# **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, 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!"



Lung Cancer Alliance is the only national non-profit organization dedicated to providing information, support and advocacy for people living with lung cancer and those at risk for the disease.

ENDING INJUSTICE AND SAVING LIVES THROUGH AN ALLIANCE OF ADVOCACY, EDUCATION AND SUPPORT.

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The mission of APOS is to advance the science and practice of psychosocial care for people with cancer.



# COPING WITH REACTIONS TO YOUR DIAGNOSIS

1-800-298-2436 LungCancerAlliance.org 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 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.

# **HOW MIGHT STIGMA AFFECT ME?**

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

# 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.

# 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.

# 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 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

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

# LUNG CANCER INFORMATION LINE

A support, information and referral line for anyone with questions and concerns about lung cancer. Free written lung cancer materials mailed upon request.

# LCA WEBSITE

A credible source for information about lung cancer, treatments, support resources, relevant news and Calls to Action.

# LUNGLOVELINK

An online community linking those touched by lung cancer to support, resources and local events. Members can ask questions, respond to discussions, create personal profiles and build a network of online friends.

# PHONE BUDDY PROGRAM

One-on-one telephone support program that connects you to lung cancer survivors and care givers. Our volunteers lend support and share information and resources.

# CLINICAL TRIAL MATCHING SERVICE

A pre-screening and referral service that identifies clinical trial options. Clinical trial specialists find available trials based on the patient's diagnosis and treatment history.

# PERSONALIZED WEBPAGE

We partner with CaringBridge to offer free, personalized websites that connect people with lung cancer with family and friends to share information, love and support during treatment and recovery.

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

1-800-298-2436 | LungCancerAlliance.org

# Remember:

YOU DO NOT HAVE TO SHARE YOUR DIAGNOSIS WITH EVERYONE. YOU GET TO DECIDE.