Lung Cancer Foundation of America

Living With Lung Cancer
ASK ME ANYTHING

Time Toxicity in Lung Cancer: What Patients Wish They Knew

Maida Mangiameli (00:00):

The biggest message I want to give people who are watching this is hope. Hope never dies. It's very important to have hope. It helps you keep moving forward.

Intro Voiceover (00:10):

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 (00:26):

I'm James Hiter and I'm living with lung cancer and joining me today is Maida, who is also living with lung cancer with small cell lung cancer. So Maida, welcome.

Maida Mangiameli (00:36):

Thank you, James. I'm happy to be here with you.

James Hiter (00:38):

Nice to be here with you as well. When we talk about lung cancer treatment, often we talk about the physical aspects of the impact of treatment. So there's side effects, there's the actual physical toxicity, there's the financial impact. But one of the things that we don't talk about very often is about time. And so some people have said having lung cancer treatments is like a full-time job. Maida, what was it like for you when you first started treatment?

Maida Mangiameli (01:10):

Well, I agree, James, that to a certain extent, it is like having a full-time job. I was diagnosed in 2018 with extensive stage, which means the cancer was in an area other than just my lung. And I knew nothing about it. So I had no concept of what kind of time it was going to take. When my oncologist told me the treatments I would get, I didn't know what he was talking about, so I just had to trust him. I knew nothing. When the treatments get started, that's when your time just moves like a snail or at times you feel like you're rushing through your life.

James Hiter (01:50):

So what was a typical week like for you when you were going through treatment?

Maida Mangiameli (01:57):

A typical week. Well, the treatments consisted of getting chemotherapy, two types of chemotherapy, which by the way, had been developed for non-small cell lung cancer. There was nothing for people with small cell cancer specifically. And it was going to the infusion center three consecutive days, spending a couple hours with a needle in your arm. Some people get a port, which makes it easier for the techs to connect your treatments. But I didn't. I decided to just go with a needle in the arm. And so it was three consecutive days and on the fourth day, I would get a shot that was supposed to help with my white blood cell count because often that goes down. So there's four days a week. I lost my appetite. I began to lose a lot of weight. I went through this series of infusions for four months. You would have three to four days in the center, three weeks off, and then the next series.

(03:05):

Once that was done, and by the way, I had also lost my hair by the second time. I went through 28 consecutive days of radiation, chest radiation. So time was ... It didn't really exist, actually.

James Hiter (03:26):

Well, it sounds like you, in addition to having all the toxicity that we think about, losing your hair and not feeling well and all of those things, that was really time consuming.

Maida Mangiameli (03:37):

Well, it's amazing. You can't eat. I mean, most people, not everyone, but many of us find it very difficult to eat. And so the time I did ... I was awake because when I'd go home, I would want a nap. And you tend to want to sleep a lot while you're going through all that. And the times I was awake, I had my care partner, my husband driving me crazy. "You have to eat, you have to eat. "Well, when you have lung cancer or any cancer, I believe, and you're going through treatments, we know we have to eat. It's just very difficult.

James Hiter (04:13):

Oh, Maida, my wife, same deal. She was my caretaker and she would say," All right, how about this? "And she would name a food. And I'm like, " I am so not hungry. I feel so sick. "And then she would say," How about this? "I'm like, " Really, if you keep on going, I'm going to throw up on your shoes. Stop talking about food. "And then she'd say," How about ... "And she'd name something else, veggie soup. And I'd be like, " That sounds perfect. "And she would fix me veggie soup and I would eat it, but it was her persistence in getting through that, that I finally was able to find the thing that I wanted to eat.

Maida Mangiameli (04:47):

That you were happy with. The persistence on my husband's part though only made me angry. I mean, there was one of the times I was in the cancer center getting my infusions, I asked him to leave the room. I was very depressed at that point. They sent in a social worker who sat with me and we talked and it helped. And I told her," I think maybe I need a divorce. "And truly, James, that's not unusual. I've talked to so many people now over the years who've gone through those periods. Then your sense has come back to you and you know they're just trying to help.

James Hiter (05:22):

Right. Who's going to bring me my veggie soup?

Maida Mangiameli (05:24):

There you go. Plus the great thing about my time management, well, this summer we will celebrate our 55th wedding anniversary. Congratulations. Amazing. Thank you. Even if I had a job, I raised a couple kids. I was the cook. Once I started going through all this, my husband started doing the weekend cooking. So I am a seven and a half year survivor so far and he still cooks on Friday and Saturday and some Sundays and he overcooks so that I don't have to do a lot during the week even. So that time management is turning out great for me.

