Lung Cancer Foundation of America

Living With Lung Cancer ASK ME ANYTHING

This Is Just One Chapter: Mental Health, Purpose, and Hope With Lung Cancer Transcript

Jaymie Knox (00:00):

There's more to do and there's more to see and there's more that has to get taken care of. So have your moment and go through it because it's healthy, but then you got to turn the page and move forward.

Intro Voiceover (00:09):

Living with lung cancer, ask me anything. Real conversations with people living with lung cancer. Learn from personal journeys and expert insights. Subscribe and never miss an episode.

James Hiter (00:25):

Hi, I'm James Hiter and I'm living with lung cancer. And today we're going to be talking about managing mental health in the midst of treatment. When you have treatment, we think about all of the things that come along with that treatment, but we don't often think about the mental impact, the mental health impact of that treatment. So joining me today is a great friend of mine and fellow lung cancer survivor, Jamie Knox. So Jamie, thanks for jumping in here.

Jaymie Knox (00:51):

Thanks for having me.

James Hiter (00:52):

Thanks for hosting us in your hometown.

Jaymie Knox (00:55):

Yeah.

James Hiter (00:58):

When you get that diagnosis and you hear those words, you have lung cancer. Can you walk us through dialing back the clock a little bit for yourself? What was that like?

Jaymie Knox (01:11):

So I always tell people, I think I had an out of body experience when I got my diagnosis. It was back in December of 2018. And I mean, I really was not even quite sure if I heard it correctly, if I'm being honest. They said the words and after that it was like, in TV shows and movies, you hear it just kind of fades out or it sounds like it's in an echo chamber. That's kind of like what happened. But I heard lung cancer and the way that my doctor actually explained it to me, he made it seem like I had a mild form of lung cancer and like I was going to take a few pills and I would be fine and I'd be on my way. And he didn't stage me or explain how significant it was or how serious it was. And really he missed the mark and really kind of hitting home that this is a serious diagnosis that he was handing me because he really made light of it.

(02:02):

And to this day, I'm like, if I could just go back in time and be and fly on the wall in that room, I would just be like, "What are you doing, doctor? What's going on? " Yeah, exactly. But it wasn't an easy thing to hear, especially at 32 when you're just married and excited for life and you're looking forward to the next chapter and it's like right smack dab in the middle of that next chapter is this big C word. And it makes it feel like you just, everything you wanted to do is just done.

James Hiter (02:31):

Yeah. I think of myself as being diagnosed young, but you were diagnosed really young. Yeah. And so yeah, walk us through that a little bit, the mental impact of being diagnosed at such a young age.

Jaymie Knox (02:42):

Yeah. I mean, you get the typical response that most people have like, "My life is over, your life flashes before your eyes, all the things that you didn't get to do, all the stuff that you still wanted to do and all that kind of stuff just floats before you and you're like, it's all ... " Because you don't know and you don't have that understanding that comes with having this for a while, you don't understand and you don't know that things are going to work out and things are going to be okay. So you're just overwhelmed with this sense of like, start getting things in order. This is the end, especially when you hear stage four lung cancer, that is like you're like, stage four is the last one. You don't really bounce back from that. So it's hard to get around that and start to really think about anything besides what you're not going to get to do with your life when you hear a stage four lung cancer diagnosis.

James Hiter (03:32):

So at what point then did this really feel like maybe this is the end? Was that part of that initial feeling?

Jaymie Knox (03:43):

So I had it initially, but not for long. I'm a really positive person. And so even though I had that stage four diagnosis, I was like, "Something's going to happen for me. Something's going to shake and I'm going to be that person that everyone's like, don't you have lung cancer? Are you still here?" I'm going to be that one that surprises people. So I always just had this overwhelming sense of whether it's flamingoing, putting my head in the sand and ignoring it or just straight up sheer willpower. I always just feel like it's going to work out. And so I did have that initial thought of, "This is it, everything you wanted to do, sorry, time's up." But it didn't last long. I make sure that I kind of stay in that mental head space of like, you can have those feelings, but you can't live there.

(04:30):

There's more to do and there's more to see and there's more that has to get taken care of. So have your moment and go through it because it's healthy, but then you got to turn the page and move forward.

