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# LUNG CANCER STIGMA: How to Cope



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A GUIDE FOR THE PATIENT



#### After a lung cancer diagnosis, you may have feelings about yourself or experience negative reactions from others that can be described as

## LUNG CANCER STIGMA.

## 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

Lung cancer stigma may cause a feeling of discomfort when others say or do things that unconsciously or openly blame you for getting the disease. Stigma can be experienced as disrespect by you and can prevent you from getting the care, treatment and compassion you 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 you did to yourself.

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 exposure to environmental agents, such as radon. Changes to certain genes, also known as genetic mutations, can 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.



## 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.

## 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 & FRIENDS**

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

66 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, you may receive less compassion and support than you deserve.

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

# A SPECIAL NOTE ABOUT

#### 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 do not. Although smoking greatly increases a person's risk for lung cancer, most people who smoke never develop the disease. In contrast, about 20% of people who develop lung cancer have never smoked.
- Lung cancer is seen as "the smoker's disease," even though 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.



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#### **REACTIONS TO STIGMA**

#### You may 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

#### 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 US.** History has shown that stigma can be reversed and we need your help.

## **REMEMBER:**

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





### FREE RESOURCES FOR YOU

**HELPLINE**: A toll-free line answered by caring professionals who provide information, support and referral for anyone with questions about lung cancer.

**PEER SUPPORT**: Phone Buddy and GUIDES programs connect you with someone going through the same thing you are, whether you are newly diagnosed, out of treatment or have lost a loved one.

**NATIONAL SUPPORT GROUP NETWORK**: Find an in-person support group network near you for face to face support through our national network.

**EDUCATIONAL MATERIALS**: Brochures and one-pagers provide information on lung cancer topics to help you understand your diagnosis, cope with stigma, manage side effects and learn about new treatment options.

**LUNGMATCH**: A personalized service that informs and guides you through the many medical and clinical trial choices, helping you identify the appropriate treatment options to discuss with your doctor.

**WEBSITE**: go2foundation.org gives you access to the most up-to-date information on all things lung cancer from new treatments, ways to connect with others in the community and available resources.

## WHERE CAN I GO FOR MORE INFORMATION?

For more information about lung cancer and current treatments, to discuss support options or for referral to other resources, please contact us:

HELPLINE | 1-800-298-2436 or support@go2foundation.org

BIOMARKER TESTING & CLINICAL TRIAL MATCHING | lungmatch.org

WEBSITE | go2foundation.org







Founded by patients and survivors, GO2 Foundation for Lung Cancer transforms survivorship as the world's leading organization dedicated to saving, extending, and improving the lives of those vulnerable, at risk, and diagnosed with lung cancer.

GO2 Foundation works to change the reality of living with lung cancer by ending stigma, increasing public and private research funding, and ensuring access to care.

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