



Communicating With Your Doctor Transcript

Annabelle Gurwitch (00:00):

Have you changed doctors ever? How have you negotiated this space for yourself?

Colette Smith (00:09):

For me, personally, I think of it as choosing the best healthcare that I can have and that I deserve, or being shy about speaking up.

Ava (00:20):

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Annabelle Gurwitch (00:43):

I'm Annabelle Gurwitch and welcome to Living with Lung Cancer. Ask Me Anything. And on this podcast, we are going to have conversations that we would normally have if we weren't being recorded. And my guest today is Colette Smith. Colette, you're a mother, you're a grandmother, you're a professional. You are also someone living with lung cancer, so we've got a lot to talk about. Let's do it. Alright. Okay. So to introduce our topic today, I'm going to tell you a little story and here's my little story for you. So I switched to an oncologist. It's been about a year now. I go to see my new oncologist, Dr. Ravi Sal. Let me just say his name. He's so fantastic. It's my first meeting with him.

(01:45):

I asked the question because I'm someone who is diagnosed at stage four with EGFR mutated lung cancer. I'm still on my first line of treatment. I've been so fortunate on the biomarker targeted therapy, Tagrisso. And so I said, so I'm stable right now, but I'd like to talk about what you think might be our next plan B as we see it right now. The science is always changing. And he said to me at first, he said, I am right there. We do clinical trials here. We stay abreast of everything. We'll keep track of this and don't worry about that. We'll let you know when the time comes. And I said, that's not going to work for me. I'm that patient who really, I do my research and I want you to know I'm not going to bring things from Dr. Google, but I will be asking you questions based on my knowledge of what's happening in the world, what trials are taking place and where the science is moving. Is that going to be okay with you that I'm going to want to make decisions together and I'm going to be asking you questions? And he said, oh, absolutely. Everybody wants to do things in different ways. And he said, that's what we'll do. We'll make decisions together. And I thought, okay, I have found the right doctor for me. However, I couldn't have had that conversation a couple years before. That's not how I started out.

(03:34):

So that's my way of saying today what I want to talk about is communicating with our doctors. Are we speaking the same language? How do we speak the same language? How do we get to find our voice

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with them? So I'm going to ask you, have you ever changed doctors? How have you negotiated this space for yourself? For me

Colette Smith (04:04):

Personally, I think of it as: am I going to choose the best healthcare that I can have and that I deserve? Or being shy about speaking up the best healthcare I deserve. That's how it has worked for me. And I realized that everyone may not have that courage, but you owe it to yourself

Annabelle Gurwitch (04:30):

If you can. So what does, let's talk about what does that mean? What does that look like and is this something you've learned since you've had lung cancer or is that for you, something that you came to it with?

Colette Smith (04:44):

Maybe a little bit of both. Lung cancer has given me a set of balls that I didn't have. I'm like, this is the worst thing that has ever happened to me. I am not going to spare hurting a physician's feelings because I'm feeling bashful. And it could be some of my life experiences before I'm one of 13 children. I've had to claw my way through everything, hand me downs and everything else.

Annabelle Gurwitch (05:15):

Right, right. See, it's very interesting. I think we all come, if you're diagnosed with lung cancer or really any chronic disease, one of the things that distinguishes this kind of experience is we're not in the situations where you're in a one-off.

(05:35):

For some people with different kinds of medical journeys. You're looking at, okay, we've got a situation, we have to triage it and then it's going to be done and maybe you'll have some effects the rest of your life. But there's a definite beginning, middle, and end for many chronic diseases as we know. And for lung cancer, this is not typically the case. I see my oncologist more than I see most of my relatives. So one thing I have come to see, and I wonder what you think about this is there's no perfect. So do you have a set of criteria that you evaluate whether someone's right for you or not?

Colette Smith (06:20):

For me, communication is important. I must feel comfortable and at ease with asking questions. I don't think any questions is a silly question and if I feel that my questions are not being addressed, it's a no-no. What I also do is I have three different oncologists and they know about each other because I shop around not to change physicians, but I go looking for the science. My physicians are aware of second and third opinions that I've gone for and that has worked well for me because my physicians have also changed facilities. So in the event of a life change, I have someone down the pike who knows my history and is familiar with my history that I check in with once or twice a year that I can easily transition to. I plan ahead a little bit.

Annabelle Gurwitch (07:24):

And Colette, do you follow the science or what do you do to stay abreast of things?

Colette Smith (07:30):

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Well, for one thing, I follow the science of my particular mutation, EGFR Exon 20. I found an oncologist who does research in that specific field and it's through a lot of research. But I found that person, I'm not switching my care, but I check in with that person at least once or twice a year. So I look to see what's being done. I've had conversations with her about the other nodules. I learned about a drug that's just left stage three clinical trials. It's on the market now. So I have a game plan

Annabelle Gurwitch (08:08):

If I should need it. Do you bring that up to your doctor? Will you say things like, I've learned about this drug, is that something I am eligible for?

Colette Smith (08:20):

Absolutely.

Annabelle Gurwitch (08:21):

That's fantastic. Absolute.

Colette Smith (08:22):

And I let that physician also know where I got the information open. Create some healthy competition, if you

Annabelle Gurwitch (08:29):

Will, 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 LCamerica.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. I actually heard a prompt from Dr. Jorge Gomez. That is something I think is really useful for patients in talking to their doctors and I want to try it out on you. Okay, tell me what you think. Go ahead.