James Hiter (04:40):

Yeah. Well, I was going to say, you're one of the most positive people that I have ever met. I know how. You're so much fun to be around. Yeah. So when you're in that space that's maybe not so positive and you're trying to work your way back to the positive spot, what are some of the things that you do that help you get back to that positive space?

Jaymie Knox (05:01):

So prayer is always in there. That's always one of the first things. So there's that because there's just an overwhelming sense of calm that comes over you when you do. But there's things that I think about, stuff that I've accomplished, things that ... It's all about your mindset and how you're thinking about things. So if you start getting into this idea or this habit of thinking like, "I can't do it because of the cancer or I can't do it because of X, Y, and Z," then that's the mind frame that you live in. But if you start to reframe your thinking and start thinking more like, "Okay, I can still do it. I just need to do this instead, or it might look like this rather than how I originally intended it. " That's kind of some of the ways that I stay positive because when I'm getting down on myself, it's usually because I'm thinking about things that I can't do or things, shortcomings, if you will, and stuff that I want to accomplish or want to see or want to get through and having trouble with it and thinking about it and understanding how to get there in a different way helps me get past some of that doom and gloom, if you will, that comes into it.

James Hiter (06:04):

Are there things that kind of for you trigger that doom and gloom that you have identified? Are there things that happen that you know is going to pull you in that kind of negative direction?

Jaymie Knox (06:15):

I mean, yeah, there's always just TV shows and things that are unexpected triggers. I've been watching some shows and there's a couple of them that there's lung cancer patients in there and they die. And I'm like, "Okay, let's compartmentalize that a little bit." So there's always certain triggers, things that have certain smells, certain ... I don't live in New York anymore where I was diagnosed, but I know I could walk into that hospital that I got diagnosed in and that was always a trigger. Even if I felt good that day, my anxiety just kicked up because I'm in that space where such a devastating blow was given to me. So that kind of stuff is a trigger. I think certain side effects are a trigger, shortness of breath, anything that reminds me of life pre-diagnosis where I was just kind of like figuring out something was wrong with me, shortness of breath, back pain, wheezing, coughing, all of those things, when they happen, it's like, should I read more into that?

(07:17):

Should I let it go? Those are all triggers for me. And when they come up, you got to rationalize them like wheezing. Okay, you just came up the steps with the laundry basket. Any normal person is going to wheeze after doing something like that. Putting things into perspective and calming that fear and that anxiety in your head and just talking sense into some of that anxiety is usually what works.

James Hiter (07:38):

You want to know one of the most triggering things for me when I get on an airplane and they hand me that little ... I fly united a lot, they hand me that little pouch that has the alcohol wipe. Yeah. The plane smells like the infusion center and my oncologist's office, because they use alcohol to clean it. And it is every single time I walk in, they get on a plane, I'm right back in the infusion center, I'm right back in my oncologist's office. And now I just laugh about it, but because I know that that's going to happen as soon as I'm getting on the plane, they hand me the little blue pouch and I want to stop and tell the flight attendant that, yeah, thanks for triggering me.

Jaymie Knox (08:21):

Right.

James Hiter (08:22):

So I'm curious about your care team, your oncology team, and kind of how they did or didn't help you prepare for the mental aspect of a lung cancer diagnosis.

Jaymie Knox (08:38):

Okay. My first doctor that diagnosed me did not prepare me at all, at all. I mean, he didn't stage me. He just didn't prepare me whatsoever for this diagnosis. He really just dropped the ball, to be honest with you. But my second care team, when I was treating through ... Am I allowed ... I don't know if I'm allowed to say the hospital or not, but treating at MUSC down in South Carolina, that care team was great. I mean, they checked in. It was to the point where I gave them the list of the medications, or not medications, but supplements and things I was taking just to combat some of the side effects. And they called me and they were like, "You shouldn't take this anymore because it might counteract with your medicine. How are you feeling when you take this? " They checked in with me at that level.

