



Hope With Answers: Living With Lung Cancer

Transcript for The First 7 Days: Why a Second Opinion Can Save Your Life

- Narrator:** Welcome to a Special Re-Release of this Hope With Answers Podcast. Originally aired in July 2020, Part 2 of "The First 7 Days" continues to be a crucial guide for anyone newly diagnosed with lung cancer. In this episode, Dr. David Carbone, along with lung cancer advocates, emphasizes the importance of seeking a second opinion—especially from a specialist at a university-based center—to explore all available treatment options. Their expert advice and personal stories provide patients with the knowledge and confidence to make informed decisions about their care. Listen now to take control of your lung cancer journey.
- Gina Hollenbeck:** It took a lot of courage to go tell that doctor that I was going to get a second opinion. And his answer was, "Go, get all the information you can. And if I can help you in any way, I will."
- Sarah Beatty:** This may have happened to you or to someone you love, you've just been told you have lung cancer. Chances are, the doctor said much more, but it's almost impossible to remember anything else after those four words. Now what?
- Diane Mulligan:** These three episodes of Hope With Answers: Living With Lung Cancer podcast are designed to help you answer some of the most important questions immediately following a diagnosis. You'll hear from people who've been exactly where you are now and today they are living, truly living, with lung cancer. They will be your guides through the first part of your cancer journey that we're calling The First Seven Days.
- Diane Mulligan:** It was not very long ago, just a handful of years really, that a diagnosis of lung cancer meant that there wasn't much a doctor could do for a patient, but the landscape of lung cancer has changed dramatically. And today, there are new treatments and people are living longer and healthier lives with lung cancer than ever before. I'm Diane Mulligan.
- Sarah Beatty:** And I'm Sarah Beatty. Thanks for joining us on the Hope With Answers: Living With Lung Cancer podcast. This is a special three-part series called The First Seven Days: The Steps You Should Take Immediately After Being Diagnosed With Lung Cancer. And as we talked about in the first of these three episodes, the first seven days after diagnosis might actually be 15, 20, maybe even 45 days.

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- Diane Mulligan: There's a document in the show notes that will be so helpful, it's called The First Seven Steps in the Face of a Lung Cancer Diagnosis. It will help you sort out what to do next and what information you need to gather to create a treatment plan with your doctor. But first, a diagnosis of lung cancer almost requires learning a new language. You'll start hearing terms like biomarkers, immunotherapy and thoracic oncologist.
- Sarah Beatty: So take a listen to emergency room physician and 14 year lung cancer survivor Dr. Michael Weitz about how important he thinks it is to get a second opinion from a thoracic oncologist.
- Dr. Michael Wei...: I tell everyone that they need to not only get a second opinion, but get a second opinion from a thoracic oncologist at a university based facility, because that's where the research and the clinical trials are. And that's where your best treatment is going to be and your most informed physicians are going to be.
- Sarah Beatty: So let's talk to a thoracic oncologist to find out why working with a doctor who specializes in lung cancer is so important.
- Diane Mulligan: This is Dr. David Carbone, a thoracic oncologist at the Ohio State University. So should patients go to a major medical center to find the right type of doctor? What's the best situation?
- Dr. David Carbo...: There are some really excellent community doctors out there, but the treatments for lung cancer are changing so rapidly that nobody can keep track of everything that's going on. And I think it's reassuring in any event and may uncover completely new approaches for patients to get a second opinion, even if their first opinion's at an academic medical center, but especially if it's a community oncologist who treats leukemia and colon cancer and breast cancer and prostate cancer. They may not have the latest tools that are needed to optimize treatment for lung cancer. So a second opinion at a place that, and with a doctor who sees primarily lung cancer, I think is a great idea.
- Diane Mulligan: And my understanding is that when you do the testing, you have to be with the right person or the right doctor, or you may not get the right testing, is that correct?
- Dr. David Carbo...: Yeah, yeah.
- Diane Mulligan: And that's where that second opinion is so very important?
- Dr. David Carbo...: Well, as a medical oncologist, we often see these patients for years every few weeks. I see them more often than my kids sometimes and I think you really have to feel like you are seeing a doctor who understands you, who listens to you, understands your cancer, is up to date on the latest treatments, and who you trust with your life, which in fact is what you do with an oncologist. And it is your right to change doctors if you don't have that feeling of trust, or if you're

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unsure, to get a second opinion, which may affirm everything your first doctor has said. And that's completely fine, but you should feel like you deserve to have that kind of trusting relationship and really understand what the doctor is recommending. And it's not a problem to get a second opinion, don't worry about hurting your doctor's feelings.