(09:22):

Alright, so the language that he suggests patients incorporate when they are talking to their doctor is to, and it requires some thinking before you get there, but to say, this is my goal or this is what's important to me. How close can you get me to that goal? So when you unpack what that prompt would mean, you would think in advance, what is that goal? So maybe for one person it might be, my goal is to wipe this thing out as quickly as possible. I don't care what I'm able to withstand anything I want to cure. How close can you get me to a cure? Then the doctor can say, well, maybe there isn't a cure, but we can get you as close as possible. We can try for no evidence of disease or we can try to shrink it as much as possible, whatever's going on in your body.

(10:39):

So that might be a combination therapy or trying to tolerate as high a dose as possible, but for someone else, that prompt may sound like, let's say I'm someone, I'm 85, my goal is to travel. I've retired. I want to travel. I want to do the kind of treatment that is going to make my life as much as exactly as it is now. So that's my goal. How close can you get me to that? To be as unaffected by this treatment as possible while still trying to control this disease? Well, that might mean maybe monotherapy. So that kind of prompt,

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this is how I want to live. How close can you get me to that? This is my goal. How close can we achieve that? I think that's very useful. What do you think about that?

Colette Smith (11:47):

I like that and I think what it's expressing is this is my body and this is my choice and to determine whether or not we are aligned as physician and patient. Is this something you can work with me on? I like that prompt.

Annabelle Gurwitch (12:05):

Oh, I have to ask you a question. When you go to appointments, do you take notes?

Colette Smith (12:10):

I do not. I don't take notes/

Annabelle Gurwitch (12:12):

You don't do that? Do you record the appointment?

Colette Smith (12:14):

It depends. It depends on what the conversation is going to be and I ask for the physician's permission to record. I try to, instead of taking notes to stay engaged in the conversation, I may have notes before specific questions that I have. It depends, especially if a scan is being repeated. I got tons of notes, tons of questions that I'm going to refer to. Why is this being repeated? What did you see on the last scan that's causing you concern now? What are you looking for precisely? I have tons of questions and usually my questions are met with answers

Annabelle Gurwitch (12:57):

Because if they weren't, you would not be with that doctor.

Colette Smith (13:00):

Of course not.

Annabelle Gurwitch (13:02):

Do you bring people to your appointments with you?

Colette Smith (13:05):

I do not. It's nerve wracking for me personally to do that.

Annabelle Gurwitch (13:09):

It's really interesting because there's different strategies about this. I like to go by myself primarily because this is my way of making my lung cancer treatment a part of my life. I feel like if I do this in a way my job, it makes me feel less like it's dominating my life. I'm also worried about going to, when someone comes with me, I feel like I have to take care of them, particularly if it's a family member.

Colette Smith (13:52):

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For me personally, I've taken my husband to appointments before diagnosis and he doesn't cooperate with going. I want him to get there with me like I'm upset, I want answers. Come on, let's go in and be upset and get answers together. Nope, that's not his personality type. That's so funny. That's so interesting. No, I leave him at home.

Annabelle Gurwitch (14:15):

That's interesting. I think we have to educate our providers about this because I always find that they seem surprised that I'm there by myself. I don't know if this happens with you, but they usually say things like, did you bring anyone with you? There's an expectation that that makes things easier. I challenge that expectation and I think that we have to think a little bit out of the box in terms of really what works for you. How do we each, what's going to be the most empowering position or what's going to be the way of dealing with it that's going to make it smoother to be a part of your life and not overtake care of you?

Colette Smith (15:03):

If it's a tough appointment where I'm getting news that I wasn't expecting, I want to get it by myself, process it and then explain in my own way or be able to think on the travel home by myself and not have to have a conversation with someone else.

Annabelle Gurwitch (15:22):

Yeah, I mean, I want to acknowledge that people are impacted in many different ways and I feel really lucky that I get to go by myself. That's a privilege and the benefit of science that the TKIs have allowed me to do that it has a few times backfired. There was one instance when I was at the hospital where I received treatment and I tested low for a blood oxygen level and I had to, a couple of things were happening as now I'm on an IV, now I'm being rushed into a scan. I was so nervous I had to take a Klonopin and then call my boyfriend who did not know I was actually going to the hospital that day and say, hi, I'm drugged up on a gurney and I might not have mentioned that. I have such close monitoring of my health and I'm an hour out of the city. Could you take an Uber and pick me up and drive us back? There's some conversations that had to be had there that I wasn't expecting. So it's a privilege of science and of advancements in care to get to do that, and I don't take that for granted. So I feel I agree.

Colette Smith (16:57):

I like the solitude of going and having these appointments on my own and being able to think things through afterwards or before and then calling and say, oh, everything's fine.

Annabelle Gurwitch (17:07):

I'm really glad we talked about this today, Colette, and I want to thank everyone who's watching or listening and encourage you to get that patient provider communication and also to reach out in our lung cancer community if you're concerned about how to stand up for yourself or what kind of things you can expect. Or maybe sometimes when I talk to a mentee, I'll say, I'm not sure that's a reasonable expectation from your doctor, because sometimes I think we have to also think about what is reasonable and what's not reasonable because we all want to cure and there are different things that are available for each of us. We're going to post some show notes about this topic and we have more information at LCFA's website also at my website, annabellegurwitch.com. Thank you for being with us today. I hope this has been a conversation that you really won't hear anywhere else, and I urge you to have those conversations and if you like the podcast, leave a comment, leave a little star or whatever that is on

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