(09:22):

My doctors would check in with me, the nurses would check in with me. So they all kind of held my hand through the whole process. The New York team, I didn't feel like I got that from as much at the onset. And then the care team I'm with now up here in DC is way better. I mean, I've got a history with the oncologist just from the LCFA, which is great. But he checks in, he asks me how I'm doing. He's like, "Hey, how's it going? " And lets me know what's coming up. We talk through the scans that he wants to do and I talk through any concerns or issues I have. And it's really helpful in terms of like, if we're talking about mental health and wellness, it's more just like, how are you doing? It's not like, "Are you depressed?

(10:10):

Do you have this issue? Do you have that? " It's just like a check-in, a general check-in.

Intro Voiceover (10:15):

That's

Jaymie Knox (10:15):

Awesome. But I also know that if I was to ask my doctors or say something to my doctors along those lines, they would lean in and help out. But I don't think anyone's ever asked me like, "Are you depressed? Do you have any of that kind of stuff going on? " I also probably don't give off the vibes that I have that kind of stuff going on, which is how you should also be careful because strong people also can hide it by pretending that they're not, that they're okay. But nobody has really asked me about that aspect of it, but they check in and ask if I'm okay.

James Hiter (10:44):

Yeah. Right on. Well, I know some of the ways that some people deal with the mental health side is to completely fill their calendar with other things. You recently have filled your calendar with an exciting new thing. Yeah. Do you mind sharing a little bit about that?

Jaymie Knox (11:07):

If by fill my calendar, you mean completely obliterated my calendar and have no time for anything else? Yes, absolutely. No, so I have, and it's for all those folks that have been following me over the years and have watched my stories, I have finally got foster children, two little foster children and little, little foster children as of February of this year. So they have taken over my whole existence. It's like there is nothing but kids right now just constantly on my mind. Even in my conversations, I'm like, "Wow, I literally only talk about the kids right now. This is crazy." But yeah, so I have a one year old who'll be two next week and a three year old who will be four in May. And I went from having zero kids to two kids under five in diapers. And it is a, I don't want to say it's a 180 because it's more than that.

(11:54):

It's like a 270. What's higher than the 180? So yeah, life is different lately, but it's fun and it's interesting.

James Hiter (12:04):

That's fantastic. And as you and I have talked about, my wife and I also entered the fostering space during treatment and I look back on that now and I think that for some of that it was about mental health. It was about taking my mind off, trying to make a difference, trying to have an impact with whatever time I had remaining, I wanted to have an impact. And you're doing amazing work with these kids. I'm

Jaymie Knox (12:34):

Trying. We're trying. I mean, it's definitely a labor of love. People are like, "You're doing a labor of love. You're doing God's work." And at first I was like, "Am I? " And I'm like, "I am. I am." I totally am. 100%. But I mean, it's great because I get to watch sort of my old content that I used to put out where I talked about how bad I wanted to be a mom and how I wanted to make an impact. And I tell the story that I did want the age range six to 10. I was very much set on not wanting to be dealing with diapers, but God's got a sense of humor. So I laugh because I would pray and say, hopefully we get a set of children because we're open to siblings and we have siblings, but I would pray and say, I hope that we get the children that are perfect for us and want to make an impact.

(13:23):

And I used to say, as much as I'd love to see what a baby of mine would look like, a little mini Jamie running around with pigtails or whatever, I don't know that I can do a toddler or a baby right now. I am just, a newborn, like I barely sleep as it is. With everything we have going on as advocates, it's hard as it is. So I'm like, I want to make sure that when I do become a mother, I want to impart or impact that child in a way where people don't have to tell them who I was or tell them what I was like or anything like that. I want them to be like, "No, I remember because she did this or my mom used to do this with me or I remember that this is something that I used to do with her." And I always just thought that six to 10 age range was it.

(14:09):

You get in there, you jump in there and you start making the memories now and setting the structure now, but I'm realizing a month into this game that this age range that I have is actually the one, like this is the one because the kids that we're raising now are going to be, what we're doing with these kids now is going to dictate how they are as preteens, as teenagers, as adults, and how they process their anger, their emotions, their feelings, and how they love others and whatnot. And so I'm like, very funny, God, very funny. So he gave me what I asked for. Just like I always say, it didn't look like I wanted it to look or how I originally intended it to look.

