



The First 7 Days: Initial Steps After a Lung Cancer Diagnosis

Introduction by AI Ava:

Welcome to a Special Re-Release of the Hope With Answers Podcast. Originally aired in May 2020, “The First 7 Days” remains a vital resource for anyone facing a lung cancer diagnosis. Dr. David Carbone’s expert insights and heartfelt stories from LCFA Speakers Bureau members provide guidance on gathering information, seeking second opinions, and finding the right medical team. This episode offers practical advice and reassurance to help patients and families make informed decisions. Listen now to find clarity and hope in the early days of diagnosis.

AJ Patel:

I didn't know it then, but divinity exists and you cannot tell when it arrives. You, you sometimes don't even recognize it, but it arrives.

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 are calling the first seven days. There's something so incredible about our friend AJ Patel's story you heard at the beginning of this episode, and we'll hear more of AJ's story in just a few minutes. But first, thank you for joining us for this special project on the Hope with Answers Living with Lung Cancer Podcast. I'm Diane Mulligan. And I'm Sarah Beatty.

Sarah Beatty:

This is the first of a three episode series called The First 7 Days. These episodes draw on the experience of more than a dozen people who are living with lung cancer, and it's designed to be a roadmap for what to do next in the face of a lung cancer diagnosis. We also want you to know that there's a document in the show notes that you should probably print out. It's called The First Seven Steps in the Face of a Lung Cancer Diagnosis. And it will give you a step-by-step plan for what to do

Diane Mulligan:

Next. First and foremost, you should know that we're calling the series The First 7 Days, but you know, it could take 15, 30, maybe even 45 days to get all the information you need to move forward with the

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powerful treatment plan designed specifically for you. So let's start with a conversation I had recently with an incredible lung cancer specialist, Dr. David Carbone, who is a thoracic oncologist at The Ohio State University. He's an expert in molecular genetics of lung tumors and in developing treatments that target the genetic markers and tumor cells of each patient's biologically unique cancer. Most importantly, he explains why you have more time than you think to gather all the information you need to design a treatment plan customized just to you. So we're calling this the first seven days, but there's a number of steps that we just talked about. You, you get your initial diagnosis, you want to get to an expert, you have to be tested, you've gotta get in and actually get an appointment. You feel like you have to really move fast, but at the same time, the cancer may have been there for a very long time, and as you said, it's not moving that quickly. So really first seven days for you could be first 30 days, first 45 days. But the important thing for them getting from you is that knowing and understanding what you really have, what the gene mutation is, really makes a difference in how you're gonna be treated and how you're gonna react to that treatment. Is that right?

Dr. David Carbone:

One thing I've learned in my 30 years of practice is everybody's cancer, everybody's situation is different. In some cases, there are true medical emergencies, right? That have to be dealt with immediately. In other cases, um, they, the cancer may have been there for a decade, um, and everything in between. And so I, you can't really say it's okay to wait.

Diane Mulligan:

Right?

Dr. David Carbone:

Then, it is okay to gather the needed information to design the appropriate treatment. And in certain circumstances that can happen in a few days. Others, it might take a few weeks. But in general, I try to p have people on therapy within a month or six weeks of their diagnosis.

Diane Mulligan:

In many cases, the cancer may have been there for a year or longer, right? So this, there's this tremendous urgency 'cause the patient has just heard this,

Dr. David Carbone:

Right? I call it a psychological emergency more than a medical emergency. Very often everybody's cancer history is different. Um, sometimes people fall in a parking lot and then get a, a cat scan at the emergency room and find out they have cancer and they have no symptoms at all. Other times they've had a cough and pain for months or even a year that has been misdiagnosed as pneumonia or arthritis or something. And so, um, especially the ones that just find it incidentally and through evaluation for some, you know, a fall in a parking lot, like I said, they've just learned about it. And it's particularly a panic, uh, inducing in that, that situation. But the fact is, it may not seem like it, but lung cancers actually grow fairly slowly. Often they double in size in the range of a hundreds of days. So doing testing that makes a huge difference in in what treatment is recommended, that takes a week or two or three, is definitely worth it. And even though there is a psychological urgency to getting started on something, it's much better to do the right thing.

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Diane Mulligan:

Let's go back to the beginning. So you are diagnosed by the time they found you. And so the first question to me is, how do they find a doctor like you? What, we're in the middle of rural America and you're diagnosed and it's, you know, you, you've got this from your pulmonologist or from even your general practitioner, you know, and, and you don't even know what's been diagnosed.

