Small Cell Lung Cancer Maintenance Therapy: A Survivor's Guide

James Hiter (00:00):

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Living with lung cancer, ask me anything. Real conversations with people living with lung cancer. Learn from their personal journeys and expert insights. Subscribe now and never miss an episode. Welcome to Living With Lung Cancer, Ask Me Anything. I'm James, and I'm living with lung cancer. Today, we're talking about maintenance therapy in small cell lung cancer. For some patients, treatment doesn't stop after the first round of medication. Maintenance therapy may be recommended right away to help manage the disease. We'll be discussing what it is, why it might be used, what questions patients should ask, and how to decide what's right for you. Joining me today is a fellow Lung Cancer Foundation of America Speakers Bureau member, Montessa Lee. Montessa is a long-term small cell lung cancer survivor and patient advocate.

(01:04):

Well, Montessa, thanks so much for joining us today. I appreciate you sharing your lived experience and all the things that you have gotten to, uh, know over the course of you having small cell lung cancer. Um, so I wanna just start out with the basics. Um, what is maintenance therapy?

Montessa Lee (01:22):

Maintenance therapy is a treatment or therapy that you get after they know that the chemotherapy has worked. And, um, they give you treatment to maintain or continue that treatment. So usually it's an immunotherapy.

James Hiter (01:33):

I was actually talking to somebody who said, you know, think about maintenance therapy or like the cancer's a little bit like a wildfire. Chemo is brought in to really fight the wildfire, and then we leave some firefighters behind to manage the flare-ups. What do you think of that metaphor? What, does that make any sense to you? <laugh>

Montessa Lee (01:50):

You know, people might view it like that, but really think about the chemotherapy as it came in there to knock, you know, to treat the cancer first head on. What they knew about small cell lung cancer for a long time is that the first line of treatment worked well, but it came back. And so, of course, you look like you have a good response from that chemotherapy. It knocks it out. Your, your scans are showing no evidence of the disease, perhaps, but w- what next? And so for years, they didn't have anything. You know, and now, so this maintenance treatment or keeping it at bay was really good, you know, it's promising for some patients.

James Hiter (02:24):

When I hear the word maintenance, um, I, I'm wondering if some people might think that that sounds like it's passive. Um, can you elaborate on that?

Montessa Lee (02:35):

Sure. And, and, you know, I, I, then I, I could think of another analogy with your car. Okay. If you keep up the maintenance on your car, it's not passive. It's keeping it at bay. It's keeping it so that you don't have to keep the car in the dealership or, you know, the maintenance man. And so it's keeping it at check. It's keeping that cancer, um, hopefully that it's keeping it in check and that, and hopes that it doesn't reoccur.

James Hiter (02:57):

Whenever we're talking about treatment or a new treatment, a lot of times people wonder, is this gonna be for me? So does everyone get maintenance therapy in small cell?

Montessa Lee (03:07):

We know that one size treatment doesn't fit everyone. This is what we know now. You know, when I was diagnosed a very long time ago, you know, almost 20 years in December, we didn't have options. And so now that they have options, you can have a true dialogue with your doctor and your care team to say, "Is this an option for me?"

James Hiter (03:28):

I had maintenance, um, treatment, and I know a lot of people with non-small cell lung cancer, this has kind of been kind of the norm. Um, but, uh, I, I guess, uh, now, uh, more common with the small cell side.

Montessa Lee (03:42):

Right. You know, when I was diagnosed in 2006, these options didn't exist. You know, I, I even said, you know, had a unique opportunity to sit here at the table and see the birth of those options for non-small cell lung cancer. And now they're hitting the table for small cell. So just like it provided hope for the non-small cell world, it's gonna provide hope for small cell.

James Hiter (04:03):

So, uh, I, I think that's the overriding thing that I hope people take away from our conversation, um, is that the world of small cell that felt like it was kind of mired in the mud of not moving forward much is now kind of on a rocket ship of advancement. Um, and it is so hope-inspiring. Um, so after that initial treatment, uh, that many patients might be hoping for a break, and now the doctor, or maybe they are intrigued by this concept of maintenance, um, what do you say to the person who is hoping for a break, but now maybe realizing that maybe the best thing might be to continue treatment?

