outer edges of the lungs and spreads quickly.

lobectomy When a surgeon removes an entire lobe of the lung. The lungs consist of five lobes, three in the right lung and two in the left. Lobectomies are often the most successful type of surgery for non-small cell lung cancer.

lymph nodes Small “filtering stations” that remove waste and fluids and help fight infection. When invaded by cancer cells, lymph nodes are a point from which tumors can spread throughout the body.

mediastinoscopy A minor operation that examines lymph nodes in the chest. A mediastinoscopy can determine whether the nodes have cancer in them or are enlarged simply because of inflammation associated with cancer.

metastasis The spread of cancer cells to distant areas of the body through the lymph system or bloodstream.

neuropathy Nerve pain resulting from nerve damage or as a side effect of certain chemotherapy drugs.

non-small cell lung cancer About 80 percent of lung cancers are this type. Within this category there are three subtypes: epidermoid carcinoma (also called squamous cell carcinoma), adenocarcinoma, and large-cell undifferentiated carcinoma.

small cell lung cancer Accounts for 20 percent of all lung cancers. The cells are small but multiply quickly and form large tumors that can spread to the lymph nodes and to other organs, including the brain, liver, and bones. Smoking is almost always the cause.

Resources

CancerCare

General information: 212.712.8080
Support line: 1.800.813.HOPE (4673)
E-mail: teled@cancercares.org
Website: www.cancercares.org

Alliance for Lung Cancer Advocacy, Support, and Education (ALCASE)

General information: 360.696.2436
Lung cancer hotline: 1.800.298.2436
E-mail: info@alcase.org
Website: www.alcase.org

American Cancer Society

Support line: 1.800.ACS.2345
Website: www.cancer.org

American Society of Clinical Oncology

People Living With Cancer
Website: www.plwc.org

National Cancer Institute

Cancer Information Service
Support line: 1.800.4.CANCER (422-6237)
Website: www.cancer.gov



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The information presented in this patient booklet is provided for your general information only. It is not intended as medical advice and should not be relied upon as a substitute for consultations with qualified health professionals who are aware of your specific situation. We encourage you to take information and questions back to your individual health care provider as a way of creating a dialogue and partnership about your cancer and your treatment.

All people depicted in the photographs in this booklet are models and are used for illustrative purposes only.

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Patient Care**

When your patients and their loved ones need professional support that goes beyond medical care, we can help.

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- Education
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- Information

Our trained oncology social workers can help anyone touched by cancer in the forum that is most comfortable for them—the telephone, online, or face-to-face.

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