LCFA
Lung Cancer Foundation of America
Living With Lung Cancer
ASK ME ANYTHING

Transcript: Side Effects

Ava (00:01):

Welcome to L CFA's living with lung cancer. Ask me Anything podcast where we have real conversations with people living with lung cancer, learn from personal journeys and expert insights. Subscribe now and never miss an episode. I

Colette Smith (00:21):

Remember about two months after my surgery and I explained about the excruciating pain that I was still experiencing in some of the sensitivity from, I guess nerve damage. And he says to me, well, I haven't experienced that in my practice. It's time for you to go back to work.

Annabelle Gurwitch (00:40):

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 were sharing practical strategies as well as talking about the emotional impact advances in the 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. So today my guest is Colette Smith. Colette, you are a professional, you're a mother, you're a grandmother, and you were also like me living with lung cancer. So we've got lots to talk about.

Colette Smith (01:24):

We do. Let's get it started.

Annabelle Gurwitch (01:25):

So for the topic we're going to talk about today, I've got a little story for you. So not long after I started my treatment, after I was diagnosed with stage four lung cancer, EGFR mutated, so I was able to go onto a biomarker targeted therapy. I was single and I met someone who seemed undeterred by my diagnosis. And the minute we started dating, I started getting UTIs and I asked my oncologist, is this related to the medication? I was assured it wasn't. Then I get my second UTI and I third UTI, and then it's like two months in and I have a continual UTI and I'm like, this is killing my vagina. Are you really sure there's no connection? I was told there was no connection. And what I was advised was just stop having sex. And I was like, that is the advice. I'm 60 years old.

(02:30):

I have met someone who has stage four lung cancer. I am really excited about this and you're telling me not to have sex. So this is my way of saying we're going to talk about the side effects of living with lung cancer and we have a unique perspective because I have side effects and toxicities associated with A TKI with a biomarker targeted therapy. Your experience is you've had side effects associated with the surgery you had. So we've had different kinds of ways of being affected. So if you're watching the show or listening to the show, I hope you will find something in our stories that you'll relate to and speak to, and we'll also be giving tips at the end of the episode about how we mitigate these things. So, okay, Colette, you had surgery not long after you were diagnosed. How was that recovery and how is that still affecting you 10 years later?

Colette Smith (03:44):

First of all, I want to say something about being diagnosed in early stages. Everyone assumes you're okay.

Annabelle Gurwitch (03:54):

Oh,

Colette Smith (03:55):

Interesting.

Annabelle Gurwitch (03:55):

I hadn't thought about that. Even in groups

Colette Smith (03:57):

Where I am among other lung cancer survivors or you're stage one A, you're the anomaly, you're okay.

Annabelle Gurwitch (04:05):

Oh my God, did you just feel I did that? Did you just feel I was like, I'm stage four, you're stage. Oh

Colette Smith (04:10):

My God. Absolutely not. No.

Annabelle Gurwitch (04:11):

Okay.

Colette Smith (04:12):

I'm using the opportunity to share and to perhaps lend some light on what it feels like on the early side.

Annabelle Gurwitch (04:21):

Yes,

Colette Smith (04:23):

Surgery is a big deal. Having a lobe removed is a big deal. It slows me down in a number of ways, but not only slows me down, there are side effects that I have to live with. I've learned now for the rest of my life side effects that could be from scar tissue. I have seasons where I go through stages of not being able to breathe normally, and I explain it to my physicians. I say, I can inhale, but it's the exhale. Everything doesn't come out.

Annabelle Gurwitch (05:03):

So when you talk about the way that this affects your breathing and the seasons, I mean, so this isn't something that is like you close that chapter in the book.

Colette Smith (05:15):

No, it's never closed. The symptoms have never left since, maybe I would say about after the first year I began to notice the symptoms and even after several conversations with my pulmonologist, my cardiothoracic surgeon, unless something is detectable via a scan, I've found that it's hard to offer an explanation.

