



You Don't Look Like You Have Lung Cancer

Diane Mulligan:

What does someone living with lung cancer look like? Do you envision somebody who is gasping for breath or someone who is frail? Do you assume they must have smoked? Hi, I'm Diane Mulligan.

Jordan Sherman:

And I'm Jordan Sherman. The reality is that anyone with lungs can get lung cancer. Many people living with lung cancer are never-smokers.

Diane Mulligan:

So today on Lung Cancer Foundation of America's Hope With Answers podcast, we'll talk with one of the nation's leading oncologists and a young, vibrant woman living with lung cancer on a podcast we call, you don't look like you have lung cancer.

Dr. David Carbone:

I think we all have to work hard to change the stigma of what a lung cancer patient looks like.

Aurora Lucas:

Looking okay as a lung cancer patient and not the stereotypical one, people tend to say, "You look good now, you're fine." But when it's someone that I'm just meeting, I try and take the opportunity to educate them and say, "Yeah, this is what lung cancer looks like now. People like me are surviving, but it's still the leading cause of cancer death around the world."

Diane Mulligan:

Lung cancer is a tough topic. It's a disease that affects patients, families, friends, coworkers. But first, it's a disease that affects people. The Hope With Answers: Living With Lung Cancer Podcast brings you stories about people living, truly living with lung cancer. The researchers dedicated to finding new breakthrough treatments and others who are working to bring hope into the lung cancer experience.

Jordan Sherman:

What does living with lung cancer look like? The answers definitely changed over the past decade. Our first guest is Dr. David Carbone, a professor of medicine in the division of medical oncology at the Ohio State University.

Diane Mulligan:

Dr. Carbone is also a member of Lung Cancer Foundation of America's Scientific Advisory Board.

Jordan Sherman:

Hi, Dr. Carbone. A little bit later on in the podcast, LCFA Speakers Bureau member Aurora Lucas is going to be joining us to talk a little bit more about her lung cancer journey, and specifically how difficult it was to be diagnosed with lung cancer. For her, she's a young woman, she doesn't smoke and she just doesn't fit that stereotypical mold of a cancer patient. And that can make it a really difficult for medical professionals to say, "Hey, we may be dealing with a lung cancer diagnosis here." How would you or what advice would you offer to lung cancer patients when things are just not feeling right so that they can advocate for themselves?

Dr. David Carbone:

I think we all have to work hard to change the stigma of what a lung cancer patient looks like. And it's especially important when their initial diagnosis is delayed because of this misperception that you have to be 65 years old and a heavy smoker to get lung cancer. It's really true that if you have lungs, you can get lung cancer. And I've seen many cases where patients have a delayed diagnosis, the cancer progresses while they're being treated for pneumonias or other things before the doctor thinks that this might be lung cancer. So it is critical thing to communicate to primary care doctors that they should consider even young and healthy never- smokers might have lung cancer underlying their symptoms.

Diane Mulligan:

Absolutely Dr. Carbone, and I think too that we know lung cancer therapy has really come a long way in a very short amount of time and we're thrilled about that. But people may not look like they have lung cancer because of so many of these advances. It used to be that cancer treatment automatically came with hair loss and nausea, all kinds of different things. But that's not necessarily true anymore. So how do you help prepare your patients for this new reality of how they're going to explain this to family, friends, coworkers, everyone in their life?

Dr. David Carbone:

Right. Today's cancer patient can be undergoing active treatment, have metastatic disease, and yet still be in the workplace and still go to PTA meetings and still go to soccer games with their kids. They may look completely normal, but they may have an incurable lung cancer and they may have subtle symptoms that are very different from what most people expect. In the old days when you got a diagnosis of metastatic lung cancer, basically you would quit your job and you would lose all your hair and you'd be miserable and usually you would die within a few months. But now, the treatments have a low grade toxicities much more often. And even though the person may look okay, they may have significant toxicities that just aren't apparent by looking at them. And I hope that the people around them and their employers will understand that they may look normal, but they still have the burden of knowing that they have lung cancer psychologically, and that may not be curable with current treatments. But also that they may have chronic toxicities such as fatigue. They may have a low grade diarrhea, which means they can't be far from a bathroom and other things that may impact their ability to be 100% at work and maybe just 90%.

