Shared Decision-Making in Lung Cancer Transcript

Dr. Alice Shaw (00:00):

Part of the reason I take a long time in my first meeting is because I want to get to know patients outside of their cancer. What were they like before this whole diagnosis happened? Because that really helps you understand where they're coming from.

Ava (00:12):

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Annabelle Gurwitch (00:34):

This is Living with Lung Cancer: Ask Me Anything. I'm Annabelle Gurwitch your host today on this podcast we're having the kinds of conversations that I wish I'd been able to have when I was diagnosed we're sharing practical strategies as well as talking about the emotional impact advances in science community, building our challenges, and even how we're cultivating joy while living with lung cancer. If you're a patient caregiver, you belong here. Welcome. So I was hoping we'd start our conversation today talking about one of the most important issues that starts our entire life as a person living in treatment is a communication between doctor and patient. This is a topic that when I talk to other patients, people are just the most vexed about how to get a good, what we call shared decision-making going. So how do you start that conversation?

Dr. Alice Shaw (01:38):

Well, I would totally agree. I think the communication between the oncologist and their patient is so critical, and doing that right from the beginning is absolutely essential. So I guess there are many different styles that providers have. I really like to start with maybe establishing where patients are coming from, what is their knowledge of their current situation, their cancer, and really making sure that I understand how much I may need to educate or how much they may already know, and I can even go further. So I start with that sort of just baseline. Where are we?

Annabelle Gurwitch (02:16):

Well, you told me today that you saw a new patient who was newly diagnosed, right? And when you said to me that you spent an hour and a half with that patient, do you think that that's happening everywhere? I was kind of stunned at that amount of time and moved that that patient would get that kind of introduction. Is that possible for other providers?

Dr. Alice Shaw (02:45):

I hope so, Annabelle, I mean, this was a new patient who was added on. She's newly diagnosed with advanced lung cancer, and you can imagine how a patient is feeling when they've literally just heard the diagnosis. I don't even have to imagine I had that experience. Exactly. All of those questions were exactly, it's overwhelming. There are questions from everywhere. You're thinking about them yourself, your family members are asking you. You're looking online. There's just so much going on. So I do think, again, that very first visit is so important to establish what the patient, how they're doing. I think that's the most important thing. And then understand where they're coming from. Also, I also like to know how much they want to know, where do they want to go with this? And so that's very sort of individual

Annabelle Gurwitch (03:37):

For each patient. So that's a really interesting topic. So how much do they want to know? What's your experience with that?

Dr. Alice Shaw (03:46):

Yeah, I've seen the full gamut from patients really wanting to know everything and diving into the latest literature that's come up on PubMed and wanting to go through that. And then on the opposite extreme, I've had patients who really don't want to know very much, and in fact, they will say they don't want to know that much. Just what's the best treatment.

Annabelle Gurwitch (04:06):

Okay, I have an idea about that. I want to run by you. I wonder whether when a patient says they don't want to know all that much, I wonder if that's because they're feeling like they can't possibly understand it or this is also some, we know that there are some people who for various reasons might be gender, it might be their experience with doctors in the past, they may feel intimidated or they may feel that they don't deserve to have a voice. Are you able to distinguish between that or do you address that? Because I just wonder about that.

Dr. Alice Shaw (04:52):

In the past, I used to see maybe a little bit more of that of patients actually telling me they didn't want to talk about the details or know too much. They just wanted to know what the treatment was. I see less of that now. Patients are coming in actually really wanting to know a lot. But if I do have a patient who expresses that they just don't want to hear much about this, I usually do try to probe and ask, why are you concerned about learning something that you don't know what to do with that information then, or I do try to understand why, because I do think being informed is really important for patients.

Annabelle Gurwitch (05:25):

Well, let's talk about that because I think that's one of the things that I could not have imagined when I was diagnosed with lung cancer. So I think this is for those of us who've maybe been around the block for a little bit. I've been with family members and friends and my paradigm of understanding, excuse me, this is lung cancer. The treatment options were okay, you could find out what stage you're at and then you're going to have a plan that has a beginning, a middle, and an end. You're going to get this therapy and the goal is this. So I had no idea about, first of all, how you make a treatment plan for a long-term condition and also the difference that this kind of discussion and shared decision making could have. So maybe it's a good time to talk a little bit about the landscape of what's changed and what the stakes are of having someone have a conversation.