Annabelle Gurwitch (05:41):

And there's also, we know a big under-reporting of side effects because none of us want to be taken off these medications if the medication is working. We want to stay on it as long as possible. So this was in that little story that I was telling you at the beginning. That was the tip of the iceberg for me, for the communication with the doctors and also the way that I understood what these side effects were with the TKIs. For instance, the UTIs, as it was explained to me, when people first started taking this medication, sexual dysfunction side effects were not top of mind when all the treatments were chemotherapy, radiation, people just weren't really thinking about that. So there wasn't a lot of study into that. Also, when I was first going on the medication, I called my doctor three days into taking the medication.

(06:48):

I said, my skin is on fire. I'm waking up and I've got blood on my arms and legs scratching so much. And my doctor said, well, we don't have any patients that have that rash that early in treatment. And I realized later, so first of all, I had the rash. I mean, it was so painful. One of the reasons why my doctor wasn't aware was because of under-reporting. So I started out on the medication at 80 milligrams, which is the dosage. People are starting out. No one told me that if I had really extreme side effects, we could lower the dosage and it might still be effective.

(07:40):

And this is an ongoing conversation we really need to have. There's a lot of thought and there's some possible change happening about what's the right dosage to start people at. If people are interested in this topic, you can go to a website called the right dose. It was started by some breast cancer survivors looking at the same kind of issue because people don't want to report the side effects of the biomarker targeted therapies. They don't want to be taken off it. They don't necessarily know. I didn't know that you could have your dosage lowered. It wasn't until I had such extreme gastric effects, I had such extreme diarrhea that I couldn't leave. Not only could I not leave my house, I couldn't leave the bathroom and my son found me passed out in the bathroom.

(08:48):

I hadn't made it on time. And that was when I said to my doctor, I don't think this is working for me. I was so terrified, Colette, I didn't know we could lower the dose. We had my dosage and I've been stable for five years at this lower dosage and I am clearly able to leave my house. Now, sometimes I'll be with a group of people who are on the same drug as me in the community of advocates. I was at one of our lung cancer world conferences and I'm sitting with this beautiful group of people from all over the world and we're all talking about how we carry Imodium with us. And one person said he rides a bike, he lives in Australia. And he said, I carry a map of where all the public bathrooms are.

Colette Smith (09:51):

That's funny

Annabelle Gurwitch (09:51):

In my little town.

Colette Smith (09:53):

That's funny.

Annabelle Gurwitch (09:54):

And you just wouldn't know to look at us, to look at us. We don't look like we're affected. But these things, if you can't leave your bathroom, how are you going to go to work? These are the things that are like the invisible things like I look great. I am struggling. I can't get out of the bathroom. These are things. This is why the community is so important because we need to be able to talk about it and we need to talk about how we talk to our doctors about it.

Colette Smith (10:24):

There are a couple of things that you said that's taking me back to similar conversations that I had with my cardiothoracic surgeon. I remember about two months after my surgery and I explained about the excruciating pain that I was still experiencing and some of the sensitivity from, I guess nerve damage. And he says to me, well, I haven't experienced that in my practice. It's time for you to go back to work. I don't think it was an insensitive thing. I think like you said, he's a humanitarian, but he's focused on doing what he did for me two months prior, which was the surgery.

Annabelle Gurwitch (11:04):

Again,

Colette Smith (11:04):

I had to

Annabelle Gurwitch (11:05):

Use my voice

(11:06):

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. So one of my mentees, she's on the same drug as me. She has a really terrible rash. She gets welts on her head that she has to be mitigated by having injections with liquid in them. And for the first two days she says she looks like the elephant man. It just blows her head up. Just so difficult. So she's on a telehealth appointment with her oncologist who she doesn't always see because he's not always available. She sees the nurse practitioner because she's stable in her treatment, but she's explaining to her oncologist on this telehealth appointment, what is there an alternative to what she's on? And he says, I have patients who have worse side effects than you.

