COPING SERIES

LUNG CANCER STIGMA: HOW TO COPE



1-800-298-2436 LungCancerAlliance.org

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 descibed 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.

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.



COPING

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: Through our toll-free HelpLine we can answer your questions, direct you to financial and other resources available or just listen to you.

PHONE BUDDY PROGRAM: This program matches you with another survivor so you can receive support and advice from someone who has walked in your shoes.

NATIONAL SUPPORT GROUP NETWORK: Find an inperson support group network near you for that face to face support through our national network.

LCA UNITE: Our mobile app features a chat room for survivors, appointment management, side effect trackers and a complete listing of treatment centers near you.

LUNGMATCH: This program provides personalized treatment and clinical trial navigation so you can find and understand your path to the best treatments.

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

CLINICAL TRIAL MATCHING | lungmatch.org

ALL THINGS LUNG CANCER | lungcanceralliance.org

E-MAIL | support@lungcanceralliance.org

MAIL | 1700 K Street NW, Suite 660, Washington, DC 20006

LUNG CANCER ALLIANCE

SAVING LIVES AND ADVANCING RESEARCH BY EMPOWERING THOSE LIVING WITH AND AT RISK FOR LUNG CANCER





We are a 501 (c) (3) non-profit organization. All donations are tax deductible to the full extent permitted by law.

Copyright © October 2016, Lung Cancer Alliance. All rights reserved.