Coping with the Stigma of Lung Cancer

Stigma is the negative feeling people have towards a situation or condition. People can feel stigmatized when they are met with judgement related to a behavior or trait.

Anyone can get lung cancer. Lung cancer happens when cells in the lung mutate or change. A mutation is a change in a cell’s genes that may lead to cancer growth. Various factors can cause this mutation.

Unfortunately, due to public messaging about smoking and lung cancer risk, some people with lung cancer may experience stigma in the form of judgement, guilt, or shame. This fact sheet explains the stigma you may experience after a lung cancer diagnosis and provides tips on how to overcome those feelings.

Cancer Support Community’s Lung Cancer Registry, which includes questions uniquely relevant to people living with lung cancer, was launched in December 2014. According to the 2020 Registry Report, 37% of lung cancer patients believed that having lung cancer is their fault and reported feeling guilty because of their diagnosis. If you are having these feelings, know you are not alone. Stigma and shame are common experiences of many people living with lung cancer. Remember that nobody deserves to get cancer.
WHAT YOU CAN DO
Dealing with a lung cancer diagnosis and treatment can be difficult to manage. The added feelings of stigma, shame, and blame do not help you heal. Focus on identifying what you can do to find support after a lung cancer diagnosis.

You cannot change people’s thoughts, but you can change your own and you can change your experience. It can be helpful to think about what is in your control:

- Take steps to get the care you need for lung cancer
- Surround yourself with people who support you
- Talk about your experience with a therapist, social worker, spiritual leader, or in a support group
- Take advantage of new developments in lung cancer treatment

Remember, it does not matter how you got lung cancer.

FINDING SUPPORT
For some people, it can be helpful to talk to other people experiencing lung cancer. Your health care team may be able to connect you with a social worker who hosts a lung cancer support group. There are also opportunities to join support groups online. Support groups can help introduce you to other people who are in similar situations that you can relate to.

You may want to work one on one with a social worker or therapist to talk about your thoughts and feelings. Some cancer centers may offer these services. Your insurance may also be able to refer you to a mental health provider. If you need help finding a support group or therapist, call Cancer Support Community’s Cancer Support Helpline. Our trained community navigators and resource specialists can help look for support in your area. Call 888-793-9355.
TALKING ABOUT STIGMA

In some cases, you may feel like you are being treated differently because of your diagnosis. You deserve good care regardless of your medical condition or smoking history. If your care team does ask about your smoking history, they may be asking because smoking history may impact treatment options.

It is important to find a care team that you trust and can be open and honest with. They should treat you with dignity and respect. If this is not happening, advocate for yourself. Talk to your care team about your concerns. You do not need to continue working with a care team if you are being mistreated. Consider seeing a different provider if you are uncomfortable.

Even those closest to you may associate lung cancer with tobacco use. You may be asked if you smoked. You do not need to share this information if you don’t want to. What you say may depend on who is asking. You can:

- Talk to them about the emotional impact of the question: “Did you smoke?”
- Advocate for yourself by sharing information about lung cancer from trusted resources like the ones on the last page of this fact sheet
- Remind them that you can never know exactly why you got lung cancer, but you do need their support and empathy
- Regardless of if you have a history of tobacco use or not, questions about smoking and others’ assumptions can be frustrating. All of these feelings are valid.
CANCER SUPPORT COMMUNITY RESOURCES

Cancer Support Helpline® — Have questions, concerns or looking for resources? Call CSC’s toll-free Cancer Support Helpline (888-793-9355), available in 200 languages Mon-Fri 9am-8pm ET and Sat 9am–5pm ET.

Open to Options® — Preparing for your next appointment? Our trained specialists can help you create a list of questions to share with your doctor. Make an appointment by calling 888-793-9355 or by contacting your local CSC or Gilda’s Club.

Frankly Speaking About Cancer® — Trusted information for cancer patients and their loved ones is available through publications, online, and in-person programs.

Services at Local CSCs and Gilda’s Clubs — With the help of 170 locations, CSC and Gilda’s Club network partners provide services free of charge to people touched by cancer. Attend support groups, educational sessions, wellness programs, and more at a location near you. www.CancerSupportCommunity.org/FindLocation.

Cancer Experience Registry® — Help others by sharing your cancer patient or cancer caregiver experience via survey at www.CancerExperienceRegistry.org.

MyLifeLine — CSC’s private, online community allows patients and caregivers to easily connect with friends and family to receive social, emotional, and practical support throughout the cancer journey and beyond. Sign up at www.MyLifeLine.org.

Grassroots Network — Make sure your voice is heard by federal and state policy makers on issues affecting cancer patients and survivors by joining our Network at www.CancerSupportCommunity.org/become-advocate.

Photos are stock images posed by models.

The Cancer Support Community and its partners provide this information as a service. This publication is not intended to take the place of medical care or the advice of your doctor. We strongly suggest consulting your doctor or other health care professionals to answer questions and learn more.