



## Hope With Answers: Living With Lung Cancer

### The First 7 Days: Mapping Your Treatment Journey

Ava Narrator:

Welcome to a special re-release of the Hope with Answers podcast originally aired in May 2020. This final episode of the first 7 Days podcast series provides newly diagnosed lung cancer patients with crucial guidance on developing a personalized treatment plan. The episode discusses a range of treatment options from surgery to immunotherapy and emphasizes the importance of biomarker testing and clinical trials. With insights from a thoracic oncologist and patient advocate, this episode offers actionable advice on making informed decisions and collaborating with your medical team to navigate treatment.

Diane Mulligan ([01:04](#)):

Thanks for joining us on The Hope With Answers Living with Lung Cancer Podcast. For this special series, we're calling the first seven days. So far in this series, we've talked about taking the time to get the right diagnosis, the right treatment plan, and the right team. I'm Diane Mulligan. And I'm Sarah Beatty.

Sarah Beatty ([01:22](#)):

We've also gotten more detail on the new language you need to learn to manage your diagnosis. If you haven't already, you may want to listen to the first two podcasts in this series. To find out more about all the details you'll need to gather immediately following a lung cancer diagnosis. And remember, we're calling this the first seven days, but it could be several weeks or even a month before you gather all the information you need to make a treatment plan customized just for you with your medical team.

Diane Mulligan ([01:54](#)):

We're going to finish this special series by diving into where to find accurate information about lung cancer online, and hearing how others living with lung cancer have found support from their families and for their families. Let's start with Dr. David Carbon, a thoracic oncologist at the Ohio State University who has some great advice on how to use the internet to find good information that will help you and your medical team come up with a customized treatment plan.

Dr. David Carbone ([02:24](#)):

And it is a completely new vocabulary for people. And so I think in that first seven days is a good time to research the information that they can get on, on their, on their cancer. But it has to be ideally from validated sources of information. Just Googling lung cancer, we'll get a lot of information, but most of it, uh, may be inaccurate. So what I would do is trust websites from reputable organizations like Lung Cancer Foundation of America or other, uh, major lung cancer organizations and read that information. It's written for patients to be understandable and educate yourselves on this. The, I like to say, patients are their own best advocates and they need to really understand at some level what's going on in their, their workup and their care to be give them the best shot at a good outcome.

## Hope With Answers: Living With Lung Cancer

Diane Mulligan ([03:30](#)):

Dr. Carbon has been a wonderful guide through this discussion of the first seven days from a medical perspective. And by the way, Dr. Carbon is on LCFA's Scientific Advisory Board. He helps further LCFA's mission through scientific and intellectual leadership. We are grateful for all his time and expertise on this first seven days series of podcasts.

Sarah Beatty ([03:51](#)):

Now, let's hear from our Speakers Bureau people who are living with lung cancer on how they found the most useful information online after their diagnosis. We start with Shelly Engfer-Triebebach.

Shelly Engfer-Triebebach ([04:05](#)):

Once the shock and all that stuff, and I got on my research and Dr. Google, of course, we do that, don't we? We're told not to. Everybody tells us not to. Well then of course I'm gonna do it <laugh>. It's impossible. I know. So I was on it and I'm thinking, oh, I gotta go someplace else and get some other information. And my ALK diagnosis didn't come until four months after my diagnosis. And so I was just doom and gloom. I was losing my hair, I was being sick on chemo, and it was just awful. And, and I just didn't feel at peace. So I went from doctor to doctor to try to get a different type of diagnosis or a different type of treatment plan. And finally, one of the doctors said, you fit the categories of this, this, so this. You should have ALK or the EGFR, some type of mutation.

([04:52](#)):

And so he sent my, um, same block out to the foundation one, which it had not been sent to, and it came back as positive for ALK where the initial test for just the EGFR and ALK was negative. So never give up hope, right? And I just, when I got that news after being on that site for four months, I, I was like, oh, yes, I hit the lottery. I was so excited I got this mutation. It just changes your outlook on treatment. I was so depressed and I, I, I be, I tried a cartwheel. I don't think I succeeded. But, um, it was, it was just really exhilarating and exciting to know that, and, and I wouldn't have known anything about it had it not been for these, uh, online support group is really what it was.

AJ Patel ([05:39](#)):

I believe that being in touch with the various lung foundations, there is going to be wealth of resources that will inform about the disease. And most importantly that I feel is to connect you with other survivors who are perhaps acting as buddies or survivors. And they are a tremendous support structure from not only an emotional and psychological standpoint, but from an experiential level where they know of their own experiences and treatments and protocols, and they are the voices of, of the patients. And so that's a really powerful place that you can find meaningful information that can help you better prepare for your meetings with doctors and, and treatments and so forth.