Montessa Lee (04:49):

A- and I think that's where that dialogue comes in, not only with your care team, but possibly your caregivers as well. And now in this world of cancer treatment and as the research is progressing, we not only look at progression-free survival, which means how long can you live without having another recurrence, but also what's your quality of life? Mm. And so perhaps some people might have had a really hard time with that first line treatment and they're just like, "Oh, I can't take anymore." You know, they might wanna have that conversation with the doctor, but also, you know, you can look on the research side and know it has a tendency to come back. What can I do to keep it at bay and live my best life, still have good quality of life?

James Hiter (05:29):

What are some of the goals of maintenance treatment then?

Montessa Lee (05:33):

Yeah, but I, I, I, for me, when I look at it, view it, is that, that we're keeping any options available, that we're having longer-term survivorship and that we're keeping, um, the chance of recurrence at bay, you know, trying to minimize those chances over the recurrence.

James Hiter (05:51):

Well, you, you mentioned to increase quality of life potentially. It seems a little bit of an oxymoron that you would still be on treatment and have better quality of life, but obviously that it is possible for those two things to exist together. Um, but I also think about just the potential to live longer and see more things. I know you and I have, were talking actually over lunch today about the things that we've gotten to do or see as a result of research and the treatments that we've had the opportunity to, to partake in. Um, tell me a little bit about what it's like for a small cell lung cancer patient to have that kind of hope.

Montessa Lee (06:28):

You know, when I first started, again, diagnosed in 2006 a long time ago, I only knew myself. I knew one other person that was diagnosed with small cell lung cancer, and I knew about a caregiver or two. Now, I can sit in a room with patients that have lived. Now we can calculate years. It's not a year. I'm looking at five, seven, 10. I think somebody else is close to where I am. And sit in a room where now the research is rapidly evolving, like you said too, where it's, it's so much to keep up with. But I'm sitting in a room where I'm hearing that. And that's something I always said when I started this advocacy. We needed options being plural. Yeah.

James Hiter (07:05):

Instead

Montessa Lee (07:06):

Of one size fits all. How

James Hiter (07:07):

Do doctors decide, um, which patients are good patients for maintenance therapy?

Montessa Lee (07:12):

Well, now because we have options, I think that involves talking to the patient and what I call it is seeing the patient behind the lens for, for that medical care provider. Yeah. And for the patient, sometimes they might wanna bring a caregiver with them to ask those questions, you know, like, "Hey, doc, you know, I've heard about this maintenance therapy. Um, I know that my loved one or myself have X, Y, Z, and this is what you've told me from the beginning. Is this an option for me since, as I'm about to end, you know, the first line of treatment and things are looking good? What's next?"

James Hiter (07:46):

Yeah. Uh, are there other questions that you would think that maybe the, the, a patient should ask or, or a care provider should ask the care team or the doctor?

Montessa Lee (07:56):

Sure, James, you know how we kind of talked about earlier that quality of life. A big question, and as I hear it in my circles and my groups of other patient advocates might be, what are the potential side effects? Because even patients get on social media, our patient groups are asking, "Have you had experience with this treatment or this treatment?" And so asking, "What's potentially gonna happen on this treatment?"

James Hiter (08:19):

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. 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. Uh, so I was talking to somebody in advance of this workshop or this, um, uh, get together or conversation and, um, the person said something about there may be being a feeling amongst some of, uh, her peers that, uh, maintenance therapy felt like the cancer was winning. And, um, so we had an interesting conversation, but I'm inter- interested in your perspective on that kind of that feeling that somebody might have.