(12:40):

I know, I can imagine because a humanitarian, he's not thinking about how that's impacting this one person whose head is swollen. And when I talked to her about what to say, how do you deal with that? I think it's interesting. She was saying, I just don't want to go back to him. And I said, maybe this isn't

(13:11):

The

(13:11):

Right doctor for you. I think we all have to think about these. You're not going to get everything from one person. I said, maybe you can think about saying, I know that's true, but that's not really helpful to me right now. I mean, what would you do? Well,

Colette Smith (13:32):

I had a situation with my former pulmonologist.

Annabelle Gurwitch (13:36):

Former

Colette Smith (13:37):

Being

Annabelle Gurwitch (13:38):

The operative,

Colette Smith (13:39):

Yes. And he was explaining to me, because I have several nodules still in my body, and he was explaining to me what nodules look like when they're gravitating towards blood vessels. And he was really providing some really good information and well, one of my questions, well, why do the nodules keep reappearing and disappearing? And his explanation was, this is what happens when you smoke. First of all, no one deserves cancer whether or not you're a smoker. And

Annabelle Gurwitch (14:17):

Oh my gosh,

Colette Smith (14:19):

And what a thing to say as a physician. That to me was enough for me to say, this is not the practice for me. And I said that. I said, I don't think that you're going to be able to, I'm going to feel comfortable continuing this relationship with you. And he was apologetic and I appreciated that. However, that's not someone that I want to oversee my care.

Annabelle Gurwitch (14:49):

I just remembered something with a former oncologist of mine. I at one point said that I wanted to get a second opinion and I wanted to get a second opinion. This was to do with the UTI situation. Okay. He's a male. And I actually thought this was before I met Nas Flores who told me about this connection. So he's a male. And I thought, well, maybe I will do better if I talk to a female oncologist.

(15:20):

So I wanted to see someone else within that same hospital system, but you have to get a referral within this system. So I needed him to write me a referral. So I said, I want to get a second opinion from this other doctor who happened to be female. Now, I didn't say to him that's why I wanted that, but what he said was, I don't think your case is worth her time. And I was so shocked, and I think what he meant was, but you're doing great. You're stable. I think he thought he was saying something I heard in a completely different way. Different way.

Colette Smith (16:06):

I get

Annabelle Gurwitch (16:06):

That. I heard you're not worth it. She's a really busy doctor. And I just couldn't overcome that. And so that's my former call. I get that. Oh, okay. So much to talk about. I want to talk about something we were talking about. So we've talked about this with you and I privately. Alright. The anxiety of living with lung cancer, whether you're stage one A, you're stage four, this doesn't mean you have stage four anxiety or stage four, stage one anxiety. We all have anxiety. The other day, my oncologist, a nurse practitioner who I love, let me just say I love these people so much. He said to me though, I was saying something about writing a new book about living with existential dread of living with a chronic disease. And he said, oh, do you have existential dread? He was like, what? He said, you're stable. I said, I'm stable. I'm also five years into a TKI that I know will, at some point my cancer's going to figure this out. I'm going to have to switch to a second line. So do I have existential dread? Why? Yes. I have some existential dread. And it just hadn't occurred to them looking at the numbers and everything. And so I want to talk about how you deal with your anxiety.

Colette Smith (17:43):

One of the things that I do to escape the anxiety because you escape. I escape it only momentarily.

Annabelle Gurwitch (17:53):

Yes. It's always, always there. It's something like it's not even if it's not top of mind. Right. It's in the

Colette Smith (17:59):

Very back

Annabelle Gurwitch (18:00):

Of your mind that you are living with this right here

Colette Smith (18:02):

Over my shoulder. Right here. Right

Annabelle Gurwitch (18:03):

There.

Colette Smith (18:03):

Yeah. For me, it's acts of service. I currently take care of 18 New York City street tree beds. I just clean, I beautify. And for me it creates an environment of healing, not only for myself but for my community. And as they shower me with appreciation, it encourages me. Gardening takes me to another place where I can forget cancer that's hanging over here on my shoulder.