Dr. David Carbone:

Right? Well, so I'm a medical oncologist and most people who come to me have been given the diagnosis by someone else,

Diane Mulligan:

Right?

Dr. David Carbone:

And sometimes it's, it's someone who really, honestly, doesn't know very much about lung cancer. And I've even had patients pretty commonly, uh, be told by their pulmonologist, you know, that bronchoscopy I did showed lung cancer. You have 12 months to live or you have 10 months to live. Uh, you, you need to find an oncologist, uh, by, and, uh, that kind of news is stressful to patients.

Diane Mulligan:

Absolutely.

Dr. David Carbone:

I use the analogous analogy of, uh, just walking across the street and getting hit by a bus, you suddenly change, have a very rapid change in direction that, uh, was not planned for. So one of the jobs that I have in, in that setting is to reassure patients that it's best to do the right treatment for their cancer and not the one that's the most convenient. And patients have better outcomes because of that, that kind of matching. And sometimes it takes some time. We need to do additional tests to find out exactly what kind of cancer it is, where the cancer is in that, in their body. And then now for most types of cancer, we have to do a battery of molecular tests for which we have very specific, uh, treatment matches that make huge differences in the quality and quantity of life for these patients.

Diane Mulligan:

And at the same time, it's seeing it, what I'm hearing is that it's okay to take a breath. It's okay to figure out a good plan. And in fact, the outcomes may be tremendously better because you don't wanna end up on chemo or radiation if it's not, even if you don't need it. If you don't need it. Exactly.

Dr. David Carbone:

And there are many, uh, situations where people can start therapy with a pill with minimal toxicity and great efficacy that lasts for years. And, uh, we often find those patients are started on chemotherapy inappropriately, uh, with, uh, low efficacy and high toxicity, uh, just because they didn't, uh, get the right, uh, genetic testing ahead of time.

Diane Mulligan:

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It's like you have this first seven days feeling, what do I need to do? You wanna do something right? And you must see this all the time with your patients.

Dr. David Carbone:

Yeah. Every, every day in clinic, the, the diagnosis of lung cancer is such a, a stressful thing for patients. It's historically been a terrible disease with very few options. And patients will go online and see data, um, on the way things have been historically. And they, they really have a, a panic to feeling. Uh, at first they're being forced to learn a totally new vocabulary. They're, they're being thrust into doctor's appointments for people that they have to trust their lives to. And they don't know this person from the next person. And so it's, it's totally understandable that they feel an urgency to do something. And I, I'm a cancer patient myself, and I've been through that and partially at least. But I think it's important to emphasize that cancer treatments now for lung cancer are far better than they were historically. And all of those advances have come as a result of personalizing the cancer treatment to the individual patient and the characteristics of their cancer. And that we're now able to see, uh, patients doing well with low toxicity therapy for many years, or even apparently cured with advanced stage lung cancer. Something we never saw in the past.

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. Each year we get together with a group of people living with lung cancer, the LCFA Speakers Bureau. We

Sarah Beatty:

Were with the group recently, about a dozen people who shared their experience of being diagnosed with lung cancer and learning to live with a disease for almost everyone. The process starts with a steep learning curve.

Juanite Seguro:

I didn't Google anything 'cause I was so depressed. I was so sad. I kept thinking about my five kids and my mom said, great, my mama has to bury another child. And, uh, so my husband did all the research and he researched everything and he learned about SRS, um, biomarker testing, um, what's the other one? Um, proton therapy. I mean, he knew it all. Stage three a, b and he wrote everything down. So when I went to, um, I ended up going first to, um, another hospital in Zion, Illinois. He already had his notebook with all the questions to ask. 'cause guys I couldn't do anything. I was so depressed and so sad. And like Gina said, I saw the five-year survival rate. I remember going outside and crying and my husband's like, what in the heck is wrong with you while you're crying? And I showed him on my phone. He goes, that's not gonna be you. That's not gonna be you. You are a fighter and you're gonna see your kids grow and you're gonna meet grandkids. And I have a granddaughter today.

