



Support for People Dealing with Lung Cancer

A Guide for People at Risk for Lung Cancer, Those Who Are Living With Lung Cancer, and Those Who Have or Had Lung Cancer



What is the Comprehensive Lung Cancer Patient Support Program?

The American Cancer Society Comprehensive Lung Cancer Patient Support Program brings together three American Cancer Society resources – the National Cancer Information Center, the Patient Navigation Program, and the National Cancer Survivorship Resource Center – to better support the needs of people at high risk for lung cancer, those dealing with a diagnosis, and lung cancer survivors.

The goals of the program are to help people:

- Understand the roles of providers involved in their care, how they work together to give the best care possible, and what can be done to help keep everyone “on the same page” (coordinated care).
- Access reliable lung cancer information so people can make informed decisions about their care (shared decision making).
- Feel good about the decisions they make and empower them to take an active role in their health and well-being (patient empowerment).

The American Cancer Society Comprehensive Lung Cancer Patient Support Program, funded in part by the Bristol Myers Squibb Foundation, brings together three American Cancer Society resources.

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How will this booklet help me?

This guide and its resources cover many different lung cancer topics. Whether you or a loved one has been diagnosed or is at high risk for lung cancer, you will find helpful information in this booklet. It can help you take an active, informed role as you work with your health care team to plan your care.¹

What is lung cancer?

Lung cancer is a disease that can form in any part of the lungs. It happens when cells in a part of the lungs change from their normal state and begin to grow out of control without stopping. As more cancer cells grow, they can form a tumor and spread into areas around the lungs and into other parts of the body.

The cause of each case of lung cancer can be different, and not all causes are known. But scientists know some of the risk factors for lung cancer can cause certain changes in the DNA of lung cells. These cell changes most often happen because of exposure to dangerous chemicals or substances in the air we breathe.

What can I do if I'm at high risk for getting lung cancer?

The most important thing you can do is change the [risk factors](#) that put you at high risk for getting lung cancer.^{2,3}

Smoking is by far the biggest risk factor for lung cancer.

If you smoke, it's important to know:

The longer you smoke and the more cigarettes you smoke, the higher your risk.

When you stop, your damaged lung tissue [can start to heal](#) and might repair itself.

While not all lung cancers are caused by smoking, the best thing you can do to help prevent lung cancer is avoid tobacco and stay away from other people's smoke.

Other factors that can increase your lung cancer risk include certain chemical exposures you may have at work, such as radon, asbestos, uranium, arsenic, and diesel exhaust. To help limit your exposure, be sure to use the safety equipment your employer must provide.

What about lung cancer screening?

If you're between ages 55 and 74 and are in fairly good health, the [American Cancer Society recommends](#) that you be checked for lung cancer every year with a low-dose CT (LDCT) scan if you:⁴

- Currently smoke or quit smoking in the past 15 years; **and**
- Have a 30-pack-year smoking history (a pack-year = 1 pack of cigarettes per day per year. So, 1 pack a day for 30 years or 2 packs a day for 15 years both = 30-pack-year histories.); **and**
- Have been counseled on the benefits of quitting (if you still smoke); **and**

- Have talked with your health care provider about the possible benefits, risks, and harms of getting screened with an LDCT scan; **and**
- Can go to a medical center that has experience doing high-quality lung cancer screening scans and treatments for lung cancer

Talk to your provider about your risk to help you decide if lung cancer screening with an LDCT scan every year is a good choice for you.⁴ Also talk about the costs of screening so you know how much you might have to pay for it.

What are the types of lung cancer?

There are 2 main types of lung cancer. Knowing which type you have is important. Be sure to ask your health care provider which one you have or which one you may be at risk for getting. Each type gets very different treatment.

[Non-small cell lung cancer](#)^{3,5}

About 8 out of 10 lung cancers are non-small cell lung cancer or NSCLC.

The 2 main subtypes of NSCLC are adenocarcinoma and squamous cell carcinoma. There are other less common subtypes, like bronchioloalveolar and large cell carcinoma. But they're all grouped together as NSCLC.

The subtypes of NSCLC start in different kinds of cells in the lung. But the way each NSCLC subtype is treated and the outlook (prognosis) are much the same.

Small cell lung cancer (SCLC) ^{3,6}

About 2 out of 10 lung cancers are small cell lung cancer or SCLC.

SCLC is named for the size of the cancer cells when looked at with a microscope. It's also called oat cell cancer.

