

Sound Up for Lung Cancer

A lung cancer diagnosis can be daunting, but speaking up doesn't have to be. Patient-inspired and community-led, Sound Up aims to empower people affected by lung cancer to advocate for themselves by sharing their experiences and needs.

Living with a lung cancer diagnosis

Overwhelmed. Shame. Guilt. Isolation. These are some of the many feelings people diagnosed with lung cancer and their caregivers can experience¹. These feelings can cause silence².

People affected by lung cancer may be reluctant to share what they are going through, speak up about their needs, or advocate for themselves. This can potentially lead people to delay treatment, discontinue treatment, or not seek treatment at all³.

For anyone diagnosed with lung cancer, it is an overwhelming time. But you are the CEO of your own health. Nobody cares more about your whole being, your whole health, than you do. At the end of the day, you have to be the one to ask questions, challenge things you don't understand, make final decisions, and be okay with the plan moving forward.

Jill Feldman, Living With Lung Cancer and Lung Cancer Patient Advocate

People with lung cancer may be hesitant to speak up about what they truly need and advocate for themselves. But it's not just up to the patients—their health care providers and support networks are crucial to these important dialogues.

Meet Keith



In August 2021, Keith received shocking news from his doctor—he had been diagnosed with non-small cell lung cancer, and the prognosis wasn't good. Despite this, Keith was determined to stay positive and do everything he could to fight the disease. He wanted to continue to live his life to the fullest and spend time with his family, and he made those wishes known to his doctors. "I come from a long line of strong women. I speak my mind. If I believe in something, I'm not afraid to say it," he said.

Once Keith and his team were on the same page, they worked together to come up with a care plan that was right for his type of lung cancer. He underwent biomarker testing that showed he was eligible for targeted therapy, which he continues to take to treat his lung cancer.

Today, Keith has adjusted to his new normal and has gone back to work as an electrician part-time. He enjoys spending time with his wife, Sandy, who has been his number one supporter throughout his diagnosis and treatment. By sharing his story, Keith hopes to empower other patients to advocate for themselves and seek out support when they need it.

For anyone else diagnosed with lung cancer, he wants them to know, **"Don't be afraid to speak up and ask for help. There are plenty of great people around you who want to help you and support you!"**

Taking action

Through Sound Up, we aim to empower people affected by lung cancer to speak up for themselves by asking questions, expressing their needs, and having open conversations with their health care providers about their experiences.

We want to encourage patients to speak up, to ask questions so that they really get a full understanding of the disease and the situation. It's not only important for the patient, but it's also important for their care team. If a patient is very reluctant and timid to ask to speak up, then a lot of questions go unanswered.

Oncologist, Germany

Conversations between a person with lung cancer and their care team can help set expectations and goals, inform treatment decisions, and impact care. That's why it is so important for people living with lung cancer and their caregivers to speak up. Here are a few steps people can take⁴:

- **Gather information:** Check your care center for resources like nurse navigators, oncology social workers, or health education specialists and visit websites of trusted organizations, including those from lung cancer patient advocacy groups
- **Plan for a focused conversation:** Prepare questions you want to ask your doctor at your next appointment and think about the specific topics you want to talk about
- **Take notes:** It can be overwhelming to receive a lot of information at once, so writing things down to read back again later can help. It can also guide what you want to talk about next time
- **Track your wellness:** Tracking your food, sleep, and exercise can help you and your health care team see a bigger picture of how you're doing
- **Ask about comprehensive biomarker testing:** A comprehensive biomarker test can help you and your doctor zero in on the right lung cancer treatment for you
- **Confirm when you're unsure:** If you have concerns, there is an option to get a second opinion to make sure you've explored everything possible

Resources from the lung cancer community

Patient advocacy organizations around the world have information and resources to help people living with lung cancer cope with stigma and have meaningful conversations with their loved ones and health care providers.

- American Lung Association: [How Do I Talk About Lung Cancer?](#)
- GO2 Foundation: [Lung Cancer Stigma: How to Cope](#)
- LUNGeivity: [What to Ask Your Doctor?](#)
- International Association for the Study of Lung Cancer: [Language Guide](#)
- National Coalition for Cancer Survivorship: [Becoming a Self-Advocate](#)
- Lung Cancer Europe: [Psychological and Social Impact of Lung Cancer](#)
- Lung Cancer Research Foundation: [Living with a Diagnosis of Lung Cancer](#)
- Lung Cancer Foundation of America: Hope with Answers: [Living with Lung Cancer Podcast](#)

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Additional Resource

- ["Raise Your Voice: Speaking Up About Living With Lung Cancer"](#): An online panel discussion hosted by LUNGeivity in collaboration with Novartis. The discussion features a LUNGeivity care navigator, a person living with lung cancer, and a nurse navigator who shared their personal stories, challenges, and

lessons learned.

- [Tips for Speaking Up](#): An infographic providing 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.
- [Empowering People with Lung Cancer](#): An informational brochure to learn more about how people living with lung cancer can be empowered to advocate for themselves.
- [Look Closer at Lung Cancer](#): A website to raise awareness on the importance of biomarker testing for people with non-small cell lung cancer.

References:

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List of links present in page

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2. <https://www.lung.org/lung-health-diseases/lung-disease-lookup/lung-cancer/living-with-lung-cancer/how-to-talk-about-your-cancer>
3. https://go2foundation.org/wp-content/uploads/GO2-Stigma_FINAL-1.pdf
4. <https://www.lungevity.org/for-patients-caregivers/navigating-your-diagnosis/what-to-ask-your-doctor>
5. <https://www.iaslc.org/IASLCLanguageGuide>
6. <https://canceradvocacy.org/resources/publications/self-advocacy/becoming-a-self-advocate/#toggle-id-1>
7. <https://www.lungcancereurope.eu/2020/10/15/5th-edition-of-the-luce-report/>
8. <https://www.lungcancerresearchfoundation.org/for-patients/living-with-lung-cancer/coping-with-emotions-upon-diagnosis/>
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