James Hiter (14:45):

Well, I don't know if you remember this and I wasn't even going to bring it up, but it feels like it fits. I was sitting beside you at a lung cancer conference when you were exploring the whole concept of would you still ... And I remember that being particularly tough ... I had just met you and yet I felt like I wanted to wrap my arms around you and give you the biggest hug ever as you were getting news that, like you said, at the time, maybe you were praying for something different and now this is how that's evolved. And I'm just so excited for you, even if it's different than you had a vision, but yet bringing you all the challenges and all the joy.

Jaymie Knox (15:30):

Yeah. Same thing I said. Is it more important the process or the end result? And for me, it was always the end result. And so I have my end result, like wanting to be a mom and I stepped ... I dived head first into it with and without any floaties, but it is interesting. Every day is a challenge, but it's a challenge in a good way. And it's showing me parts of myself that I didn't realize. And I'm exploring different things in terms of how I manage just kids, toddlers, like pressure, stress, all that kind of stuff. And they're a very big distraction as well. That's another thing you can add in. And like kids will distract you from having a lung cancer diagnosis. I forget because I'm so busy running behind them and wiping hands and faces and butts, to be honest, that I almost sometimes forget to take my medicine.

(16:24):

You just go, go, go and make sure that they're good. So they're definitely a way to cope with some of that anxiety that is just an absolute distraction.

James Hiter (16:35):

Well, I think for a lot of people that I talk to, and I know you talk to a lot of newly diagnosed people too, and when you're newly diagnosed, let's face it, you are in the throes of it. That's probably not the time that you're making the decision to become a foster mom or take on some new project to take your mind off of things. But once the dust settles a little, do you encounter people who have done maybe not fostering, but other things to take their mind off or fill their calendar in some way?

Jaymie Knox (17:03):

Yeah. I mean, I've got a friend, I think you know, I think I'll say her name, her name's Aurora and like she, I am in awe of her. That lady travels like it is nobody's ... It's just crazy. So I've come across lots of survivors who cope in all kinds of different ways, people who dive headfirst into work and really, really push that really hard. Folks that really push the travel button and they're like, "I'm going to see as much of the world as I can and focus on enjoying my life that way." I've seen people who dive into hobbies and things like I took up ... I also took up guitar. I don't play right now because kids, but like people that just take up hobbies and things just to ... It's like when you get that clock above your head that starts clicking and you can hear it, you start wanting to do the things that you didn't do before.

(17:49):

And so those hobbies that used to be out of the question for folks are like, "No, I'm just going to do it now. Whatever obstacle is in my way, I'm going to get past it because I want to do it. " And I find that people will distract themselves with things that they put off for a long time because it's like it's in your face now at this point.

James Hiter (18:08):

Yeah. I was talking to somebody recently who was in their 80s and it occurred to me how much those of us who have a terminal diagnosis, even if we're doing well, how much we have in common with those folks because they have come to grips, many of them with the idea that they don't have unlimited time left. And while all of us hope for continued amazing success with our treatment, this kind of connection with the reality that we're not here forever, which is something that most 30, 40, 50 year olds are not really connected to. But when you have this diagnosis, you connect to it pretty fast.

Jaymie Knox (18:52):

Yes, you do. Yeah. And I talk about that clock that ticks above your head. Everybody's got the clock above them. You don't know when it's going to stop and you don't know when it's going to speed up or skip a couple hours or what have you, but the clock is there for everybody. But when you get lung cancer or any kind of cancer diagnosis, you can hear it. It changes for us because we can hear the ticking and become very, very aware of how many or how little ticks we have left on that clock. And you start to fill your days with things that distract you from the sound of it. And so that's what I ... People dive into those hobbies and those activities and distract themselves, it's so you don't hear that clock above your head ticking.

James Hiter (19:31):

That's a great way to put it. And I love that metaphor of the clock ticking above your head. I'd love to

Jaymie Knox (19:38):

Go back to not hearing the clock.

James Hiter (19:40):

Yes. Yeah, right on. I think though for me that the part of the blessing of lung cancer has been the clock, and I know that sounds twisted, but it's that idea of we're not here forever. What is important? What do you want to do with the time that you have here, regardless of how much longer that might be? I used to say we're all terminal, just some of us are more aware. So at the risk of taking this down a little bit darker of a spot, I know for a lot of us that are in this lung cancer community, we make a lot of friends and unfortunately we lose a lot of friends. Can you share with me a little bit about what you do or how you handle that aspect? Because undoubtedly you've had people that you've connected to that are no longer with us.