SCLC tends to grow faster and may respond better to radiation and/or chemotherapy (chemo) than NSCLC.

Other types of lung cancer ^{3,6}

A small number of lung tumors are carcinoid tumors of the lung. Most of these grow slowly.

Other types of lung cancer, like adenoid cystic carcinomas, lymphomas, sarcomas, and lung tumors that aren't cancer, such as hamartomas, are rare.

These aren't treated the same as the more common types of lung cancer.

What is biomarker testing?

Biomarker testing is the same as genetic testing. It's done by taking some of the cancer cells out of your lung. (This is called a biopsy.) The cells are sent to a lab that checks them for gene changes (mutations) that are linked to lung cancer.^{3,7,8}

How does biomarker testing affect my treatment options?

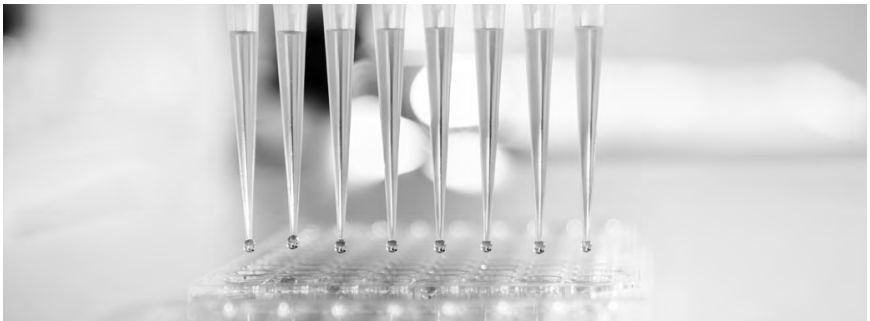
Not every person with lung cancer has biomarker changes on their cancer cells. (Or at least not any of the changes that we

know are linked to lung cancer.) But if you do have them, certain treatment options might be better for you. For instance, you may get targeted therapy instead of chemo. It depends on the kind of changes found in your cancer cells.

Some targeted drugs work by focusing on gene changes in cancer cells. If the changes aren't there, the drug might not work.^{5,6} For example:

- The most common gene change in both NSCLC and SCLC happens in the *TP53* gene.
- Right now, you can get drugs used to target this change in clinical trials.

The epidermal growth factor receptor (*EGFR*) is a protein that's found in high amounts on the surface of more than half of all NSCLCs. It helps the cancer cells grow. Drugs that target *EGFR* work best if you have a lung cancer with changes in the *EGFR* gene. But these same drugs aren't as helpful if your cancer cells have changes in another gene called the *KRAS* gene. Testing for changes in the *EGFR* and *KRAS* genes can help decide if these drugs might be a good treatment option for you.



Some NSCLCs have a change in a gene called *ALK*. Your cancer cells can be tested for this gene change to see if drugs that target this change might be a treatment option for you.

A very small number of NSCLCs have a change in the *ROS1* gene, which might make the tumor respond to certain targeted drugs.

Other, much less common gene changes that may need to be checked include *RET*, *BRAF*, *FGFR*, *HER2*, *HER3/4*, *MET*, *PD-1*, and *VEGF*. There are targeted therapy drugs that can be used to treat lung cancers with these changes, too.

Should I have biomarker testing?^{3, 7, 8}

A common subtype of NSCLC, called adenocarcinoma, most often has changes in the *EGFR*, *ALK*, *ROS1*, and *BRAF* genes.

Even though small cell lung cancers (SCLCs) sometimes have these changes, too, tumor testing is not always done. But if you have SCLC and never smoked, tumor testing should be done.

If you have lung cancer, talk to your health care provider about testing cancer cells for biomarkers.

What can I do if biomarker testing isn't available in my treatment center?

Most major cancer centers do biomarker testing.

If biomarker testing isn't done in your cancer center or isn't covered by your insurance, there may be ways you can still have it done. Talk to your health care provider about options near you.

What if I already had a biopsy but biomarker testing wasn't done?

If your cancer cells were not tested for biomarkers, there may be saved tissue that can be tested. If not, another biopsy or even a blood test can be done.

The blood test used is called a "liquid biopsy." It's done as a simple blood draw. A liquid biopsy can find many biomarkers, but it's not as good as a tissue biopsy.

Making treatment decisions

It's important to discuss all of your treatment options as well as their possible side effects with your family and your cancer care team to make the choice that best fits your needs.