- Diane Mulligan: That's really important. I think a lot of people really can take that into consideration.
- Dr. David Carbo...: A doctor who objects to you getting a second opinion is a doctor you want to find another doctor to replace.
- Diane Mulligan: Getting a second opinion is something members of the LCFA Speakers Bureau feel very strongly about. You hear Gina Hollenbeck at the very beginning of this episode talk about how scared she was to ask her doctor about a second opinion.
- Sarah Beatty: But a second opinion might confirm that your original oncologist is right on target with your treatment plan, or it could open up cutting edge new treatments or clinical trials. And your doctor should always be open to getting additional information about your treatment options.
- Dr. Michael Wei...: I think good doctors are never threatened by a second opinion, and that's so important. It's not about the doctor's feelings, take that totally aside. Just be your own advocate and insist upon it because two doctors' opinions, sometimes you end up with three opinions, but at least you'll be able to discern what the best course of action is. And again, to go to the second opinion should be a step up to go to a university based hospital that has thoracic oncologists. Not just any oncologist, not a pulmonologist, but a thoracic oncologist in a university setting is the best you can do.
- Shelly Engfer-T...: I think it's important that you weigh all your options and treatment options. I just didn't feel at peace with mine. I went through four oncologists within my first four months because I wasn't at peace. When I finally went to the fifth one, and he was the one that took the time to send my block into foundation one testing and it came back ALK positive, I mean it was such a relief. But it was just, you have to do that, you have to be your own advocate and do what's best for you. It's vital.
- Lisa Buonanno: Different generations too look at things a little bit differently I think. And personality wise, a lot of people are like, "Oh, but I trust my doctor," or, "This is what my doctor said," or, "I've always listened to him and I just do what I'm told," type of thing. And obviously you do it in a respectful way. It has nothing to do with trust I guess, you can't be looking at it as like, some people even say, "Now I'm going to have a bad relationship with him," or, "I don't want to upset my doctor."

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- Lisa Buonanno: This is your life. He's not your friend. You need him to be in your corner and it doesn't mean because you're reaching out and getting a second opinion that you don't trust him, that you don't honor or validate whatever his options are. But if the second doctor comes back and says the exact same thing, then cool, you know that okay, this is probably the best path for me then. But what if there's more information out there? What if it's not a thoracic oncologist, which like we know, 80% of people are seen in the community setting and they may not have had a lung cancer patient under 75 years old before or they're not up to date on biomarker testing.
- Gina Hollenbeck: When I first got diagnosed, I loved my oncologist. He was absolutely amazing and so kind and generous with his time and really explained everything to me. But I went home and I just was like, "I've got to have the best of the best because I've got two little boys that I'm fighting for so I've got to get a second opinion." So it took a lot of courage to go tell that doctor, whom I loved, that I was going to get a second opinion. And I was so afraid that he was going to be mad at me, but his answer shocked me when I told him, "Hey, I'm going to go to a major teaching hospital instead of my community hospital here because I've got to get the best of the best." And his answer was, "Go, get all the information you can. I am here to help you with whatever I can. And you bring back that information, and if I can help you in any way, I will."
- Gina Hollenbeck: And I just feel like if you have a doctor who is not willing to take in the opinions of other physicians, that isn't humble enough, then you know what? See you. Because this is, just like Lisa said, I mean you're paying them to do this. They're not your friend.
- Kim Norris: Right.
- Gina Hollenbeck: And so it's not even about bedside manner. It's like are you taking in the opinions of other people and really using all the information and sources to give your patient the very best care? And I think that's really important.
- Diane Mulligan: You just heard from Speakers Bureau members Dr. Michael Weitz, Shelly Engfer-Triebenbach, Lisa Buonanno and Gina Hollenbeck about the importance of working with a lung cancer specialist called a thoracic oncologist.
- Sarah Beatty: You also need to get a second opinion from a thoracic oncologist who can help you sort through all your options for treatment. Your options are going to depend on whether you have a biomarker and we'll get into what that means next.
- Diane Mulligan: The Hope With Answers: Living With Lung Cancer podcast is produced as part of LCFA's mission, raising the public's awareness and serving as a resource for patients or anyone seeking answers, hope and access to updated treatment information, scientific investigation and clinical trials.