Jaymie Knox (20:34):

Yeah, it's hard. I will say it almost makes you not want to get close to people. I hate to say that, but we know we've got the clock and you don't want to be close to somebody else because you see their clock too and you're like, "Ah." But there's something special about those friendships with those people. There's something deeper that you could be friends with for decades and still not feel as deeply connected to them as you do to somebody who's got the same lung cancer diagnosis as you. And you lose people and it's inevitable and there's nothing you can do about it and it really sucks. And honestly, you just grieve for them. That's all you can do. There's no special cookie cutter answer to that question. There's no special trick or sneak tip I can give anybody. You lose people like anybody else loses people.

(21:24):

It just hurts a little bit more because you see yourself in them when you lose them because they have the same thing you have in some capacity and no matter how strong you are, no matter how much you think you've got a handle on it, you see yourself in that person when they pass and you think, "Well, damn, what if that's me next?" No matter how strong you feel you are, everybody thinks that when it happens, but you grieve, like you grieve anybody else.

James Hiter (21:50):

I was talking to a buddy of mine who was in the military and as he was talking about the camaraderie that is developed when people are in a situation where they are facing their own mortality in a very different way than we do, but they bonded in ways that are different than most people bond. But I found there was similarity in the way that he and his buddies bonded in a situation where their lives were on the line. And then I think about, "Man, that sounds so familiar." This is that common threat to our life that my lung cancer friends and I also face together.

Jaymie Knox (22:28):

Let's hear it for trauma bonding. Yeah,

James Hiter (22:31):

Exactly. Right on.

Jaymie Knox (22:32):

Yeah. I mean, there is something to be said for it. That's why it's just a little bit deeper of a connection because there's something about the possibility of losing your life that brings you close to somebody who also is possibly losing their life and it's a weird thing to say. But yeah, I mean, like I said, you grieve the people just like you grieve anybody else. It just hurts a little bit more sometimes because you see yourself in it. It's almost like you're grieving a little part of yourself too. Absolutely. And trauma bonds are good, but they're also very, very hard because it is a deep connection that you have to somebody. Yeah.

James Hiter (23:09):

I think too, we tend to make friends faster. Yeah. When you think about how you make friends outside of this circle or before your diagnosis versus now.

Jaymie Knox (23:19):

Man, we try to make friends after 30 is like, "Hey, you like to work. Do you like to eat food?" You don't know what you're saying to people, but like in the lung cancer community, it's like you go to a summit or something or you go to an event and you're like, "Hey, I have that too." And it's just like automatically, you want to go get some fruit? It's a lot easier. It takes the nervousness out of it because automatically you already know you have something in common. It's a really terrible thing, but you can cut past all the small talk because you're like, "Hey, so yeah, what stage are you? " Get right to it,

Jaymie Knox (23:51):

Get

Jaymie Knox (23:51):

Right in there, you just start talking. And most of the time when we share our stories with each other, we find how similar we are in our journeys, in our diagnosis, in where we are with things, and we bond over that a lot quicker. And then we find out, "Oh, we also have all these other things in common." And so it's just a lot easier. I wouldn't recommend getting lung cancer to make friends, but the silver lining in the cloud is that you do make a lot of friends easier.

James Hiter (24:19):

Absolutely. Yeah. I was at World Lung Cancer Conference this past year and met these two guys. They're both from Australia, they knew each other because of lung cancer, but within about an hour, it was as if we had been friends for our entire life. They're a little bit older than me, but it was like we were high school buddies. I felt like I was hanging out with some of my high school buddies and even to this day, so now it's been months ago and still probably every day, every other day, we're sending texts back and forth. Pictures, of course, the time change is a little bit of a challenge, but it gets at that. The way you cope with some of this is to just make the most of it. And having great friends, that's a part of coping, at least for me.