How do I find out about my treatment options?

Your team will talk with you about your lung cancer treatment options. If there's anything you don't understand, ask to have it explained. Together, you'll decide what's best for you.

Both [local and systemic treatments](#) can be used to treat lung cancer.^{5, 6, 9, 10}

Local treatment: Surgery and radiation are used to treat only the part of the lung with cancer. They're local treatments; they don't affect the rest of the body.

Systemic treatment: Chemo, targeted therapy, and immunotherapy drugs are carried in the blood. They can reach cancer cells almost anywhere in the body. That's why they're called systemic treatments.

The treatment plan that's best for you depends on:

- The stage of the cancer
- The chance that a certain treatment will help
- Your age
- Other health problems you have
- Your feelings about treatment and the side effects that may come with it

What about clinical trials?¹¹

[Clinical trials](#) are research studies that test new drugs or other treatments in people. They compare standard treatments with

others that may be better. Clinical trials are one way to get state-of-the-art cancer treatment. In some cases, they may be the only way to get newer treatments. They're also the best way for doctors to learn better ways to treat cancer. Still, they're not right for everyone.

If you'd like to find out about clinical trials that might be right for you, start by asking your health care provider. If your clinic or hospital doesn't take part in clinical trials, your provider can help you find trials that are looking at the kind of cancer you have. If there are trials that could be options for you, it's up to you whether to take part. And if you do sign up for a clinical trial, you can stop at any time.

What should I think about when making treatment decisions? ^{5, 6, 9, 10}

Your cancer treatment options are based on your needs. Certain types of cancer respond better to certain types of treatment. Knowing the exact type of lung cancer you have, where it is, and how much there is are key details in deciding which treatments are best.

Your health, lifestyle, and personal preferences also play a part in deciding which treatments are best for you. Be sure you understand all your options. And don't be afraid to ask questions. Get the information you need to feel good about the decisions you make.

You may have different types of health care providers and other professionals who are part of your cancer care team, depending on the stage of your cancer and your treatment options. However, you may want to get a second opinion. Another provider might give you more information or different treatment options.

Who will be on my cancer care team?¹²

There will be many different [health care professionals](#) involved in your cancer treatment. Here are just a few:

Thoracic surgeon: a doctor who treats diseases of the lungs and chest with surgery

Radiation oncologist: a doctor who treats cancer with radiation therapy

Medical oncologist: a doctor who treats cancer with drugs like chemotherapy, targeted therapy, and immunotherapy

Pulmonologist: a doctor who specializes in treating lung diseases

Nurses: Registered nurses (RNs) might do things like give you chemo, help you through radiation therapy, and teach you and your family about what to expect. Advanced practice nurses might oversee your care or examine you and write prescriptions.

Radiation therapist: the person who helps you get in position and uses the equipment to give you radiation therapy

Dietitian: a food and nutrition expert who can help you with your diet before, during, and after cancer treatment

Social worker: a health professional with special training in dealing with social, emotional, financial, and work problems that may come with cancer

Quality of life

Side effects and palliative or supportive care^{13, 14}

[Palliative care](#) is sometimes called supportive care. It can be offered, started, and given at any time during the cancer journey. While palliative care can be provided when you are getting treatment for your cancer, it doesn't focus on treating the cancer itself. It focuses on easing problems (side effects) caused by the cancer and cancer treatment.

Palliative care is a key part of good cancer care so your quality of life is the best it can be.

The type of palliative care you need depends what side effects you're having. Your needs might change over time. Here are some [common side effects](#) and the palliative care that might help.

Side Effects	Palliative Care
Pain	Pain medicine
Shortness of breath	Oxygen
Fatigue/feeling tired	Rest and limiting activity to what you can tolerate and is OK with your doctor. You may have blood transfusions or medicine if blood cell counts are low.
No desire to eat	Drugs that improve appetite or nutritional supplements
Easy bleeding or bruising	Platelet transfusions
Infection	Antibiotics
Diarrhea or constipation	Diet changes or medicines
Depression or anxiety	Emotional support, counseling, or medicines
Nausea and/or vomiting	Anti-nausea drugs and diet changes
Skin dryness, sores, or rashes	Mild lotions and soaps, steroid creams, or antibiotics

Be sure to talk to your cancer care team about side effects so you know what to watch for. There may also be things you can do to help prevent side effects.