James Hiter (06:05):

That's fantastic. That's fantastic. Well, actually you bring up something that I hadn't really thought about in the context of preparing for today's conversation. It was the time for our caregivers. So we think about the treatment consuming a lot of our time as patients, but for a caregiver, this is a big time commitment as well.

Maida Mangiameli (06:23):

It is. I was not working. I had already retired. My husband just retired in January. So he was working. He was traveling and that made it even more pressure for him. But I was so deep into this thing in the beginning that it was hard for me to have the grace to understand what he was going through.

James Hiter (06:49):

Yeah. I think a lot of ... You mentioned the word grace. My wife and I talked about that a lot, having grace for each other about the time and about all of the things, and getting on each other's nerves sometimes in ways that maybe we didn't before treatment. Well, Maida, just to give people a little bit of a sense for it. So some people that are listening obviously are going through the same thing. They know this all too well, but some people might be listening or watching that are not really connected to how much time it actually takes. So when you talked about going into the infusion center for three days and then another day for a dose of medicine to help manage the side effects, how much time are we talking about in those days?

Maida Mangiameli (07:32):

I was fairly lucky because it was only about a 35-minute drive to my infusion center. But then you think about that. It was 35 minutes to get there. It was checking in. It was being put in a room. It was them doing their usual checking blood pressure, checking oxygenation, checking your weight, and then sitting in that chair for a couple hours, and then another 35 minutes home. Now, I feel like I was lucky because I've met people over the years who live two or three hours from their infusion centers. I can't even imagine the difficulty with that. However, if you want to keep surviving, you do what you need to do, right?

James Hiter (08:15):

That's exactly right. You do what you got to do. But that time commitment is something that I think gets lost on a lot of folks. I mean, I think if you ask people about cancer treatment, lung cancer treatment, they're going to talk about toxicity, they're going to talk about a lot of those things, and we just don't really think about how much time the actual treatment itself takes up.

Maida Mangiameli (08:38):

I think that's something that maybe thoracic oncologists or medical oncologists could incorporate into their talk with newly diagnosed people so that we're better prepared for that because we didn't have a clue how much time it was going to take. And unfortunately, many oncologists don't relate to their patients on a human level. They don't understand our emotional balance that we need.

James Hiter (09:10):

Yeah. I think for the oncologists that I've talked to, it seems like there's a lot of focus on their main job is to keep us alive, help us have a chance to get better and at whatever cost. And I think if you talk to most patients, we would agree. We tolerate a lot of toxicity as it relates to our body, but also then this concept of time and financial toxicity. But at the end of the day, I think you're right, it's important for the care team to acknowledge the time commitment that this is and also make sure that people are ready for that, especially if you have a job and you're still working. I know when I was going through treatment, we had many ... So I would get my infusions on Wednesday in the morning and my wife would take me to the airport and I would jump on an airplane on Wednesday afternoon and fly someplace to do my job and then try and dash home, fly home on Friday night because I knew by Friday night and Saturday morning I was going to feel

Maida Mangiameli (10:13):

Awful.

James Hiter (10:15):

But that time, you had to maximize that time if you're also going to try and balance treatment with working.

Maida Mangiameli (10:23):

Absolutely.

James Hiter (10:24):

And especially if your job involves having to travel. But for me, that meant that she had to be there to take me to the airport and then also come pick me up from the airport and all of that as well.

Maida Mangiameli (10:35):

Yeah. I'm sure you've given her many, many thanks as I've tried to do with my husband. It

James Hiter (10:40):

Sounds like you need to thank your husband

Maida Mangiameli (10:42):

A lot actually. I mean, cooking alone is a biggie.

James Hiter (10:46):

That's awesome. So I want to shift gears just a little bit. And I know neither you nor I have been through a clinical trial. We've both benefited from the work that's been done because of clinical trials. And I hope that if either one of us has a recurrence in the future, we have progression with our cancer that we will continue to benefit from and maybe participate then at that time. But we both know people who have been through clinical trials. So for the people that you know, let's talk a little bit about how much time it takes for them to get connected to the right clinical trial. 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.