Janet Freeman-Daily ([06:32](#)):

It's not just statistics on the internet. There are sites that tell you what questions to ask your doctor, what testing to ask for, where to go for a second opinion. What's the standard of care for treatment. You can learn so much on the internet if you go to the vetted sites. And the trick is finding those vetted sites. But there are the lung cancer, um, advocacy organizations. LCSM chat on Twitter has a page of vetted sources. Um, there are a page, uh, I think it's the NCI that puts out a page of how to find good sources of information on the internet. So I would, I would not say stay away from the internet, just don't put too much stock in statistics, which are at least five years out of date.

## Hope With Answers: Living With Lung Cancer

Lisa Goldman ([07:16](#)):

I stayed away from looking at statistics. Frankly, I was terrified of them. And, and something in, in me told me to, to sort of click to the next page as soon as I saw numbers pop up. But I, I really counsel against, I've heard too many patients tell me and my own doctors tell me, stay off Google. You know, you're not a doctor. I'm the doctor. But I think it's so important for patients to educate themselves and go into their appointments, knowing what questions they might wanna ask or understanding when it's time to seek a second opinion. All this sort of information really makes a difference in survival outcomes, honestly, and options you may have. So I think it's incumbent on patients to do some internet research, but do it wisely. So there are great sites out there to find. Um, and, and they're not, not that hard to, hard to find if, if, if you're, if you just look around for a little bit.

Lysa Buonanno ([08:17](#)):

Say, it's hard to tell people, um, to stay off the internet because I think education is crucial. I mean, we have to, I mean, it's hard. I'm trying to put myself back into the place I was when I was first diagnosed. It's easier to say now. You know, educate yourself and, you know, look for these credible sites, of course. But I know when I was diagnosed eight and a half years ago, you just found statistics. You didn't find a lot of hope or other stories. And I was able to, um, connect to others online as well and learning from the other patients because I knew I didn't have resources or that kind of support around me, other people that could help me navigate that, that whole thing. You know, what do I do now? And learning from these other patients that had been around or had a little bit more experience than I did, you know, telling me about the biomarker testing and telling me, you know, how to deal with the side effects I was dealing with.

([09:13](#)):

And, um, I mean, knowledge really is power. I mean, you have to, like she said, it statistically, it does show that people have better outcomes and survive longer by how can you make informed decisions about your treatments if you don't even know what all your options are. So I tell people all the time, you have to at least learn the basics about your disease. Even the ones that are still trying to bury their head in the sand, you know, it's, I'm sorry, but this is your life. It's, you have your little pity party and be sad, but now it's time to get ready and move forward. Like you have to be in survival mode.

Diane Mulligan ([09:47](#)):

That's a great description by Lisa Bonano. You have to be in survival mode to make sure you're getting information from trustworthy sites on the internet. You heard several speakers Bureau members talk about finding accurate information and comradery on the internet after their diagnosis.

Sarah Beatty ([10:03](#)):

That's right. And you heard from Shelly Infer, Friedenbach, AJ Patel, Janet Freeman Daily, Lisa Goldman, and Lisa Bonano. Coming up next, you'll hear the group talk about how they found support from their families and for their families.

Diane Mulligan ([10:22](#)):

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.

([10:44](#)):

## Hope With Answers: Living With Lung Cancer

Welcome back. Family support is such a critical part of living with lung cancer, but often talking to family members about a lung cancer diagnosis is very emotional and challenging. Oh, of course it is.

[\(10:57\)](#):

The challenge is to be direct and honest, but also hopeful in supportive. And that support goes both ways. So take a listen as members of the LCFA Speakers Bureau shared some of their experiences and ideas for talking to family members,

Terri Conneran ([11:15](#)):

Some of the members of my family, 'cause my kids are all in their twenties, were trying to become oncologists overnight and experts. And that's not what we needed. What we really needed was to know the right questions to ask.

[\(11:27\)](#):

And of course, you know, everybody's handling it their own way. So it really was a matter of going in there, finding out what we needed to know so that we could ask the right questions and get that kind of piece. And as far as looking at the other sites, if there was no story of hope and there wasn't any good news, it was the wrong place for me to be. Um, and at that time, the, a new drug had just been released and it was all over in commercials. And I had friends calling me up and I said, I remember telling them, and I was in the hospital pretty doped up from, from uh, being full of fluid. And they're like, well, you know, I heard about this new medication. And I said, you know, if my doctor has to hear about it, like on the nightly news, that's not the drug that I think I want <laugh>.