Annabelle Gurwitch (18:35):

Yes. I love that you and I have so much in common. One of my happy places is that I'm here in New York right now to do this volunteer project. I do call the Campfire Project. We create therapeutic arts for young refugees seeking asylum. So I lead writing workshops and we create theater, music and dance. And when I am doing this project and when I'm doing that kind of service, I don't have time to be Annabelle IC living with cancer. I'm just there to give back. And I honestly thought that lung cancer was going to take that from me. When I started treatment, I had been for many years a volunteer at my local high school working with seniors on their college essays and it was our program that we did change their requirements and I had to be fingerprinted to participate in the program. My fingerprints disappeared from the medication that I take.

Colette Smith (19:50):

Wow.

Annabelle Gurwitch (19:51):

It's an unusual side effect. But when that happened, I couldn't do that anymore. And I thought, oh my God, I hate you lung cancer, you're taking away my happy place. For me, this is one of the biggest ways I tackle my anxiety with cancer is giving back. And we also have a lot of that being a model for us in our community. A number of people who've been diagnosed have started organizations and are patient advocates. And they're doing that also to give back. And that is just one of the most important strategies that I have.

Colette Smith (20:31):

And even if not starting an organization

Annabelle Gurwitch (20:34):

Connecting, not everyone as a start

Colette Smith (20:35):

Organization, I'm

Annabelle Gurwitch (20:36):

Not doing that.

Colette Smith (20:36):

Definitely connect yourself with one, my oncologist, Dr. Cardinal Smith, the humanitarian extraordinaire. When she heard some of the challenges I was having, she connected me with Mount Sinai's community advisory board. It's been an amazing experience. I commit myself to service to that community and it makes me feel purposeful, if you will,

Annabelle Gurwitch (21:08):

And both of us work, but it's a very different thing and it's one of my big strategies. The other thing I wanted to talk about is asking for help and support. So a few, well, no, it's actually been a year now. I was diagnosed with a second cancer, and so it was stage zero breast cancer. When that happened, I was like, okay, really? Okay, okay, okay. I have to be an, I always say I'm a cancer slacker. I don't want to achieve a cancer. I'm like, I think I'm overachieving now. I had a moment where it sort of took my breath away even more than lung cancer. Like, oh, okay. A second thing to deal with. And actually I had a lobectomy. I've carried on. I'm doing great.

Colette Smith (22:05):

And that's good to hear.

Annabelle Gurwitch (22:06):

Thank you. But when that happened, I really leaned on a lot of our community, but I thought I needed some extra help. And a friend of mine said, why don't you call the chaplaincy service at the hospital? You qualify for that. Take any help you can get. Take any help you can get. One of the things we know on another podcast, I want to go deeper into side effects and mitigation of side effects in particular with various different therapies people are on because there's some very specific things that people can do to mitigate that. But in general, I wanted to talk about how this has been my experience of mitigation for side effects, like I get muscle cramps and I have issues that are not covered by health insurances. And I wanted to ask you about things that you do and what your experience has been with that.

Colette Smith (23:09):

Okay, good question. So after experiencing all of the difficulties and side effects after the surgery and the constant back and forth with my physicians, I sought care of my own with a massage therapist. And after six months of that therapy, I found a formula that works for me and that is something that's not covered by my health insurance plan, but it's something that I do because it gives me relief. So that has worked for me.

Annabelle Gurwitch (23:50):

When you say that, I think it's really important for people to hear this, and one day I would like to find a way to address that in some kind of advocacy because the actual mitigations that help us, I've found some acupuncture helps. The massage is one of the few things that helps me. A really deep massage where muscle cramping is a very calm side effect from TKIs and it's not covered by our health insurance, which is really a lack of understanding. It's really sucky. Yeah, it's shocking. It's a lack of understanding of how profound the side effects are and we'll have to figure out how we can work towards addressing that. But one of the reasons why I wanted to bring that up is also all these issues are interconnected. That costs money.

