

Tips For Speaking Up About Living With Lung Cancer

#SOUNDUP4LungCancer

A lung cancer diagnosis can be overwhelming. Many people with lung cancer may be hesitant to speak up about what they truly need and advocate for themselves, which can potentially lead people to delay treatment, not remain on treatment, or not seek treatment at all.¹

Below are tips and guidance from people living with lung cancer, caregivers, and health care providers on how they can advocate for themselves, feel empowered, and speak up throughout their treatment journey.

Tips for People Living With Lung Cancer:



During your appointments, it can be overwhelming to receive a lot of information at once, so **take notes!** Writing things down to read back again later can help and inform what you want to talk about next time.



Come prepared to have open conversations at your appointments. Bring **pre-written questions** and think about the topics you want to address. These may include asking about available treatments, recent advancement in care for patients or what support resources may be available.



Take advantage of resources available to you at your health care facility, such as nurse navigators, oncology social workers, or health education specialists. They are there to advocate for you, provide educational support, and help you make decisions.



Be clear with your doctor on your goals for treatment and what you are experiencing. This helps you and your health care team make collaborative decisions to determine the best treatment option for you.



Track your wellness. Utilize a journal or app to keep track of what you ate, your sleep habits and your movement to better help you and your health care team see a bigger picture of how you're doing.

“It’s really important for patients to **utilize whatever resources are available in their treatment center** and to **ask someone** on the care team to refer them to these resources.”

-Patricia, Nurse Navigator



Utilize in-person and online support groups as a way to connect with other people affected by lung cancer. These are often available through trusted patient organizations or your treatment center.



Remember you are an **expert in your lived experience**, and it is important to continue to advocate and trust yourself while working with your care team.



Ask about **biomarker testing**. A biomarker test can help you and your doctor select the appropriate lung cancer treatment for you.



Don't forget what makes you, you! As able, engage in your favorite hobbies, activities, and spending time with loved ones.



Gather information! Conduct online searches for more details regarding your diagnosis and potential next steps using trusted resources. By understanding your diagnosis and the next steps in your treatment process, you may feel more confident in advocating for yourself.

“It is important that you lean into the experiences that bring you joy. Before your diagnosis, you're a whole person living inside of your life, and then your diagnosis happened. Connect with that self that you were before your diagnosis. **You're still that person.**”

-Lavern, Living With Lung Cancer

Tips for Caregivers:



Join your loved one or friend at their appointments. Come prepared with any questions that you both may have and be their eyes and ears, writing down notes. Continue to bring these questions to your care team to discuss over time.



Caregivers can include a **team of people**. It can be helpful to lean on each other to create a network — whether it's a ride to appointments, picking up groceries, or someone to talk to.



Support doesn't always look a certain way, it may be physical, mental or emotional — embrace your role to help your loved one as best you can.



Don't forget to **take care of your own health**, so you can show up as your best self when caring for your loved one. Make sure you are eating healthy, staying on top of your own health appointments, and seek out mental health treatment if you need it.

I encourage them to ask whatever questions they have without feeling any hesitation, any embarrassment, or without thinking whether any question is worth asking or not. I encourage them to **ask everything that's on their mind.**”

-Oncologist

For more information, visit www.novartis.com/diseases/lung-cancer/sound-up

References:

1. Carter-Harris L. Lung cancer stigma as a barrier to medical help-seeking behavior: practice implications. *J Am Assoc Nurse Pract.* 2015;27(5):240-245. doi:10.1002/2327-6924.12227.