Dr. Alice Shaw (06:33):

So a lot has changed in the last one to two decades for lung cancer. In the past, say 20 years ago, we didn't know that much about lung cancer. We knew there were different types. We would call them adenocarcinoma or non-small cell lung cancer, et cetera. We would talk about that with patients, but actually treatment was fairly simple because we didn't know very much and we didn't have many options.

Annabelle Gurwitch (06:53):

So

Dr. Alice Shaw (06:54):

It's so different now.

Annabelle Gurwitch (06:55):

It's chemo, radiation, surgery. That was it. That was it. Was it, so a shared decision making is not as, let's say, doesn't have the kind of consequences or stakes because there's one choice on the menu. Exactly. They're just so few choices.

Dr. Alice Shaw (07:12):

Now we're in a totally different era where actually there's such a greater understanding of the biology of lung cancers, and so even not even getting to the treatments yet, but even understanding what kind of lung cancer does a patient have that is very, very

Annabelle Gurwitch (07:27):

Important.

Dr. Alice Shaw (07:28):

And so I do think that it's important for patients to not understand this. Not all the nitty gritty details, but just even the simple concept that lung cancer is not all the same. There are many different types of lung cancer. And so really understanding what type you have, what is there a potential, we call it an oncogenic driver, some alteration in the cancer that we can identify and then target. Is that relevant for you?

Annabelle Gurwitch (07:56):

This is something that a lot of us who are involved in patient advocacy do, we do mentorships. So when someone reaches me who has just been diagnosed with lung cancer, of course the first thing I say is that sucks because I always think it's really important to affirm how someone feels, but it's important to do that first. But then I ask, do you know what? Have you been tested for biomarkers? And I had never heard that term before. And I try to ease my own way into it. Obviously they should talk to their doctors, but I'm going to tell you how I explain it and you tell me whether I'm helping or hurting patients. So what I say is, for instance, I have EGR mutated lung cancer, so that this EGFR protein or gene is sitting on a cell and it's like a disgruntled employee who is planning a corporate, a hostile takeover. I'm the corporation, my body is the corporation. It's organizing all of the other workers and their planning. And that's how I describe what could be called an over expression of a gene. How do you like my corporate takeover?

Dr. Alice Shaw (09:24):
I think that’s a good metaphor.

Annabelle Gurwitch (09:25):
I bet that resonates well folks.

Dr. Alice Shaw (09:27):
I use a different one.

Annabelle Gurwitch (09:28):
I want to hear.

Dr. Alice Shaw (09:29):

Yeah, so I talk about genes when they're changed or altered can cause cancer. And actually the analogy or metaphor I like to use is gas and brakes on a car. And so these alterations that can occur in key genes now are putting the gas down, putting your foot on the gas pedal, and there's no brakes around. The brakes have all been removed, and so you're just go, go, go. That's kind of how I explain what it means when we say you have an oncogenic mutation or oncogenic driver.

Annabelle Gurwitch (10:01):

Right? Okay. So yours is better than mine. Not that it's competition, but you're the professional. Now, I have to ask you this. So when you were receiving training, was this, having these discussions and even coming up with that metaphor that was that part of your training? Because when I hear other patients say, my doctor doesn't know how to talk to me or this and that, I mean, I think these are very nuanced conversations. Was this part of your training? Are people being trained in this way now?

Dr. Alice Shaw (10:32):

So again, this has evolved a lot over the last one to two decades. And I would say no, two decades ago we didn't have formal training, but that started to change and we did start to have much more focus on how physicians should interact and talk with their patients. But to be honest, I think where most of us really learn those skills is actually with our mentors. So when you're a medical student, when you're a resident and you're often working with an attending physician, that person, that's who you see and how they interact with patients, how they treat patients is something that I think that's the best way to learn. So you learn a lot on the job as well. But I do think nowadays there's, for the newer physicians, there is more formal, I would say, destruction around how we discuss, and especially around what you said earlier, how do we care for patients and do this shared decision making.