Jaymie Knox (25:13):

Yeah, definitely. And there's something to be said for friends in the community because you could talk to your parents, your family, your loved ones as much as you want, but if they don't have lung cancer, they don't understand. All they can do is empathize, but they don't understand. Talking to a friend who understands because they're in the same boat like, "Yeah, man, I couldn't breathe today." It was hard to breathe in there, right? And they're like, "Yeah, you understand." And it's like you say that to your significant other or whatever, like, "I couldn't breathe." And they're like, "Why?" I don't know, I don't understand, but there's just this level of understanding that comes with other lung cancer survivors and other people in the community that if you have some weird thing that, "My surgery spot was aching today," and they're like, "Yeah, mine too." These kinds of things, it makes you feel seen.

(25:58):

It makes you feel like you're not crazy or you're not on this journey by yourself because there's somebody right next to you who's like, "Yeah, they got the same thing going on, so I know I'm not the only one. I know I'm in good company."

James Hiter (26:11):

I think part of dealing with mental health is having a really good community or really good support network. Can you talk a little bit about your support network and maybe how you've enhanced that since your diagnosis?

Jaymie Knox (26:23):

Oh my goodness. My support network is huge. I love it. They're the ones that probably keep me in the good mind space that I'm in. My support network, sometimes I'll just get a random text message from people that's like, "Hey, you were on my mind today. I hope you're doing good." And I'm like, "Ah, recharge. Thank you. " That kind of stuff. But my support network started small when I first got my diagnosis. There were only a few people who knew. And it's weird to say that now knowing how much in ... I'm not going to say I'm in the spotlight, but if you ask me to share my story, I'm going to share my story. I don't shy away from telling it. I don't shy away from publications or anything like that. When I first got my diagnosis, the total opposite. I was keeping it very close to my chest.

(27:04):

I was not telling anybody, not talking about it really. My mom knew, my dad knew, obviously the close family and friends knew, but I wasn't out, if you will. It wasn't out there yet. And that was my network and I was okay with it for about a month or so. And then I got the calling to share my story and I did. And my network just got exponentially larger from people that came out of the woodwork that also have lung cancer or people who have somebody whom they knew had lung cancer or just people that just in general wanted to support and stay in touch. And people that I haven't talked to in years from elementary school, high school, whatever, have reached out just to check on me or to share my story or to just say, "Hey, thinking about you. " But they would reach out and they would just support.

(27:51):

And it's crazy the areas where you find encouragement. And I've also found a lot of encouragement in strangers, to be honest with you. I'm not even going to lie about it. Strangers will randomly reach out to me on social media and say, "Hey, I saw your story and I also have lung cancer and you've given me so much hope and just long paragraphs of just how I've inspired them. And it'll be like a video of me doing something totally random, like a random Derek video or a sneaker video or something. And they just see me living. They see me out here existing and not letting it take over my entire existence. And that's inspiring to people. And immediately they jump on the encouragement wagon and the support training you're supporting back and your network grows and it's just a beautiful thing. Network and community is important.

(28:38):

It's so important in this journey, in any cancer journey.

James Hiter (28:42):

Well, I think without that support network, it's so much harder. And I know you've probably talked to people who are going through this diagnosis and are trying to hold those cards close to their vest for a really, really long time. I spoke with a guy recently who was diagnosed and he wasn't even telling his mother. And he had his reasons for why he didn't want to do that, but it just speaks to like that very, very tiny support network that he's having to deal with, as opposed to having a few more people that you are connected to. Every week on the Living With Lung Cancer Ask Me Anything podcast, we explore the questions that matter most to people living with lung cancer. We talk about new treatments, everyday challenges, breakthroughs in research, and the stories of patients and caregivers finding strength and hope.

(29:39):

If you want these insights delivered straight to you, subscribe on any podcast platform or go to lcfamerica.org. And if you know someone who could benefit from understanding and encouragement, share the show with them and don't forget to subscribe. Now, let's get back to our conversation.