[\(12:13\)](#):

And it's certainly not the doctor I want. So, you know, one medication is not a fit all, but I need to have that kind of confidence in my doctor. And the only way I can have that confidence is being able to ask them questions and intelligent questions. And then if I had more questions, come back and re-ask the question. And as annoying as it gets with my, take my husband to the doctor. 'cause he asks the same questions five different ways. Five different times. And I'm like, so moved on <laugh>. But a lot of times he gets more information out of it than I do. You wanna be honest, you wanna be open, but you also know they Google and they've got numbers and they're gonna read your mood more than they're gonna read anything else. And it was my daughter's birthday and she turning 25, and I didn't know what to do, and I didn't know what to say.

[\(13:09\)](#):

I thought, you know, I'm gonna need the night to sleep on this. So, uh, we slept that, I slept that night. Well, I slept, we'll call it that. And woke up the next morning, my lung collapsed. I ended up in the hospital, um, filled with fluids. I had to tell the kids and went into the hospital through the emergency room, thinking of having a heart attack, thinking it's from the anxiety. The doctor had just told me he had lung cancer. And so I'm in there and they're like, okay, well why, why is it you think you're here? Like, well, I have lung cancer. The doctor says, oh my God, I'm so relieved. I thought I was gonna have to tell you <laugh>. So how did you know? I, they called me yesterday and this man spent most five minutes telling me what a relief it was. And I'm thinking, in the meantime, I've gotta call my kids tell'em, I'm in the emergency room, and explain to them why and how, and legitimately and how did I tell them? Um, it kind of had to happen. And I still had every time, like I've had three recurrence, three recurrences every time. That is still the hardest part. And I wish I had an easy recipe for it. Open and honest is the only thing you can do. It's open up a whole new level of communication that's still hard.

Caregiver wife? Janice ([14:28](#)):

## Hope With Answers: Living With Lung Cancer

Going back to kind of the things that you would wanna do in the first, you know, stage of your diagnosis, having the perspective of my husband being diagnosed 14 years ago and being a mom, I think one of the things that we decided early on that really, I'm, I'm so glad we did it this way, is we decided, Michael and I decided we would never lie to our children.

Terri Conneran ([14:50](#)):

Right?

Caregiver wife? Janice ([14:50](#)):

That was extremely important because that would break the trust that we had with them. And so we were very open, but we followed their questions. If they didn't ask, we didn't tell. But when they asked, we would explain things to them. We knew they were gonna go online. We knew they were gonna read all the worst statistics, but we kept telling them, you know, we've got the best medical care. We're taking great care of dad. And we were very open. And, and I, to this day, they, they really trust us. They know that, you know, if we say things are okay, they're okay. And I'm really glad we made that decision from the very beginning. 'cause the easier thing would've been to just lie about it and try to cover it up. So I'm really happy, you know, for any, anyone that has children, I think it's really important. But you do have to take care of yourself. And I have wonderful friends that would take me to lunch, and I kept up my exercise and I had my routines. And I think that's also super important. Plus it's very important to, as a wife, that our relationship just isn't based on me being a caregiver.

([15:53](#)):

I still want a husband and he still wants a wife, and that's outside of the illness. So I think it's, you have to make a conscious effort to make that part of your relationship still. It's very, very, very important. So these are the things I've learned.

Lysa Buonanno ([16:08](#)):

I think we forget that a lot as patients. Our caregivers are those unsung heroes that so much is focused on us as a patient that, um, I even said to her one time, we've traveled together before with both of our moms, and one night we were saying, I said, you know, I can't remember the last time I like really asked my mom, how are you right now with this? You know, because they just put on that face and get in that mode of helping and taking care of you. But we forget that there's so much that they're dealing with and they feel like they don't wanna burden you with, but at the same time, they're carrying so much of that weight. I'll

Kim Norris ([16:45](#)):

Never forget my husband's doctor, we were at an appointment and he turned to Roy, my husband, and said, you know, Roy, you're going to get all the best care and attention that, that we can give. You're gonna be taken care of. And then he said, I wanna know who's gonna take care of her. And he said that. And we were both like, well, no, I'm fine. Of course I'm fine. But of course I wasn't fine. But just him saying that kind of gave me permission to say, yeah, I do need help through this journey.