Annabelle Gurwitch (11:26):

When you're in a room, when you're in that exam room and you're talking and I think about what it must like to be you in your position and the difficulty of breaking news to someone or talking about these different choices, knowing how it's going to impact someone, and I have so much compassion for the doctors. We all know there's amazing doctors. Then we also know there are providers who are stressed out or for whatever reasons haven't maybe been given the language tools. That would be really helpful. So I try to have compassion. And then one of the things I do is, and this is hard because you want to say to a patient, okay, here's another thing you have to learn. I mean, no one wants to do that, but I think that we are just as much as a doctor has to learn how has to practice communication in a way we as patients, we need to have some education in how to talk to our doctors and to be asking questions that help us get the answers that we're really looking for. So I've developed my own little way of talking about this with mentees. Can I try it out on you?

Dr. Alice Shaw (12:46):

Yes.

Annabelle Gurwitch (12:46):

Okay. So now I've taken some direction from Dr. Jorge Gomez, thoracic oncologist from Mount Sinai. He has a way of introducing a conversation that he suggests for patients. And that language is to say, this is what my goal is. How close can you get me to achieving that? That's the language that he, I don't want to say, instructs patients to give, but he's suggesting that a patient uses what their doctor says. And when I heard that, I thought, okay, that's really great because what is that doing? That's asking me as a patient to first think about, well, what is my goal for treatment? Because as we know, so we're not necessarily, if you're diagnosed at late stage as opposed to an early stage lung cancer, we're not looking at a treatment plan, which is we are going to possibly do radiation or chemo or use a targeted therapy to shrink your cancer, then do a surgery, and then maybe you'll be as close to cure as possible.

(14:00):

Right? We're looking at the long-term. I am five years into treatment for stage four lung cancer. I've been so fortunate to be stable on A TKI, but at some point for me, we know we develop resistance to these drugs. And so when you're talking with a patient about what the next step is or what even a first line treatment looks like, how they want to live, how much impact we want to have on their lives with their treatment are the big issues. That is an opportunity for a patient to say, well, okay, my kids are little. I want to throw everything at it. I'm maybe a very hearty, robust person. Let's do everything possible. So I have every bit of chance of being around when the next line or next cure comes, someone who is maybe a little older or has a different lifestyle. For me, a priority is traveling and working. I want to minimize any, I think the word is minimize. I want to minimize any impact on my brain or my ability to travel and have as close an identity as I can. So I might have a different goal than someone else. So that's a paradigm that I think is one of the reasons why shared decision-making is important, because we have different goals. What do you think of my question?

Dr. Alice Shaw (15:32):

Well, I love that suggestion actually for patients. I have to say that this comes up in our conversations. Usually even in the first time we're meeting patients. Part of the reason I take a long time in my first meeting is because I want to get to know patients outside of their cancer. What were they like before this whole diagnosis happened? That really helps you understand where they're coming from and also when they do start to mention goals, and that all comes together in a way. So I learned a lot about that even from that first meeting. I don't have patients saying exactly that, but I think that's right on meaning that I think if I did have a patient say it so explicitly, here are my goals. One, two, and three, how closely can you get me there? I've never had someone say it like that, but I feel like our conversations ultimately get to that.

Annabelle Gurwitch (16:19):

Okay, I have a new goal in life, which is to talk to as many patients as possible. Yes, you should give them that language. I think it's great. Then have you called me one day and said, I think it's amazing. Oh, I got one of those patients who use that language. Because part of the issue I think is we don't get questions answered if we're not asking the questions. And I'm going to give an example for anyone who's watching or listening to this, well, what does that actually mean in a life? So I'm going to use myself as an example. So for instance, and this is so crazy, and I'm actually getting very excited because this represents when I think about hope for us people in treatment and for the providers. So I know they are such great stakeholders. When I was first diagnosed and I was so fortunate to be diagnosed, I mean at this time in history, when a biomarker targeted therapy was available for and that we could know that I had EGFR mutated lung cancer at the time of diagnosis five years ago, the drug that I'm on was a standard protocol.