Jaymie Knox (29:58):

I am somebody who didn't have anxiety before having cancer and I now have scanxiety. I did notice it at first and then I realized I was getting aggravated and irritable and just genuinely not happy, not pleasant to be around about a day or two before my scans. And I realized once the scan was over, I was kind of back to normal again. And I realized, oh, okay, this is my fear manifesting in other ways, whether it's just straight irritability or whatever. But scanxiety is real. It happens. There's nothing wrong with you. It's a totally normal function. It's how you deal with it that can make or break you. Scanxiety is just there to make you scared. That's it. The scans are going to be what the scans are going to be. It does you no benefit to worry about it. As long as you have a care team and a hospital team, a support team that knows your situation and are on top of it, the scans are going to be what the scans are going to be and you're going to tackle it.

(31:00):

You've tackled it thus far. Even if it's your first scan, you've gotten through what you've gotten through so far. This is just the next step and you're going to be fine. So it's like, I think the most important thing is to like, yeah, you have it. It's going to happen. There's nothing you can do about it, to be honest. Treat yourself when you're done. That's all. Make yourself feel better. Take the fear out of it and just be. Just go get the scans, get them done. And then after everything's done, go get an ice cream. Go treat yourself to something nice. It makes you feel good. And it's a justification for buying things and eating things that you probably shouldn't be doing.

James Hiter (31:37):

Well, yeah. I just had scans this past week and my wife and I in preparation for that were talking about scanxiety. And I said, when I was first diagnosed, I think the fear of progression was so strong.

Jaymie Knox (31:56):

Yeah.

James Hiter (31:57):

And I think since then we've come to understand that it's not necessary. Even if you get a bad scan, it doesn't mean the end of the road. It just means a fork in the road.

Jaymie Knox (32:09):

Right.

James Hiter (32:10):

And trying to just keep that in your mind just helps take some of that pressure off, takes maybe a little bit of that anxiety away.

Jaymie Knox (32:18):

You are so right about that. And I think one of the main things that I tell people is it's just a chapter of your life. It's not your whole story. So even if ... And I've had bad scans. Like you said, we were in that conference and I got not so great news about my PET scan. And that was my first time getting not so great news on a scan. And I mean, I was dramatic, dramatic as hell. I was in the bathroom and I was all upset. And I did the whole slide down the bathroom wall. I am just embarrassed. Now it's like, girl, pull yourself together. You're fine. You have a state of the art care team and you're good. I will say my anxiety has gotten better as I've ... So, okay, that's weird. Let me start back. My scanxiety was bad at the beginning, and that's because when I was starting my diagnosis, I'm still on alectinib, but that was the latest and greatest.

(33:10):

So there was nothing else. So every scan that I went into, I was nerve racked because I'm like, if there's progression- What's next? What is the fork in the road? You know what I mean? What is my next step? Now I don't know what to do. And that was what was fueling this anxiety was like, oh my gosh, if there's a problem, I don't have another leapfrog thing to jump to. Now there's probably a handful more medications for ALK-positive lung cancer. And so I go into my scans knowing, okay, God forbid, if there is progression, my doctor's already got a plan. There's already new and improved medications out there, so

I have another step. But when there wasn't one, definitely 100% scanxiety the whole time. Now my scanxiety comes in for a different reason because I've been on this medication for so long, way past the average time that people stay on this medication.

(33:59):

Every scan's a little more nerve-wracking because I'm like, "Is this when the shoe's going to drop? Is this when the shoe's going to drop?" Now I'm just waiting for that threshold like, "All right, when is my body going to develop this resistance and I'm going to have to switch to the new medication?" So scanxiety is going to come in different ways and for different things and for different aspects of it, but you just have to face it head on and realize the scans are going to be what the scans are going to be. And your scanxiety is not going to make or break them or change them. So might as well not waste your time worrying about it. Just make sure you get the plan in place after everything's all said and done and go get yourself a treat afterwards.

James Hiter (34:33):

Good advice. Well, so as we're wrapping up, what would you say you have learned about yourself through this whole process?

Jaymie Knox (34:45):

I'm stronger than I think I am, apparently. You don't realize how strong you are until you have to be and you don't have another choice. And so I think that's one of the main things. But I would also say I handle things a lot better than I give myself credit for. Yeah. I don't know how to explain that a little bit better, but I just know things happen, hiccups happen, obstacles come and go. And I think I've really got a really firm and good mindset and a good head on my shoulders to deal with a lot of things. And I think that's what helps me get through a lot of this journey is just I've got a very good grasp on who I am, what I have going on, what I'm capable of, and what God has in store for me. And all of that partner together makes my walk with this a little bit more like not as debilitating and scary for me because I just have ultimate faith in things going right.