Montessa Lee (09:20):

And I could see that because you think I've already done this first round of treatment. If I already had the chemotherapy, I want it to be over with. You know, from my experience, I, I had a huge tumor. It went through radiation and chemotherapy. Part of that tumor is still there is scar tissue. Mm-hmm. I remember asking the doctor and thinking in my head, "Can I have more chemotherapy to get rid of it? I want no part of this left in my body." And so thinking of it as we're, we're, you know, this is still an active treatment, but we're doing it so that we're keeping that cancer at bay. It's for the good. It's for the better good.

James Hiter (09:57):

Yeah. So more proactive, um, than not. Mm-hmm. But I know after my last surgery and the decision was made not to have treatment, I felt a little bit naked. Uh, I felt a little bit like, wait, what? We're not gonna do, we're just gonna wait and see what happens. It feels weird having been on two and a half years of maintenance therapy myself. Mm-hmm. Um, but I think it can be certainly part of a long-term treatment plan and help people stay progression-free, hopefully a little longer, maybe forever.

Montessa Lee (10:30):

And it might help level some anxiety. You know how we talk about in, in our lung cancer survival world, we talk about ski anxiety. And so perhaps I'm going to get these scans and maybe the anxiety is a little lessened because I know I'm on this maintenance therapy.

James Hiter (10:45):

Mm-hmm. Now, many patients wanna get back to, um, you know, their regular life, back to work, back to family, back to travel. And this maintenance ther- therapy seems like it could be contrary to that. What do you say about quality of life as it relates to maintenance therapies?

Montessa Lee (11:04):

And I think that goes back to, because each individual is their own. We know that, you know, one, again, one size doesn't fit all. So that goes back to talking to your care team. And, you know, so you had that conversation before you went on the maintenance therapy and you're asking what are the potential side effects? Then you come back to the care team and said, "I'm experiencing X, Y, Z." I notice. So for like myself, my, mine was memory and multitasking. I can't do, um, I, you know, I'm trying to multitask, cook, do this and this, and I can't do that the same as I used to. What can I do to help me? You know, so various treatment options are gonna have different side effects and it might impact what you used to do daily. I'm too fatigued to get up and go run every day like I used to.

(11:45):

I'm too fatigued to get in the pool and swim. But those are conversations with your doc - your, your care team. And you have a multitude of a care team. So it's not just your oncologist. You know, if, if you have, at a center where you have a patient navigator, you know, for me, I even had a speech and language pathologist help me because I had, I could not remember words. Word would come to the top of my head and I was like, "What's the word again?" So, you know, whatever that treatment is, how can you keep, keep those side effects at bay in check too, counteract those side effects?

James Hiter (12:14):

You, uh, and I'm gonna deviate just for a second because you have such an interesting story and I, I wish we had time to just dive into that because I think it's just such a compelling story. But you were diagnosed while you were getting your master's degree, right?

Montessa Lee (12:28):

Correct.

James Hiter (12:29):

A- and you were able to eventually, you weren't sure, but able to finish?

Montessa Lee (12:33):

True. And so, see, that's one of those, I didn't even think about that. That's one of those side effects and the quality of life. I was in the middle of my master's program. And matter of fact, I was on my way to class the day that, uh, they finally diagnosed me with a tumor. I was on my way to class to take a test. I had stabbing chest pain. The chain, pain had came back. You know, it was over this three-month period before they diagnosed me. But I was like, "Oh my gosh, I have to go take a test." <laugh> So, uh, you know, I'm, on my mind is, I have to go to school to take this test. Went to go take the test, and on my way back, my cousin was gonna take me to the ER. And I just, you know, just my life was one way.

(13:12):

And I call it the train I was riding, derailed. And I thought my memory, when I found out that you could have chemo brain and I was having some memory issues, I was like, "I don't know if I'm gonna have to have accommodations to finish my degree. Will I be able to finish?" But I have since finished two degrees.

James Hiter (13:28):

Yeah. I should call you Dr. Montessa Lee, uh, with your PhD wrapped up now.