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- Diane Mulligan: Everyone's lung cancer journey is different, and as we mentioned earlier, you may gather all the information laid out in the Seven Steps in the Face of a Lung Cancer Diagnosis in any order. But one thing is for sure, you'll be learning a whole new vocabulary along the way.
- Sarah Beatty: So let's talk about biomarkers. A biomarker is key in today's world of personalized medicine. Lung cancer biomarker testing, also known as genetic mutation testing or genomic testing, looks for mutations or specific biomarkers in the cells of a tumor. These biomarkers can be used to determine the best course of treatment for an individual lung cancer patient.
- Diane Mulligan: It is absolutely essential to get a biomarker test because that will guide every aspect of your treatment plan. It's also critical to get a biomarker test before you start any kind of a treatment like chemotherapy or radiation.
- Lisa Buonanno: Everyone with adenocarcinoma should be getting tested at this point for biomarkers. And even if you're not eligible, like you said, for a targeted therapy, it still guides your treatment, right? You know, "Okay, well then that's not my path, but then that makes this path more likely for me." But again, it's just like throwing something out there and hoping it sticks. If you don't have that information, it's a guessing game.
- Patty Watkins: Four months later, after my diagnosis, my doctor decided to send my tissue off for testing. And sure enough, I had ROS1 mutation and I was treatable. So here I am today, six years later.
- Janet Freeman-D...: It is so incredibly important. Not only do you need to get the biomarker testing, that unless you have very serious symptoms that need immediate attention, that you wait for the results of the biomarker testing before you start treatment.
- Kim Norris: "But I've got to do something now!"
- Janet Freeman-D...: And we've all been there, but the standard of care for most people right now is a combination of chemotherapy and immunotherapy. And if you happen to have a type of cancer that has a biomarker in it, you won't respond to that. And it could actually keep you from being able to take the targeted therapy.
- AJ Patel: And typically, even though you're worried that you have to do something, the biomarker testing is actually returned in a relatively short time. It's no more than seven days they can get the results back and you can make a phenomenal decision that will change the direction of your cancer with that information.
- Lisa Goldman: A lot of people don't quite hear that everybody should, I just want to repeat again that everybody should get the biomarker testing because I've heard so many times, "Well, only if you're a non or never smoker or only if you're under 50 or something." I think everybody with a non-small cell lung cancer diagnosis

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needs that biomarker testing. I don't care what your smoking history is or anything else. It's so critical before making your treatment decisions.

Diane Mulligan: That was Lisa Buonanno, Patty Watkins, Janet Freeman-Daily, AJ Patel and Lisa Goldman driving home just how important biomarker testing is in the process of creating a treatment plan for you and your type of lung cancer. Dr. David Carbone with the Ohio State University also weighed in on the importance of getting a second opinion with a thoracic oncologist. Of course, lung cancer doesn't just affect the patient, it also impacts spouses, family members and friends.

Sarah Beatty: Coming up on the next episode of The First Seven Days in the Hope With Answers: Living With Lung Cancer podcast, we'll hear how many of these folks handled their diagnosis with their families and friends. I'm Sarah Beatty.

Diane Mulligan: And I'm Diane Mulligan. Join us next time.

Diane Mulligan: Make sure to subscribe to the Hope With Answers: Living With Lung Cancer podcast. You'll be notified every time a new episode is available. So visit us online at lcfamerica.org, where you can find more information about the latest in lung cancer research, new treatments, and more. You can also join the conversation with LCFA on Facebook, Twitter and Instagram.