(11:44):

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. But we both know people who have been through clinical trials. So for the people that you know, let's talk a little bit about how much time it takes for them to get connected to the right clinical trial.

Maida Mangiameli (12:18):

If and when my cancer begins to grow again, a clinical trial is something I will look forward to because in most cases you get even better care when you're in a clinical trial. They're checking on you more often. You usually are assigned someone you can contact no matter what your issue becomes. I know many people who've been in and are in clinical trials. I know one woman who's on her fourth clinical trial. The first one worked for about a year, the second one also. The third, I think she lasted two years before progression, and she has non-small cell. This fourth one she's been on for a couple years is working miracles for her. And the great thing about a clinical trial, one of the greatest things is once these clinical trials, once you've been put through the ringer and they know that this is a chemical that's going to work, then it goes to the Federal Drug Administration, the FDA for approval.

(13:20):

If you have small cell lung cancer, there was really nothing for us forever until the last couple years. People who are diagnosed today with my kind of lung cancer are living in a new world. These clinical trials have produced so many new treatments and are producing so many new treatments. It's thrilling. The problem then becomes time again, because some people have to go to a different city. Some people have to drive six hours to get to where the drugs are available. Some people have to fly and then stay in a hotel. There are some nonprofits that help people who can't afford to pay for it themselves with financial support, but not everyone can get financial support. So again, we're looking at financial toxicity, we're looking at time management. There's a lot of hoops you have to go through, but it's so worth it if you're in a clinical trial.

James Hiter (14:27):

Absolutely. Yeah. I think about what you were saying with your friends that you know who've been in multiple clinical trials. And I think ... Can you talk a little bit about how maybe your friend found their way into those trials and how did that come about?

Maida Mangiameli (14:46):

Unfortunately, many oncologists don't bring up clinical trials. It's generally up to the patient to learn about these things and talk to their doctors and say, "Do you think I would be a candidate for this? " That's why joining nonprofit organizations is important. We can learn so much. The Lung Cancer Foundation of America is loaded with information about the entire scope of lung cancer, but they're not the only ones. And the first three years after I was diagnosed and treated, I didn't know anyone, anyone who had had lung cancer. Once I found a Facebook group, which led me to several nonprofits, I was able to begin to relax. I think you understand, James. When you meet people who know exactly what you're going through, exactly what your treatments have been when you compare notes, it makes you feel more relaxed, you're more confident and you're heard and you're seen more.

(15:52):

But I also believe in pushing oncologists. My oncologist laughs every time he sees me. I always have something new. I told him about the very first immunotherapy developed and approved for small cell lung cancer before he'd ever heard of it, and now he uses it. So clinical trials are everything.

James Hiter (16:13):

Yeah. I think my doctor probably ... Yeah, we spend a lot of time talking about the new developments and the things that are coming. Luckily, my oncologist team, they're very much tuned into research and are part of some research cooperative groups, but that's something that I'm interested in. And I always feel bad that I'm taking away time that somebody made in my appointments.

Maida Mangiameli (16:38):

Yeah. I used to feel that way too. You sit in the waiting room for up to an hour waiting to see your doctor until I realize it's because every patient my doctor sees, he spends as much time with them as they need. So if he's going to do that for me, then I want him to do it for everyone else. And in fact, I've spoken to people in the waiting room, newly diagnosed, because I know I can give people hope with the idea that in July I will be an eight-year survivor of extensive small cell. But can I go back to time? One other issue about time management. When you're first going through all the testing, when you don't know exactly what's wrong with you, and you're seeing a radiology oncologist, you're having an MRI, you're having a PET scan, you're having CT scans, you're going through all of these tests.

(17:30):

That's the other thing that you're not prepared for. So for anyone who suspects they might have lung cancer, it's important for them to know that there is going to be a lot of time involved just finding a diagnosis. But once that diagnosis is in place and you have a treatment plan, it makes all the difference.

James Hiter (17:52):

Absolutely. Yeah. I hadn't really thought about that. We were talking mostly about once you're diagnosed and in treatment and the time commitment, but you're right, that kind of limbo land between I feel fine and then maybe something's a little bit up. For me, I actually had the flu. They wanted to make sure I didn't have pneumonia, so they did a chest x-ray, but the chest x-ray found something. So then that's the beginning of that time of waiting and time of wondering, and then a more advanced scan, then a surgery to really rule it in or out, and then the fun really begins,

Maida Mangiameli (18:35):

Right? Right. Oh, and the biopsy. I mean, I forgot about that because it took a full morning to take a sample of my tissue, of my lung cancer tissue. So there are so many time issues involved, as you and I now know, that people are not prepared for. And if I can do one thing talking to you, well, two things. One would be trying to get people prepared for the fact it will take time and you need to find patients. And the other thing, of course, is talking about clinical trials.