If you notice any problems or changes tell your team right away. Treating side effects as soon as they start can keep them from getting worse. Many of them can be controlled, some can be prevented, and most go away after treatment ends.

Diet^{5, 6, 15}

If you're at high risk for lung cancer, [good nutrition](#) can help keep your body and your immune system strong and healthy. While no diet or supplement can prevent lung cancer, a healthy diet with lots of fruits and vegetables might help reduce your risk.

Eating well during cancer treatment can help you feel better and keep your body strong. It can help you better tolerate treatment and also help you heal and recover faster. But sometimes it's hard to do because cancer and cancer treatment can:

- Affect your appetite. You may not feel like eating.
- Change the way things taste, so some foods taste bad
- Cause mouth and throat problems that make it hard to eat
- Change the way your body uses nutrients

Talk to your cancer care team about your diet and what you can do to eat well. You may want to meet with a dietitian to learn more.

If you want to use herbs, vitamins, or supplements, talk to your health care provider first. They're not all safe to use. For instance, studies have found that a supplement called beta carotene increases lung cancer risk in smokers.⁵

Exercise¹⁶

[Exercise](#) helps you have energy so you're able to do the things you need to do. It can have physical and mental benefits so you feel better, too. It can help lower your cancer risk, as well as your risk for diabetes and heart disease.



If you're at high risk for lung cancer, being active can help keep your body strong and help you get to and stay at a healthy weight. It can help improve your hormone levels and how your immune system works.

Exercise is safe for most people and can help you feel better during treatment. For example, it can help:

- Keep your muscles in shape, which can reduce your risk for falling and breaking bones
- Keep your blood flowing to help reduce your risk for blood clots
- Maintain your independence and ability to take care of yourself
- Lessen tiredness and fatigue
- Help lower anxiety and depression and improve your overall mood

After treatment, regular exercise can help you recover and get back to your every-day activities.

Talk to your provider about the types and amount of exercise that may be best for you. Remember to start slow and build up over time. No matter what your activity level is, increasing it has many health benefits.

Emotional support¹³

Most people have some degree of anxiety, fear, depression, and/or stress when facing cancer. Don't be embarrassed or ashamed. Don't try to hide your feelings or suffer in silence.

The [emotional impact](#) of cancer is real. These changes may be due to things like the cancer itself, the stigma that can come with lung cancer, chemical imbalances in your brain, or treatment drug side effects.

Be aware that the people close to you might have these feelings, too.

There are a lot of ways to get support:

- A social worker can help you figure out the cause of your distress and refer you to helpful resources.
- Support groups are a way to meet people who've been there and can understand in a way others can't.
- Counseling can help you and/or your family work through your feelings and learn how to cope with them.
- You can learn relaxation and meditation exercises that can help you control distress.

Sometimes anti-depression medicines are needed to help get you through this time.

Not caring for your emotional health can lead to things like:

- Trouble making treatment decisions
- Not following your treatment plan
- Social isolation
- Relationship problems
- Hopelessness
- Sleep problems
- Eating problems
- Thinking about cancer and death all the time

Your cancer care team knows that emotional changes are common for people dealing with cancer. Talk to them. Get help.

Pulmonary rehabilitation for breathing problems

Pulmonary rehabilitation (rehab) is a medical program that helps people with lung diseases. (Pulmonary is the medical word for lung.) You can be taught how to manage and improve your breathing through pulmonary rehab. It can help you understand how your lungs work and improve your overall physical, mental, and social functioning.¹⁹

Pulmonary rehab programs often give you tips on how you can save energy and breathe easier. The therapists may teach you about your lung condition, exercise plans, nutritional counseling, weight management, and smoking cessation. Stress also can use up energy and make you short of breath. That's why many pulmonary rehab programs teach relaxation skills and ways to avoid or ease stress.

Some hospitals and health care providers offer pulmonary rehab services. Ask your cancer care team if there are any near you that might be helpful.

You can read more about managing your breathing problems on the [LUNGevity](#) website.

Other lung cancer survivorship issues

Smoking cessation²⁰

This is the single best way to help reduce your risk of lung cancer: Don't smoke and don't breathe in other people's smoke.

If you have lung cancer and smoke, it's not too late. Quitting is still important. [Quitting tobacco](#) has been shown to help people with lung cancer live longer, even if the cancer has spread. It also lowers the chance of getting another lung cancer, which is especially important if you have an early-stage lung cancer (the cancer is small and only in 1 part of your lung).