James Hiter (35:43):

Excellent. If somebody has stumbled on this podcast and let's just say they're in a particularly dark spot right now, as you and I both know, even when you're super positive, I think of myself as being pretty darn positive, you're super positive, but even when you're super positive, you have those dark spots. What would you say to that person?

Jaymie Knox (36:03):

For starters, it's normal. It's absolutely normal. I'm not going to sit here and be like, "Oh, I got this diagnosis and it's butterflies and rainbows." And it always has been, it wasn't. We all go through those periods of darkness where it really doesn't feel like there's a light at the end of the tunnel. Everything seems like the options are all off the table. There's nothing left you can do. You're just in a really dark spot. It happens and we all understand, but you can't live there. This is just one chapter of your book. It's not your whole entire story. So while it may be a really crappy chapter, this is just one footnote in who you are as a person. Don't let it become your whole thing. So go through your dark spot because it is normal and it is healthy to have that and to feel those emotions, but you can't live there and you can't stay there.

(36:47):

You got to find a way to turn the page to move forward and to find something that brings a little bit more light back into your life, whether it's, like you said earlier, a new hobby, whether it's just finding something to just bring you a little bit of joy, a little bit of time at a time every day until you feel like you can see that light again. Things are going to get better. Things are going to happen.

(37:07):

It's going to ebb and flow. Right now you're in that ebb part or that flow part. You just got to get to the other side of it. So just keep going and you're going to be okay.

James Hiter (37:15):

Awesome. I think having a person or two that you can really connect with, I know for me, I ended up connecting with somebody you said earlier, like when fellow survivors can talk about things that as much as I have an amazing relationship with my wife, there's only so much of this that I can talk to her about that she completely connects to. And so having people that are in your life that you can talk to about how awful it was to be constipated or whatever it is. Not that I couldn't talk to my wife about that, but it's amazing the things that you find yourself talking to somebody about that you haven't known that long, but yet you've connected and bonded with through this process.

Jaymie Knox (38:06):

Yeah. It's important to have people around you for sure.

James Hiter (38:09):

Is there anything, when you look back on your lung cancer journey, is there anything that you would tell your immediately diagnosed self that you have learned in this process?

Jaymie Knox (38:25):

Everything's going to work out. Like this is not the end. I would tell myself everything I tell everybody else. This is just one chapter in your story. It's not your whole story. So keep it moving. You got stuff to do and you got people to impact and lives to change.

James Hiter (38:40):

That's awesome. Well, Jamie, thanks so much for taking time to come chat with us about this topic that often gets overlooked, but yet is the one topic that we often talk to people when we're talking to somebody, the mental impact is what often comes up, but yet it's not talked about publicly a lot. Yep. So thanks for helping to uncover some of what keeps you so positive.

Jaymie Knox (39:04):

Yeah,

James Hiter (39:04):

Absolutely. And also to keep it real that it's not always positive.

Jaymie Knox (39:08):

No, it is not.

James Hiter (39:09):

And yeah, but thanks for helping out and yeah, I hope- Thank you for

Jaymie Knox (39:15):

Having me.

James Hiter (39:15):

Have a good time this evening with those two little ones.

Jaymie Knox (39:19):

Yeah. Schedules are key. There

James Hiter (39:21):

You go. Well, very good. Well, hey, if you're looking for more information about mental health or anything else related to lung cancer, I would encourage you to check out lcfamerica.org. There's really a storehouse information at that location, great videos and other content that I think you'll find really helpful as you're either caring for or experiencing lung cancer yourself. Thanks for listening to Living with Lung Cancer Ask Me Anything. I'm James Hider. If today's conversation was helpful and I really hope that it was, please follow or subscribe and share the episode with someone who might find it useful. Together we can really change the way we talk about lung cancer. And if there's a lung cancer related topic that you'd like for us to explore, please let us know in the comments. And you can find a lot more information at lcfamerica.org. Thanks for watching and listening.

(40:13):

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