Colette Smith (24:54):

It does

Annabelle Gurwitch (24:54):

And time and it's, there's a really big impact for that. You also have to have time. You have to be able to have time to be able to do those things. You have to have money to do those things and you have to have some knowledge that might help. And if we can counter one thing today, it's in sharing our experience too, and this is one of the reasons why the community is really important. I often turn to the Facebook website

(25:23):

For

(25:23):

The EGFR resistors because all of us are on the same drug or many of us are on the same drug. And so going into the chat room and saying, do you have this? What do you do for this? It can be really helpful. So turning to the community if you're having side effects and finding out what other people are doing, because our doctors just don't always know that stuff is happening. So I want to urge people to. I think that's all the time we have. Thank you so much for being a guest and sharing your experience. Colette, wait, before we end though, anything else you want to add? Any other things about side effects? I

Colette Smith (26:06):

Have a little nuance.

Annabelle Gurwitch (26:11):

Oh yes.

Colette Smith (26:11):

Something I'd like to share. I love nuance. I have a little gift for you.

Annabelle Gurwitch (26:15):

What going

Colette Smith (26:17):

To explain this in a minute? I hope it's a

Annabelle Gurwitch (26:20):

Massage. Is there a massage in your No,

Colette Smith (26:24):

This is something that I carry around with me.

Annabelle Gurwitch (26:26):

Okay. What is that?

Colette Smith (26:28):

Well, this is not your gift, but

Annabelle Gurwitch (26:30):

Okay, I get it.

Colette Smith (26:31):

It's condensed milk. And if you look at the can, there's an expiration date somewhere. And this condensed milk reminds me of my childhood and a recipe my mom used for this dish. It's porridge we're Caribbean people rice porridge. And this was a major ingredient in that. And so that gives me some kind of comfort that my mom is still here with me, but it's also a reminder of life and how sweet it is and how important it is to know that we have an expiration date. So we must live. We must live. My son went to Antigua for about a week and I made a request of my sister, and it was for moments like this I wanted

Annabelle Gurwitch (27:26):

To share. You're giving me some of that porridge because I sound so good.

Colette Smith (27:33):

Look what I got you. A mini can of condensed milk so that you can walk around with that in your purse or wherever you want to remind you of how sweet life is. Life has an expiration date.

Annabelle Gurwitch (27:49):

I love it.

Colette Smith (27:50):

And I hope it is something that you can physically carry with you to remind you that life is worth living and you got a lot of it left in you.

Annabelle Gurwitch (28:00):

Oh, I love that message. I think one of the things I want to say, Colette, is that acknowledging we have an expiration date can sound to some people like a profoundly dark thing. For me, this experience, my journey has also reminded me of that in a way that encourages me every day to get up and engage with the world. Knowing that we have an expiration date can also be really empowering and a great reminder to keep connecting. And I am with you on that. I'm not sure how long this is going to last in my bag because I love condensed milk. And one more thing I want to say is one thing you and I also have done to mitigate our side effects and our anxiety is make enjoyment of life a really big priority. And for me, when I got diagnosed, one of the very first things I did was I said, why aren't I eating bread? I had given up bread to fit into certain pants and I'm now like, I am eating the bread. I'm eating dessert. Now I am an everything in moderation

(29:27):

Person,

(29:28):

But condensed milk, a little pudding, a little, some sort of creamy dessert. I'm all for it.

Colette Smith (29:37):

For me, it's cheesecake,

Annabelle Gurwitch (29:39):

Cheesecake

Colette Smith (29:40):

And oxtails.

Annabelle Gurwitch (29:41):

Okay. Thank you so much for listening and watching. We're going to have more information about this show and things we're talking about at L CFA's website. You can go to my website, annabel grammar.com, and I urge everyone to connect with the community. An empowered patient is a patient who has a better quality of life. Talk about these taboo subjects. Reach out to all of us. I know all of us are available to you. And if you like this show, leave a little comment and leave a little rating on Apple, whatever it is, and subscribe to our podcast and thanks for being with us. Thank you for having me. Thanks, colla. Oh, this is the best. Thanks for listening to Living with Lung Cancer. Ask me anything. I'm Annabell Ger, 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@lcfamerica.org. You can find me on socials or at my website, annabellegurwitch.com.

Ava (30:56):

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