(17:30):

So the idea of me starting that as a first line was really the only, and probably let's say, best advised for my case. Absolutely. Now we have more choices even for someone like me whose surgery is not an option. So for me at this moment, the potential of adding another, what we call combination therapy, adding a form of chemo to my targeted therapy is a choice someone might have at first line. So that's what we're talking about. And it's interesting because I do get patients who come to me to ask me for my advice about that. And the question is, and what's so interesting is they all do different things. So some of the people I mentor have decided to do A-T-K-I-A targeted therapy and the chemo to hit it really hard at first. Others, and this will be unimaginable, imagine this conversation 15 years ago, one of the people I mentor, it's been very important to her to not tell her employer that she is in treatment for stage four cancer. This could have never happened in the past. And why has she done that? She's getting to live as close as she can to her normal life with keeping working. In fact, she has decided not to tell anyone outside of her immediate family. Now, that's a path I haven't followed clearly. I'm wondering about how you counsel patients in that? Do they talk to you about community? Because this is one of the values that we talk about on this podcast, and do you connect them with the community?

Dr. Alice Shaw (19:29):

Yes. Well, wow. I would say that these days, I feel like most patients typically will share with family members and friends and really seek out a community. That wasn't always the case. I would say probably in large part because communities didn't always exist. So again, back to when we were talking about 20 years ago when we didn't have almost any good options for lung cancer at the time. Unfortunately, patients didn't live very long. We couldn't even form the communities for them at that time. And so I think one of the most amazing things I've been really so lucky to witness over the last 15 years especially, is that hand in hand with these new and really effective treatments, targeted therapies, especially, we have seen this sort of blossoming now of communities for patients with lung cancer and lung cancer that's advanced, right? SAGE four lung cancer. And so we have a number of these communities, EGFR resistors, we have ALK positives, we have the Ross Wonders.

Dr. Alice Shaw (20:29):

We have so many amazing communities, Ross Kickers, and I have to tell you, I would say the majority of patients now, at least the ones I see are interested. And do you tell them? Do you give them the

Annabelle Gurwitch (20:40):

Resources? I do. Oh, that's fantastic.

Dr. Alice Shaw (20:42):

Well, also because you may appreciate this, that otherwise patients will just Google and look for the Google lung cancer stage four, and you know what you find.

Annabelle Gurwitch (20:51):

Yes. Dr. Google was my bad boyfriend when I was diagnosed. He just told me all sorts of wrong things and things down the wrong path.

(21:02):

And I was in a very bad relationship with Dr. Google until I actually discovered LCFA. But it was completely by chance, LCFA happened to be my initial contact into this world just through a friend of a friend of a friend's. I mean, that's one of the reasons why we're here is to interrupt that cycle, right? And I love that you give your patients that information because I felt so completely isolated when I met the very first person that I met who was living with lung cancer. I just burst into tears. I just honestly had never seen anyone who was a survivor. It was so important. So I love that patients are being given that information.

Dr. Alice Shaw (21:45):

I mean, those communities are so important, not just for creating that community, that sense of community, that you're not the only one out there dealing with this, not just for inspiration, that there are patients who literally are living with their lung cancer for 10, 15, 20 years is incredible. But also what I've seen in particular is that there are some incredibly smart and savvy and experienced patients

Annabelle Gurwitch (22:10):

And they help each other. Yes,

Dr. Alice Shaw (22:11):

They help

Annabelle Gurwitch (22:12):

Each other. That's exactly what I want to talk about next. Every week on living with lung cancer, ask me anything. Podcasts, we explore questions that matter most to people living with lung cancer. We talk about new treatments, everyday challenges, new research, and we share the stories of patients and caregivers who are finding hope and strength. If you want these insights delivered straight to you, subscribe on any of the podcast platforms or go to lcf america.org. And if you know someone who could use some understanding or encouragement or both, share this program with them and don't forget to subscribe. Now, back to our conversation. Now, how do you see it? Tell

Dr. Alice Shaw (22:51):

Me. Well, I've seen it in particular in many different ways. But for example, a patient may be wondering about how to manage a side effect. That's exactly what I was thinking.

Annabelle Gurwitch (23:02):

We were

Dr. Alice Shaw (23:03):

Completely, and I've been so impressed that they get great advice from other patients and sometimes maybe even better advice from their own providers because they're talking to patients who are living with the same side effects.