Elizabeth Moir ([17:24](#)):

Obviously it's a lot thrown at you in a very short amount of time. And those first few days after my diagnosis, my husband was crying all the time. Um, we were high school sweethearts. We've been through a lot together, but definitely nothing like this. And I had to sit him down one day when the, I

## Hope With Answers: Living With Lung Cancer

have a, at the time they were two and a half and six months old. Um, and I had to sit and look him in the eye and say, you have to crying because I am not dying. Not yet at least. So please stop crying. And for him, a light bulb went off that I wasn't gonna go anywhere, at least not anytime soon, even with the dire circumstances. Um, and then for my dad, a turning point within those first couple weeks was me talking about the future. And he looked at me and he kind of funny, and he said, I'm just really proud of you. I said, what? He said, you're, you're choosing to live. You're choosing to fight this thing. And I can see that a lot of people, you know, even in your circumstances with young children, some people would just not fight. And I kind of looked at 'em like, what are you talking about? I mean, how can you not try to live? Um, so me actually standing up and being the strong one for my particular family, um, was kind of the turning point for everyone in their own coping.

Diane Mulligan ([18:52](#)):

That was such a powerful conversation among our Speakers Bureau members, most of them currently living with lung cancer. And as you've heard, several family members caregivers.

Sarah Beatty ([19:04](#)):

One of the voices you heard was Kim Norris, the co-founder and president of Lung Cancer Foundation of America, who lost her husband Roy to lung cancer in 1999. We wanted to bring her in to wrap up this series on the first seven days, a project that's partly based on her own experience.

Kim Norris ([19:22](#)):

Uh, this part of what LCFA does is near and dear to my heart, because you never quite forget when you're newly diagnosed, whether you're the patient or or the family member, it leaves the profound impact. But in, in hindsight, I look back and I realize Roy didn't get his first treatment until about six weeks after he was diagnosed. Now what were we doing all that time? We were looking for a doctor. Roy used to say that he would know, he found the right doctor when the doctor looked at their, his scans and rather than backing up and saying, oh, no, leaned in, and said, Hmm, interesting. And we did, we finally found that doctor. But it took a while. And then we, we gradually started educating ourselves. It's like learning a whole new language. And back then we didn't even have the choices you have now.

([20:31](#)):

So today, a crucial part of that is because there's so many treatment options available, which is amazing and incredible, but you need to understand it. You need to understand what's the difference between immunotherapy and targeted therapy? What's a biomarker? What does testing mean? What does next generation sequencing mean mean? Those are all new terminologies that you never thought you'd have to learn before. And the other thing that's really important is putting your team together. And your team is not only your medical team, as I said, it took us a while before we found the right doctor for us. So it's not only finding your medical team, which means you don't have to go with the first doctor. You see, ask around, ask around for recommendations to find a thoracic oncologist, someone that really specializes in lung cancer. I would highly recommend that. But also your family and friends, the team you need there who's not only gonna go with you to doctor's appointments and help you understand everything they're telling you, but also who's gonna take the kids to school and who's gonna help you do the, the grocery shopping when you're overwhelmed and you can't do it.

([21:58](#)):

It's important to put the team together. And as a part of this, this series, the first seven days, and again, understand, we just randomly pick seven days. It could be seven weeks. We put together a document of seven steps that you can be looking into. And again, it's not just seven, we're just using that as a

## Hope With Answers: Living With Lung Cancer

metaphor, as something to work from. But I think if you go to that, think about it. And probably the other thing I wanna recommend is when you're first diagnosed, you're so overwhelmed. Take a deep breath, and I know you wanna get it out really fast. I know that just feels imperative, but there's so many options. Now think of it this way. It's important that you get the right treatment for the right patient at the right time. And the good news about lung cancer is most of it, not all of it, but most of it is slow growing. So waiting six weeks for the most part, probably won't make a difference unless you have a critical medical need. So with all that, that those steps and what needs to be done, I just, I'm sorry you're on this journey, but we're gonna do everything we can to help you through it. And I think this first seven steps can really help make a difference.

Diane Mulligan ([23:29](#)):

Thank you to Kim for everything she and LCFA are doing on behalf of lung cancer patients and their families. Thank you also to all the members of the LCFA Speakers Bureau and Dr. David Carbon of the Ohio State University for sharing their expertise and wisdom for this first seven day series of podcasts.

Sarah Beatty ([23:51](#)):

Thank you for listening. And join us next time on The Hope With Answers Living with Lung Cancer Podcast.

Diane Mulligan ([23:59](#)):

Make sure to subscribe to the Hope with Answers Living with Lung Cancer Podcasts. You'll be notified every time a new episode is available. So visit us online@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.