

RESOURCES

The following resources can help you connect with others who have been diagnosed with lung cancer:

Lung Cancer Alliance (LCA) Information line: 1-800-298-2436. Call for answers to your questions and concerns about lung cancer and to find national and local resources.

SOCIAL SUPPORT

Lung Cancer Support Groups: For information about a lung cancer-specific support group near you, call the LCA Information Line or visit www.lungcanceralliance.org.

Phone Buddy Program: Sometimes speaking to a lung cancer survivor or caregiver about his or her experiences with stigma can help. To be connected by phone with someone who understands what you are going through, please call the toll-free LCA Information Line.

LungLoveLink: LCA's online support community is available 24 hours a day, seven days a week online at www.lunglovelink.org.

CancerCare: A national organization that provides both telephone-based lung cancer support groups and online lung cancer support groups. Call 1-800-813-4673 or visit www.cancercare.org.

Cancer Support Community: A national organization providing in-person support groups across the country as well as online support groups at www.cancersupportcommunity.org.

COUNSELING

APOS (American Psychosocial Oncology Society): Provides help finding cancer-experienced in-person counseling in your area. Call 1-866-276-7443.

CancerCare: Available for limited telephone counseling and assistance in finding other resources. Call 1-800-813-4673.

SMOKING CESSATION

QuitLine: Telephone-based tobacco cessation services available in all states. Call 1-800-QUIT-NOW (1-800-784-8669).

BecomeAnEx.org: Developed by the American Legacy Foundation to provide online support for those who want to quit smoking.

*Remember:
You do not have to share your diagnosis
with everyone. You get to decide.*



ABOUT LCA

Lung Cancer Alliance knows that stigma must be addressed at all levels. That's why we are working toward a more compassionate and comprehensive public health strategy to address lung cancer while educating the public about the disease and its misconceptions.

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LUNG CANCER

Coping With Reactions to Your Diagnosis



AFTER A DIAGNOSIS OF LUNG CANCER, YOU MAY HAVE FEELINGS ABOUT YOURSELF OR EXPERIENCE NEGATIVE REACTIONS FROM OTHERS THAT CAN BE DESCRIBED AS LUNG CANCER STIGMA.

What is lung cancer stigma?

Stigma is the expression of negative attitudes toward someone or something thought to be socially unacceptable. This can lead to fear and misunderstanding and may result from lack of information. Stigma is not new and is not unique to lung cancer.

Lung cancer stigma may cause a feeling of discomfort when others say or do things that unconsciously or openly blame the person with lung cancer for getting the disease. Stigma can be experienced as disrespect by the person with lung cancer and can prevent people from getting the care, treatment, and compassion they need.

Why does lung cancer stigma happen?

As the dangers of smoking became known, well-intended efforts to restrict it often caused a negative reaction to smokers. Because a history of smoking is so closely associated with lung cancer, the disease is still seen by many as something a person does to oneself.

It is now understood that many other factors are involved in the development of lung cancer, including exposure to industrial chemicals, such as asbestos and arsenic, and environmental agents, such as radon. Changes to certain genes, also known as genetic mutations, may also cause lung cancer to develop in some people.

Stigma can affect anyone diagnosed with lung cancer. While not everyone experiences stigma, this brochure can help if you do.

Levels of stigma

Individual (self-stigma). Smokers and former smokers may blame themselves for developing lung cancer.

"I feel a lot of guilt and shame, believing that I caused my own cancer because I was a smoker, and then believing that other people feel that way about me too."

Family and friends. Loved ones may express blame due to sadness, anger, and concern.

"I overheard my wife say, 'These were to be our happy years... I'm so angry at how his smoking has taken away our future!'"

Society. Lung cancer may be perceived as a "smoker's disease" by some individuals (in the public, media, government, and healthcare profession). As a result, people with lung cancer may receive less compassion and support than they deserve.

"When I told my neighbor that I had lung cancer, he said, 'What did you expect? You smoked—you got lung cancer!'"

How might stigma affect me?

People respond to stigma in different ways. Reactions may include:

- Reluctance to share the diagnosis
- Social isolation
- Increased feelings of guilt, shame, stress, anxiety, anger, and depression
- Delaying treatment, not remaining on treatment, or not seeking treatment at all
- Stress in relationships with family and friends
- Loss of hope

"This stigma makes some people angry, but I just need to realize why the stigma exists and maybe try to educate society as a whole and make people understand what it's really all about."

COPING WITH STIGMA

How you cope may depend on the day, the situation, and the audience. These ideas may work in a variety of settings:

Create a "teachable moment." Empower yourself by learning the facts about lung cancer, and use the opportunity to educate others.

Tell your story. Give a face to lung cancer by letting others know that it affects a wide range of people—smokers and nonsmokers, mothers, fathers, daughters, sons, and people of all ages, races, religions, and economic status.

Be honest about your feelings. Tell the person who has made you uncomfortable why a remark was hurtful, and explain that lung cancer deserves the same understanding and compassion as other diseases.

You have the right to compassionate care from your healthcare team. If you are not getting that, consider switching doctors or facilities.

Find others who understand. There are a number of ways to connect with other lung cancer survivors. See the resources section for ideas on how to connect.

Volunteer with Lung Cancer Alliance. History has shown that stigma can be reversed, and Lung Cancer Alliance is leading the way!

A SPECIAL NOTE ABOUT SELF-STIGMA

Lung cancer stigma comes from its association with smoking. Here are a few things to remember:

- Most people start smoking when they are young and become addicted before they are capable of understanding the risk
- The majority of people who develop lung cancer today started smoking before its impact on health was fully understood
- It is not fully understood why some people get lung cancer and others don't. Although smoking greatly increases a person's risk for lung cancer, most people who smoke never develop the disease. In contrast, about 10% of people who develop lung cancer have never smoked
- Lung cancer is seen as "the smoker's disease," yet smoking increases the risk for developing heart disease, stroke, and many other cancers
- Research has shown that for some people, nicotine (the addictive substance in cigarettes) is as addictive as cocaine and heroin

We cannot change the past. Guilt and shame can drain your energy. Try to stay focused on yourself and your treatment. If you need help, consider talking with a therapist about your feelings.