Quitting smoking can have other health benefits, too, including lowering your risk of some other cancers and diabetes. It also helps your blood vessels work better.

If you need help to quit smoking, talk to your health care provider or call the American Cancer Society at 1-800-227-2345.

Safe and effective quit smoking methods include FDA-approved medicines that are used along with counseling.

E-cigarettes (vaping devices) are not currently approved by the FDA as an aid to help quit smoking. So far, studies show they're less harmful than regular cigarettes. But most e-cigarettes and all JUULs contain nicotine, which is from tobacco. E-cigarettes also often contain other harsh chemicals that may cause health problems.

The American Cancer Society strongly encourages everyone who smokes or vapes to do their best to quit all tobacco products, including e-cigarettes. For people who smoke but won't try to quit and won't use approved medications, they might decide to switch from regular cigarettes to e-cigarettes. But people should never use both regular and e-cigarettes at the same time.

The health effects of long-term use of e-cigarettes are not yet known. More research is needed.

Stigma associated with lung cancer

Many people find that there's a stigma or judgment about lung cancer and the people who have it. This usually doesn't happen with other kinds of cancer.

The personal feelings that come as a result of the stigma of lung cancer are very real. People can avoid or delay seeking help or treatment, they can feel distressed and overly worried, or they might not feel comfortable talking about their illness due to being afraid people will judge them.

You might find that you face judgment or bias about having lung cancer. Sometimes this comes from yourself, from people in your community, from social media or TV shows and advertisements, or from members of your family.^{17, 18}

- **Personal.** A lung cancer diagnosis might cause you to feel guilty – like you brought the cancer on yourself, or you deserve it for smoking despite the warnings you heard. This can lead to things like stress, shame, depression, and anger. It might even keep you from getting the cancer care you need.
- **Society.** Lung cancer is strongly linked to smoking. It’s often seen as a “smoker’s disease” – a risk you chose to take. You may feel like society judges you or doesn’t treat you the same as people with other kinds of cancer. This can impact your emotional health and overall outlook.
- **Family.** Sometimes family members might make you feel guilty about the cancer diagnosis, especially if it’s a result of smoking. They might seem angry, sad, scared, or resentful. They may feel guilty, too. This can affect your relationships.

If you struggle with stigma because of your lung cancer diagnosis, be honest, find others who understand, and work with your cancer care team to get support. Because cancer impacts your entire family, think about talking with a social worker or counselor to work through the mix of emotions that can come with lung cancer.

Survivorship care plans

From the time a person is diagnosed with lung cancer, they become a cancer survivor. The focus of survivorship changes as you go through your cancer journey. Because of this, you should ask your health care provider for a [survivorship care plan](#).

A survivorship care plan helps your care teams work together so your care is as coordinated as possible.

A survivorship care plan helps to detail the care you need from both your cancer care team and primary health care team.²¹

Your care plan might include things like:

- A summary of the type of cancer you had and your cancer treatment

- A list of your cancer care team members and their contact information
- A schedule for follow-up exams and tests
- A schedule for other tests you might need in the future, such as
 - » Early detection (screening) tests for other kinds of cancer
 - » Tests to look for long-term health effects from your cancer or its treatment
- A list of potential late or long-term side effects from your treatment, including what to watch for and when you should contact your provider
- Suggestions for things you can do that might help improve your health, including possibly lowering your chances of the cancer coming back

You'll still need routine physicals with your primary health care provider to watch for other things like high blood pressure, high cholesterol, and blood sugar changes that you may have. You'll also need vaccinations, like flu shots.

Lung cancer resources*

American Cancer Society: www.cancer.org

LUNGevity: www.lungevity.org

American Lung Association: www.lung.org

Lung Cancer Alliance: www.lungcanceralliance.org

NCCN Guidelines for Patients – Lung Cancer: www.nccn.org

National Cancer Institute: www.cancer.gov

Cancer Care: www.cancercare.org

Survivorship A to Z: www.survivorshipatoz.org

Get Palliative Care: www.getpalliativecare.org

Lung Cancer Research Foundation:
www.lungcancerresearchfoundation.org

Lungcancer.org: www.lungcancer.org

** Inclusion on this list does not imply endorsement by the American Cancer Society.*

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For cancer information, day-to-day help, and emotional support, call the American Cancer Society at **1-800-227-2345**. We're here when you need us.



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