Annabelle Gurwitch (23:13):

Yes. That's one of the reasons why I always try to encourage people to become part of the community. And for me, it's not a lack of caring from a doctor. It's simply the life experience of living with the disease. I think it really supplements each patient's

Dr. Alice Shaw (23:31):

Knowledge about the drug they're on or their experience that they're going to have.

Annabelle Gurwitch (23:36):

And there's something, it's kind of amazing. I mean, this is one of the amazing things that we have in terms of social,

Dr. Alice Shaw (23:45):

It's amazing.

Annabelle Gurwitch (23:46):

And so if you're having some issue in the middle of the night that isn't a medical emergency, I mean, let's make that distinction. It's really helpful. The community has sourced so much information that is helpful. But I do want to talk about the way we talk about toxicities and side effects with our doctors because again, I think there can sometimes be a communication gap. So I'm going to use an example of one of my mentees. So she is on targeted therapy and she's had some really bad rashes, and that's not uncommon with all the different targeted therapies. And the question that comes up, it's come up for her, and it came up for me as well, was how much am I supposed to live with? How much is too much discomfort? And so she was having these raised welts, the kind of rash on her scalp, and they were breaking open and it was painful and she couldn't go in the sun or even leave the house.

(24:54):

I mean, it was really difficult. And she was on a telehealth appointment with her doctor and he said, well, I have patients who have worse side effects. Now, is that the right thing or wrong thing to say? Are we talking to a doctor who maybe has, God we don't know, kind of emergencies he or she's had all day or maybe hasn't actually seen the effects. I mean, we don't know why someone gets a response like that. So without saying, this is just a bad doctor, how do we repair that kind of conversation? And what is the answer or isn't there an answer? Okay. It's a lot, Alice. It's a lot. I just ask a lot.

Dr. Alice Shaw (25:51):

Well, I do think on the physician side, I think the patients have to be able to articulate very clearly how this is affecting their life, their activities, their normal function, their interactions. Otherwise a physician, especially if it's a telehealth visit and it's quick and they're trying to get through, they may not understand the impact.

Annabelle Gurwitch (26:16):

So one thing we can take, right? Here's one little tip here I think that you're saying is that we need to make sure we are communicating. So for instance, when I told my doctor I was having terrible gastric effects, I was having diarrhea. The helpful thing for him to understand what that's doing is I need to say, I can't leave the bathroom. I passed out in front of the bathroom last night. I need to really give that picture exactly.

Dr. Alice Shaw (26:51):

I had six episodes overnight. That means you're not sleeping overnight. Or like you said, I wasn't able to go out to dinner because I was so worried about having diarrhea. I mean, being pretty explicit about

Annabelle Gurwitch (27:02):

Its impact is really important. I think it's hard, and someone listening to this or watching this might say, God, I just didn't know I needed to say all that. Or I mean, some of these things I think are things that we can sometimes feel embarrassed about. I felt like maybe I had done something wrong. It was my fault. I mean, I know that when I say this now, it sounds a little like, why would you think that? But I feel like we as patients feel like maybe we are

Dr. Alice Shaw (27:38):

Failing. No, no, no. And so we had to figure out how to remove that feeling. That's completely incorrect. I mean, I think it's just so important. There's no other way a physician can really help them if they don't fully understand how the side effect is impacting someone's life, the quality of life, or their ability to just do their normal functions. One of the side effects that I think is a tough one is fatigue. So a lot of targeted therapies do cause fatigue, but you could imagine if a patient sees their physician and they say, I'm kind of tired. If that is where it ends, the physician doesn't probe and the patient doesn't volunteer more information, you might very well just say, just keep going with your drug. We can't do that. We have to probe more. And so it's on the physician as well. For that particular example, I will usually ask patients, how is that fatigue affecting you? And I usually actually ask them to even try and quantitate a little bit. If you were at a hundred percent before we started this drug, where do you think you are now? That helps give me a really good sense of how much this new drug may be impacting them.