Montessa Lee (13:34):

Well, I guess an EDD, educational doctorate in education, but it's the same. Yes, it was a lot of work. And, um, it's amazing that I'm sitting here today and could tell you that I have finished both.

James Hiter (13:44):

Yeah. Well, I, I know for both of us, um, peer support has been a big part of getting through lung cancer in general. Um, having someone to talk to. I know for me, initially, I actually had a friend who had had breast cancer - uh-huh. But had been through chemo and was helping me understand how to handle the nausea and some of those sorts of things. I, I wanna ask you about peer support, specifically though on this topic of maintenance. How, how might peer support or talking to a peer, uh, help somebody with this decision and, and managing the outcome?

Montessa Lee (14:18):

And this, uh, I could see live now, you know, years ago, I wouldn't have seen this, but of course, just, just like in your world of non-small cell lung cancer, they have the birth of the oncogene group. Well, we have the birth of Facebook groups and social media groups. And I see patients on there often, our caregivers sometimes, and they'll say, "I've, I'm experiencing this treatment option. Has anybody else on here experienced this? And my mother or father or myself are experiencing these side effects. Have you?" And, um, e- even doctors will chime in. So that whole support group, the network, monthly meetings now that we have this world expanding and a care team, people will call you, um, and talk to you because there's nothing like hearing it firsthand. Somebody who has walked the road that you have, um, and, and sitting there in, in your shoes.

James Hiter (15:04):

Yes. It's one of the most rewarding aspects of being an advocate is the opportunity to talk to newly diagnosed people in particular, or people who are going through a recurrence, and just need a little bit of guidance, but also a little bit of hope. Mm-hmm. Um, if there's something, one, one or two things that you hope that somebody's listening to this conversation would take away from, uh, from it regarding this maintenance therapy, what, what would you say to them? Or what would that one or two things be?

Montessa Lee (15:34):

I would say that we are in a new era. A new era for people diagnosed with small cell lung cancer patients, new patients diagnosed. And every day the research is changing. And so if there's. We know people that have been on maintenance therapy that are living for a long time, you know, that have lived and, you know, that even somebody on, just today, I was reading on social media. They're finishing the, I think their second year of the maintenance therapy. And going on, what's next? So here we are to the what's next, you know, opportunity.

James Hiter (16:05):

Yeah.

Montessa Lee (16:05):

Going down the road to future possibilities.

James Hiter (16:09):

It's, it's exciting. I, I said somebody told me when I was first diagnosed that my job was to stay alive so that the research could catch up. And I know this is not the case for so many and my heart breaks for those people and their families. Um, but it's so true. The advancements are coming so fast a- and, um, it does give hope.

Montessa Lee (16:30):

Yes. Yep. And my brain can't keep up. I mean, and, but this is what I've hoped for, for a very long time to see small cell. Like, I used to have a presentation in the research because, like you said, the non-small cell world had maintenance and targeted treatment options for a very long time. It, well, relatively speaking for

James Hiter (16:45):

A

Montessa Lee (16:45):

Very long time. Yes. But you guys were ahead of the race and I had a picture of where one person lagging behind, but we were catching up, you know, trying to catch up in the race and we're finally here.

James Hiter (16:55):

Yeah. Well, having had the opportunity to attend, um, ASCO, the American, the Society of Clinical Oncology's meeting this year, and so much excitement around small cell, uh, lung cancer and the developments there, it's, it's truly remarkable.

Montessa Lee (17:12):

Yes. I saw some, um, studies post - you know, I didn't get to go. I w - I hoped I would've been able to go, but hearing feedback from that and just to have, you know, there was a time where you wouldn't see that. You might have seen one poster for small cell or two, but now, again, just the advancements, there's hope on the horizon.

James Hiter (17:29):

Sure. Yeah. Um, well, I, I just wanna say, um, thank you for taking the time to share your lived experience with small cell lung cancer and sharing with the audience about, um, maintenance therapy and how that might actually be something that would affect them in the future.

Montessa Lee (17:47):

Thanks for having me, James.

James Hiter (17:48):

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