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Welcome to our training: Messaging in a Way that Unites us

I am your host, Carly Ornstein, National Director of Lung Cancer Education at the American Lung Association.

During this training, we will discuss some points for you to consider when you engage in lung cancer advocacy activities. These activities might include talking to your congress people, doing interviews with the media, speaking at events or even just talking to people in your network about lung cancer. The way you frame your message can impact lung cancer stigma. Stigma is a complex issue. The only way we are going to be able to tackle it is if the lung cancer community changes the way it talks about lung cancer. Today I will go through some guidelines for you to consider as you share your story so you can be the best advocate you can be and help move the needle on lung cancer stigma.

In today's training, we are going to:

- Review some stigma reducing messaging guidelines
- Discuss ways to respond to the question "Did you smoke?"
- Then I will review the major points we discussed
- And close with some parting thoughts and where you can access more resources including a copy of this training transcript for future reference.

Let's jump right in. One point you might want to consider when thinking about how to tell your story is not placing an over emphasis on your smoking history. For some people this is not something you ever think to factor into your story and for others of you it is something you usually include. The bottom line is, is that when we separate ourselves by smoking status it can create divisions in the lung cancer community. And in order for lung cancer to get the attention it deserves, we need to unite as one community. Also if smoking status is always part of the conversation, it only reinforces to the public that it is acceptable to ask if someone smoked when they hear of a lung cancer diagnosis. I want to be clear and say that we know smoking is the number one risk factor for lung cancer. And when we are talking about lung cancer prevention, it is important to recognize this fact. But once someone is living with a lung cancer, we should think carefully about whether or not a discussion of their smoking history is really relevant to their needs and hopes for the future.

Some people do feel like their smoking status needs to be included. If you feel like sharing your smoking history is an important part of your story, there are certain words you should avoid that can worsen division in the lung cancer community. Words like "deserve, blame, cause and bad" can be very stigmatizing to other lung cancer patients. Unless you are saying, "no one deserves lung cancer or no one is to blame". I am going to give some examples.



For example, if you want to share that you were a never smoker you might say: **“I wasn’t at high risk for lung cancer so I was completely shocked,”** instead of “I didn’t deserve lung cancer. I never smoked a day in my life.” Another way to frame the message would be **“I share that I never smoked so people know lung cancer can affect anyone,”** instead of “Lung cancer isn’t only a smoker’s disease.”

If you have a smoking history you might say, **“When I became addicted to cigarettes at a young age I never imagined I would end up with lung cancer,”** instead of “I knew I shouldn’t have started such a bad habit” (which downplays the incredibly powerful nature of the addiction). Another option is to say, **“I knew I had an increased risk because I smoked but nothing prepared me for actually hearing those words.”** instead of “I know smoking is bad and that it caused my lung cancer but it was still hard to receive the diagnosis.”

You can see that sometimes the distinction between the two phrases is minor, but they have very different impacts. Some elicit empathy and a sense of community, while others allude more to personal responsibility and can divide lung cancer patients based on experience instead of uniting them.

But you may not want to share your health history at all. The risk factors you may or may not have been exposed to may not play a large part in your personal story or might not be a choice of focus when you share your story. What you include in your story is your own personal choice. However, taking a step back and thinking **“Is there a way I can say this that is more unifying or inclusive?”** is a valuable task and will make your message much stronger and less stigmatizing.

The other major contributor to the fear and stigma surrounding lung cancer is the low survival rate. Fortunately, incredible advancements have been made in lung cancer in just the past few years, and lung cancer outcomes can improve. Including messages that are hopeful and speak to lung cancer progress help to reduce stigma because it begins to show that lung cancer isn’t a death sentence. Therefore, as you tell your story you might want to focus on making sure you include messages of hope and the impact that lung cancer research and advancements have had on you.

I want to touch on the topic of uniting the general cancer community. Unfortunately, cancer is something that has touched most families in some way. If it has touched your family, it is devastating, no matter what kind of cancer it is. Also, we know that innovations in other cancers have helped pave the way for some lung cancer advancements, like is the case with immunotherapy. It can be tempting to compare the attention lung cancer gets to other cancers like breast or prostate, but that is another message that can be dividing. It could also offend or isolate someone who might have a personal connection to another type of cancer. This is another item for you to consider as you frame your messaging.

Unfortunately an all too common question lung cancer patients and their loved one have to field is “Did you smoke?” or “Did he/she smoke?” Patients report this question being the most distressing behavior they encounter. That is why it is so important to address it when it comes

up. There are a few ways to address this question that can help change the conversation about lung cancer. There is no “right” or “wrong” way to answer. The approach you choose is based on the situation you are in. You might respond to a stranger differently than you would to a close friend who’s asking the question. Or you might respond to a journalist differently than to someone you’ve just met. Whether or not you have a smoking history may impact how you choose to respond as well. Lastly, your comfort level plays a part. Some people prefer a more compassionate or educational approach, while others might rather be more confrontational.