Annabelle Gurwitch (28:39):

Okay, I'm going to just say that I've never had a doctor ask me those questions in that way. And I think that's really impactful to hear that. And I think if anyone's, of course, listening to this, this is something we want to look for in a provider, but we don't all have choices depending upon where we live. We don't have as many choices of finding the right match, then you complete me. And so there is some responsibility that we have to step into if we can, as patients in helping our physicians to help us. And that's really specific what you said, and I don't know that I've provided that information because I am that person who, well, I was falling asleep all the time. I was falling asleep in the middle of a conversation. I actually say now that sleep is my superpower, I can sleep anywhere. Before we wrap up today, I want to talk about one more issue to do with this. Well, actually two more things. I'm going to try to fit in two more things. One is, okay, in terms of the side effects and being heard, because when I talk to people about doing this podcast, I put it out to patients, what do you want to talk about? This is one of the biggest issues. My doctor doesn't hear me and manages to talk about side effects. So one of the issues is dosage levels.

(30:27):

So I wonder how you deal with this. So I am someone who was on a reduced dose when I started out at a higher dosage. That's when I couldn't leave the bathroom. That's when I was scratching my skin till I was bleeding, falling asleep during conversation. I mean, this was not living for me. And I did that for a few months thinking I had to suffer. I was so happy I wasn't on traditional chemo. And then finally I was like, I'm not living. This isn't working. And one of the reasons I didn't say how bad it was at first, I didn't know that a reduced dose could work. It wasn't brought up to me. I wonder how you parse that issue.

Dr. Alice Shaw (31:12):

So this is a really important topic. It does come up a lot in terms of managing patients who are being treated with oral targeted therapy pills. And as you know, for the most part, most of the pills we're prescribing in lung cancer are prescribed at a flat dose. Everyone starts the same dose. And what does that dose, how does that dosage arrive? Well, that has arisen from typically what we call a phase one dose escalation study, where we've tested typically three or six patients at different dose levels, typically in an escalating fashion. We've tried to then understand side effects at that particular dose level, drug levels that are achieved, and of course looked for signs of response efficacy, but it's not a huge, huge study with hundreds of patients at every dose level. So we have somewhat limited data that then drives our decision to select a dose and basically now have a standard dose. And again, for the most part, it's a flat dose for most patients. If you think about all of the patients that we treat, think about how individual every patient is.

Dr. Alice Shaw (32:18):

So in a way, it kind of makes sense, like intuitive sense that one single dose may not work for every patient. So I do think we as physicians do have to be comfortable with, first of all, understanding all the data behind the dose levels, but also recognizing toxicities when they've reached a point that they're really not acceptable for a patient, and then feel uncomfortable in knowing how to modify the dose. Typically, it may be a hold of the drug. Oftentimes it ends up being also a reduction in the dose of the drug.

Annabelle Gurwitch (32:48):

So in your practice, do you tell a patient at the onset that there's a possibility that the dose could be reduced?

Dr. Alice Shaw (33:00):

I almost always do because almost every one of our oral targeted therapy pills have some side effects. Some are more, some are less. Of course, I would say for the oral pills that we use where we know that there's a fairly significant number of side effects, I will absolutely always talk about what those side effects are and how commonly we will need to interrupt dosing or even dose reduce. So I do do that because otherwise the patients will be really caught off guard.

And then like you were saying, they might not realize, well, wow, this is really bad and I'm just going to put up with it. They didn't really hear much about it. I'm just going to live with this, and that's not what we want.

Annabelle Gurwitch (33:36):

That I actually had justified in my mind this idea that, well, I guess my doctor didn't tell me because he wanted me. He didn't want me. He wanted to make sure I got the most, I mean, obviously I understand you want to try to give your patients the best chance of a medication working, but I had sort of justified this idea that if he told me that I could possibly go on a lower dose, then I might not give it a chance at first. And I think that's unfortunate, to be honest. And I know a lot of patients have that experience because that's what gets us thinking. We have to suffer. I don't know what this metric is. So dose reduction, I kind of wish that was a standard conversation.