James Hiter (19:11):

Absolutely. Well, the one thing I'll also say about the time commitment, I just want to put in a big plug. I've not really ever had a platform to thank the people at my work at the time. I was working at the time of my diagnosis, as we talked about earlier, but my team really pitched in because the time commitment is no joke. And when you are either out because you don't feel well, so there's the time of actual treatment, but then there's the time that's just lost because you don't feel right. I mean, I didn't ever sit on the couch before my diagnosis. That just wasn't part of my ... I wasn't a sit on the couch kind of guy. And all of a sudden I had to become a sit on the couch guy. And my wife would say, "Just embrace it. As much as you can enjoy sitting there,

(19:57):

Just enjoy it. " So I think it takes a mental shift, especially if you're a go, go, go person. In fact, I was just talking to a newly diagnosed guy last night on the phone here at the hotel and was talking to him about that whole mental shift of being go, go, go, to embracing the downtime. And that's hard, but actually brings me to another question that I would have for you, which is, do you have any suggestions or tips or anything that you would give to somebody who's newly diagnosed? I mean, we just touched on a little bit of that, but anything else that you can think of that we've not talked about?

Maida Mangiameli (20:39):

Well, it's hard to prepare yourself for all the emotions you're going to go through. So I think mainly I tell people, well, I talk to a lot of people about the fact that they tend to find out they have this cancer, especially small cell, and they assume they're just going to go home and die. And so it makes me want to share with them that that's not necessarily going to happen. I try to tell people not to Google for information because most of what they're going to find is outdated statistics and no one can tell you have six months to live or you have two years to live. You need to embrace ... Great word, James. You need to embrace the fact that there are treatments and that there's reason to hope that they're going to mean something to you. You're talking about sitting on the couch.

(21:31):

I was always athletic. I was running up and down stairs in my house all the time, can't do that so much anymore. But when I was going through everything, I had my dog, my heart, my little shelty. I'm on my third shelty now, but this was the last one. And I would come home and I would lay on the couch and I didn't just lay on the couch. I would lay on the couch and sob after each infusion. And that little guy would jump up on the couch and lay with me and bring me back. So find your reason. My main reason for going on is that my only granddaughter was one when I was diagnosed. She's turning nine next week and we're buddies. And so I have that to keep me going forward because I want to be here a long time for that sweetheart.

James Hiter (22:21):

That's amazing, Maida. Yeah. The milestones are all what make it worthwhile to keep fighting and to keep trying in time, toxicity, financial toxicity, all the physical toxicity. You endure all of that to get to those milestones.

Maida Mangiameli (22:39):

Exactly.

James Hiter (22:39):

This past weekend, we actually celebrated my daughter with a little get together. She is expecting our first grandchild.

Maida Mangiameli (22:47):

Oh, how wonderful. Congratulations.

James Hiter (22:50):

When you talk about these milestones, now you almost made me cry when you're talking about your dog because I had some tearful moments with mine too. So I'm going to avoid that topic because I probably will cry. Well, I think that we've covered a lot about time toxicity. We've talked about the importance of talking to your doctor about clinical trials. And even though those may involve even more time commitment, how much they're worth it to get access to either the standard of care, that's the care that you would've gotten without the clinical trial or gaining access to some of the latest and greatest and newest things that will be the treatments of tomorrow today. I really appreciate you taking time and joining us here. And yeah, it's always a pleasure to hang out with you and chat.

Maida Mangiameli (23:40):

Thanks, James. It's always great to see you and a baby. I'm so excited for you. Oh,

James Hiter (23:46):

I can't wait. I can't wait. Yeah.

Maida Mangiameli (23:48):

Thank you so much.

James Hiter (23:48):

Thank you. And if you're looking for more information, I'm going to encourage you to check out lcfamerica.org. There are lots and lots of videos there and other articles that I think you'll find really helpful as you're navigating your own cancer journey or helping someone else manage theirs. So thanks again for joining us with Ask Me Anything. 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. Your support helps these stories reach more people.

(24:42):

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