The message suggestions I am about to go through are designed to be guidelines for you to consider. It is always best to phrase responses in your own words, in a way that feels comfortable to you. The most important thing is that you are speaking up.

As I mentioned before, there are different ways you may want to approach this question. Your response can be educational, like discussing the multiple risk factors for lung cancer or educating about the impact of the question. Your response can be challenging which can make the questioner reconsider why they are even asking “Did you smoke?” in the first place. Or your response can be empathetic. Acknowledging that most people don’t intend to be hurtful, but that is how the “Did you smoke?” question often comes off. Now I am going to go through some sample responses.

If someone asks did you smoke you might want to say:

**“I did (or I didn’t) but did you know that never smokers can get lung cancer too? In addition to smoking, other risk factors include exposure to radon gas, secondhand smoke, asbestos, air pollution and family history.”**

You might want to follow up by mentioning that in many cases, people don’t know what has caused their lung cancer and that anyone with lungs can get lung cancer.

Another way to answer this question that is a little more confrontational is to say: **“Does it matter?”** This is a good way to challenge the person asking the question to think about his or her own biases. You might want to follow it up by saying:

**“It shouldn’t matter why or how I got lung cancer, I really need support as I go through treatment.”**

**“No one really knows exactly why I got lung cancer and I prefer not to focus on that.”**

**“No one deserves lung cancer, no matter whether they smoked or not.”**

This type of response can be effective in catching the attention of the questioner, but may shut down communication if the person feels attacked. It is important to consider this point when using this response.

Another way to go is to appear empathetic to the person asking the question but use it as an opportunity to educate about the impacts of the question. You might say, **“I know where that**

**question comes from but do you know how hard it is to hear it when you are diagnosed?”**

You can follow it up with:

**“I understand why you might ask that. You want to know why I got lung cancer or you are worried about your own risk. I know it can be hard to know what to say.”**

**“I know you didn’t mean any harm by your question. But it assigns blame to those of us with lung cancer, it assumes people with lung cancer deserve to be sick if they ever smoked, and it doesn’t make me feel very supported during this time.”**

Most people have never thought about the impact of asking, “Did you smoke?” Sharing the negative effects of this question can be any eye opening experience for the questioner who will hopefully think twice before asking another patient if they smoked.

Another direction you can take is to answer the question honestly but then educate about the powerful addictive nature of tobacco. The bottom line is many people lack empathy for people with a smoking history, which is a major driver of lung cancer stigma and one reason the disease has remained in the shadows. It is difficult for the public to think of smoking as an addiction rather than a habit. The truth is, smoking is incredibly addictive. Most people started young, and we know the tobacco companies have targeted minors. The powerful addictive nature of tobacco is something that can be hard for people who have never smoked to understand. No one should be judged for a choice they made. Most people who smoke or used to smoke wish they had never started. The bottom line is that all lung cancer patients deserve empathy and support and no one deserves lung cancer. Encouraging the public to have empathy for all lung cancer patients will be a step in the right direction for reducing lung cancer stigma and uniting the community and these types of messages I just mentioned can be helpful in getting there.

I hope we’ve given you some food for thought and you will consider some of these guidelines in your advocacy work. Let’s recap what we went over. Let’s start with some things to avoid:

- An overemphasis on smoking status can divide the lung cancer community instead of uniting it. Emphasizing smoking history reinforces that it is acceptable for the public to ask lung cancer patients if they smoked. It can also make some patients who smoked feel as though they are being blamed. Focusing on shared experiences of lung cancer patients helps bring the lung cancer community together and empowers other advocates to speak up.
- Words that are stigmatizing and divisive, including deserve, blame or cause. Think about if what you are saying includes those words or implies them (unless you are saying no one deserves lung cancer or no one is to blame, as I mentioned).
- Also comparisons to other cancers can isolate people who have experience with other cancers and in order to move the needle on lung cancer, we need to all join together.

We also need to remember that advances in other cancers can help lung cancer as I mentioned.

- Lastly we want to avoid ignoring stigmatizing behavior. It can sometimes be uncomfortable to speak up or challenge someone's ideas or questioning, but it will get easier the more you do it.

Now let's talk about to include.

- When you frame your story or messages do include hopeful stories to counteract the fatalism associated with lung cancer. Speak in a way that is empathetic of all people living with lung cancer. Ask yourself if you are isolating other lung cancer patients with your tone or words.
- Also effective is sharing how lung cancer advancements like screening or drug approvals have personally affected you. It is a great way to grab the attention of congress people and journalists and make a strong case for further support of lung cancer research. As I have mentioned before, messages that unite the community are powerful.

When you are considering how to craft your message and story, some questions to consider might be: What challenges are we all facing? How can we all come together to change the way people think and talk about lung cancer? How can we empower more patients and their loved ones to speak up? How can we bring lung cancer out of its shadows together? Sharing your story is a great first step and I hope what I have shared today empowers you to do just that.

For more information on lung cancer stigma, including our report: Addressing the Stigma of lung cancer, visit [Lung.org/stigma](https://Lung.org/stigma). Thank you for your time and all you do to raise awareness of lung cancer.