Dr. Alice Shaw (34:39):

It should be, especially for some of our targeted therapy pills where it's quite common to dose reduce. And so even today when I met my new patient and we were starting her on a new pill, I absolutely talked about the likelihood which is high, that we might need to

Annabelle Gurwitch (34:54):

Dose reduces. I really appreciate that. That's another goal is to address how the conversation goes about dosage. I'm going to wrap up in a minute, this conversation for today, but I want to touch on just one more thing, and before I do that, I want to mention, we've been talking about these oncogene driven cancers, lung cancer, and just I want to make this one little comment. So for some people who've been recently diagnosed, that word is unfamiliar. And when they also hear maybe the phrase gene targeted therapy, I think it's just important to acknowledge that when we're talking about that, we're not talking about an inherited trait.

Dr. Alice Shaw (35:40):

Exactly.

Annabelle Gurwitch (35:40):

This is sometimes an association people have.

Dr. Alice Shaw (35:43):

It is No, in this case, for all of these different types of genetic alterations we've talked about, these are not hereditary. In fact, sometimes we will even say they are somatic, which means they're only in the cells of the lung, in this case for lung cancer. They're not in any of the other cells that are passed on to your children.

Annabelle Gurwitch (36:02):

So the last thing I want to talk about in our conversation about communication between doctor and patient shared decision making is okay, let's say we're maybe at an impasse. What do you think about second opinions? Do you encourage that? How do you talk about that with patients?

Dr. Alice Shaw (36:28):

Yeah. I mean, I think if we have a treatment decision that needs to be made, obviously I would've walked through what I think the treatment options could be. And if it feels like, well, it's just not clear what to do. I mean, oftentimes a patient will ask, would it help if I got a second opinion? And I always support that because from my experience, it never hurts to get another pair of eyes on a case. There may be something that you've been following a patient for a few years, but you haven't seen that, right? So I think it never hurts to get a second opinion. And so yes, I encourage that, especially at times when it's not clear, the path forward is not necessarily clear.

Annabelle Gurwitch (37:09):

And that's actually becoming not a rare occasion now. Exactly, because we have so many options. So you encourage a second opinion. That's really great to know because I think sometimes a patient can feel, I know I've had this experience nervous about asking a doctor, if I can get a second opinion, okay, here's my big worry. I might be nervous about asking that because I might think, oh, is my doctor going to feel that I don't trust them? Do you feel that way?

Dr. Alice Shaw (37:43):

I don't. But I guess I would say that if you were a patient and you were being seen in say, a community center

Annabelle Gurwitch (37:51):

Where

Dr. Alice Shaw (37:52):

They don't see many patients like you, because you know that certain types of oncogene driven lung cancers are somewhat rare. Even EGFR in this country, 15% or so, ALK four or 5% ROS one, even more rare, 1% or so of patients.

Annabelle Gurwitch (38:06):

Or if you're being treated by someone who's not a specialist.

Dr. Alice Shaw (38:08):

They may just not have that experience or even have seen enough of these patients to know all of the 15 different options that are literally unfolding. And so I definitely think that seeking out a second opinion is really important. And in my experience, because sometimes I see those patients, I have found that the referring oncologist is usually really excited to actually learn what's coming and what's in clinical trials and to become sort of partners with us.

Annabelle Gurwitch (38:43):

So if someone's doctor says, I don't think you need a second opinion, maybe that's not the right doctor. It

Dr. Alice Shaw (38:52):

It always depends on the situation, but I do think folks should be open. I would hope physicians would be open to having another expert pair of eyes look at a case, especially if it's a tough decision that needs to be made.

Annabelle Gurwitch (39:05):

I really appreciate that you feel that way. I think it's important for patients to know it's okay to ask for a second opinion and not to feel like you're breaking a compact or something.

Dr. Alice Shaw (39:22):

Absolutely. This therapeutic landscape of lung cancer is so complicated now. There are so many new developments. There are so many clinical trials. I think it's absolutely, I would hope most of his oncologists would feel like it's absolutely reasonable to get a second opinion.

Annabelle Gurwitch (39:40):

Well, I really appreciate that, and I think everyone listening and watching, I appreciate that too. Thank you so much. Thanks for listening to Living with Lung Cancer: Ask Me Anything. I'm Annabelle Gurwitch, which if today's conversation helped you follow, subscribe, share this episode with someone who might need it together. We can change the way we talk about lung cancer. And if there's a lung cancer related topic you want us to explore, let us know in the comments. Find out more at lcfamerica.org. You can find me on the socials or at my website, annabellegurwitch.com.