Gina Hollenbeck:

For so long I knew something was wrong and nobody would take me seriously. And so I self-paid for a chest x-ray. And once I self-paid for that chest x-ray and took it into the emergency room, then the sequence of events started happening really fast. And, um, the pulmonologist, um, finally did an ebis. And I remember him calling me, 'cause I, before I went under for anesthesia, I said, make sure you tell me if you think it's cancer. And, um, when I woke up, that was the first thing I said, do you think it's

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cancer? And he's like, no, no, we, you know, but we're waiting on the pathology. And it took seven days to get that pathology back. And I remember he said it, it's tumor cells. And I said, does that mean it's cancer? <laugh> <laugh>? And he said, yes. And, um, he said, is adenocarcinoma. So the first thing I did was got on the internet and I started looking it up. Information that I got on the internet was pretty scary.

Diane Mulligan:

Yeah.

Lisa Goldman:

Um, I didn't see a good prognosis, but I did see, um, places where, um, you know, there were, there was a chance, there was a small chance. And I kept thinking, I'm gonna be that percentage. I'm not gonna be that percentage.

I have kind of a less typical story, which is, you know, I was diagnosed and hospitalized at the same time, so I didn't get to go home, not get to, but I didn't have that time between being told I have lung cancer and getting second opinions, researching, figuring out what I was gonna do. I had a biopsy and 24 hours later I was hooked up to chemotherapy. So there was no time to do the secondary research. But what helped was, I do remember being in the hospital bed and doing a little online research, but I was so overwhelmed by the science. I knew nothing about lung cancer. I didn't know anybody who had it. I hadn't had any risk factor. I had no reason to know anything about it. So, uh, that piece was totally overwhelming. Not to mention that they had put me on all kinds of drugs and things, so I was a little out of it.

But what was really helpful was I stumbled onto a few other patient blogs. Now there's a lot more out there at the time. There was just a handful, like two or three. But what was really impactful was seeing photos of people that looked something like me that were seemingly doing pretty well. So I remember seeing Luna and, uh, she had most recently posted a picture of her in a spin class. And I had been a spin instructor, just taught a class a couple weeks before I was diagnosed. And I, you know, immediately that was all like, pulled away from me. And I thought, I'm never gonna do anything like that again. And then I pull up this blog where there's a person with my same exact diagnosis on a spin bike. And that was just so I, I clung to that like you wouldn't believe. So that was just really powerful to not the science content, but just the encouragement of seeing other patients living with this.

AJ Patel:

I couldn't function, I couldn't think. And when I went away and, uh, tried to absorb the information at home, you, you completely paralyzed. Yeah. I dared to look at the internet and I, it was, it was even more doom and gloom and it was so difficult to move forward. But as the news spread to, to my family, I didn't know it then. But divinity exists and you cannot tell when it arrives. And you, you sometimes don't even recognize it, but it arrives. I, I received a phone call from thousands of miles away from another country, from my mother's mom's brother, who I've had a very difficult, rough relationship with. And he called me and said, I heard the news. Um, but I want to tell you something, health is your business. It's not the business of doctors. So what I want you to do is shake off the difficulty of this moment of this diagnosis.

I'm flying right over. I'm on the next flight over, and we will go through this together. And it was a divine intervention because he sat down as an enormous support structure, has no background in medicine, and was able to research and find things and draw questions that we needed to move forward with the next stage of handling this disease. And it has forever kind of etched in my being of just how I've always

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viewed this relationship as something that was really difficult to handle. And I didn't really want to talk to him, but how the divine spirit came through and acted through him, and through his gentle handling and nurturing support, I began to grow strength. And today that strength flows so strongly within me that I'm truly touched and blessed by this unfortunate experience.

Diane Mulligan :

I can tell you, we had chills in that room listening to AJ talk about the unexpected family visit that helped him and his family navigate his lung cancer diagnosis. And by the way, you heard from LCFA Speakers Bureau members, Juanita Segura, Gina Hollenbeck, and Lisa Goldman in that conversation. And we are so grateful to them for sharing their experience and learning to live with lung cancer.

Sarah Beatty (17:37):

Thank you also to Dr. David Carbon of the Ohio State University for joining us on this episode to talk about The First 7 Days on the Hope with Answers: Living with Lung Cancer Podcast. Coming up on the next episode, we talk about learning a new language to manage a lung cancer diagnosis. I'm Sarah Beatty.

Diane Mulligan (17:59):

And I'm Diane Mulligan. Please join us next time. 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 lcamerica.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.