Jordan Sherman:

It really is, and you may look well too, and I know that's the whole premise of this podcast is the lung cancer patient may look okay to colleagues and friends, but they're not. And the reality is

many of the things that you just pointed out Dr. Carbone. So diving into that a little bit deeper, is there a three-step tips that you offer to your patients such as develop a routine or maybe it is researching where some of the side effects are for the therapies that they're on so they can adapt at their life and eventually try to keep things as normal as possible, but also acknowledge that you're living with a terminal illness?

Dr. David Carbone:

So the psychological burden of this and potentially financial burden really can't be underestimated as well. I think the best reference for patients who are on these chronic therapies with the low grade toxicities really is the patient advocacy programs. Because I haven't personally experienced these side effects. I can see them secondhand. But when you connect patients with their disease group, KRAS Kickers, ALK-positives, the EGFR Resisters, that'll instantly put them in touch with hundreds of other patients getting exactly the same treatment who may have discovered one way or another to deal with these symptoms.

So I think by far the number one most effective thing I can do for these patients in this respect is to connect them with other patients undergoing the same thing and dealing with it. But the other thing I can do as a physician is advocate for them in whatever conflicts they may have. Sometimes it's just writing them letters to their employer to help them manage with the exigencies of being treated. Sometimes I've been to court with the patients to support them in ways that relate to their dealing with their lung cancer. So I think there are lots of ways I can help, but these patient groups are extremely important.

Diane Mulligan:

They're really important. And you've talked a little bit about some of the side effects. You've talked a little bit about fatigue and diarrhea. And the side effects aren't obviously as noticeable as chemo. So maybe if you could give us some more information about these side effects that are somewhat more subtle, but still, as you said, day-to-day and can take a terrific toll.

Dr. David Carbone:

Yeah. Jill Feldman has a terrific slide where she's standing on this beach or whatever and she's holding up her hands and says she looks great, but then around her are all the different side effects that you can have from these treatments.

Diane Mulligan:

You may be wondering who Jill Feldman is. She's a member of the LCFA Speakers Bureau and a lung cancer patient who is a terrific advocate and talks a lot about this issue.

Dr. David Carbone:

As a medical oncologist we see our patients frequently over the span of years now, which is fantastic that that's actually the case with metastatic lung cancer patients. But you have to give them the opportunity to express how they're feeling and what their issues are. My nurses always make a joke that the nurse will go in and get the patient in the room and talk to them how they're doing, and then I go in the room, the patient says they're feeling fine, they don't have any

issues. But then I listen to what the nurse got from the patient, and there's a whole list of things that the patient is not in ways that the patient is not doing well.

So as a physician, you have to be aware of that phenomenon and listen to your nurse and have a good nursing staff that can communicate with patients and get the real story from them and also look at the spouse. Often these people come with a spouse, and so often I'll ask the patient, "Are you having pain?" And he says, "No." And the spouse is saying, "Yes."

Jordan Sherman:

Dr. Carbone. The bottom line here is appearances can be very misleading, and while people who are living with lung cancer should be supported in doing the normal activities of life. The patient is the best judge of these limitations, not their appearance to others. Would you agree?

Dr. David Carbone:

Yeah. Absolutely. And we actually also have formal programs for our patients. At my institution, we have something called the care program where cancer patients, we refer them and they get a 360 degree evaluation for nutrition and physical therapy and emotional support and whatever they need. It's about five different consults in one day. But to take care of everything that surrounds the treatment of the tumor, because my focus as a medical oncologist is making that tumor shrink. But there's more to cancer therapy than measuring the size of a tumor. It involves treating the whole patient and giving them the best quality of life, and sometimes referral to programs that address nutritional needs and exercise needs and functional needs, how to get up and down stairs, how to deal with these kinds of things are beyond my immediate expertise. But oncology programs should invest in such services for their patients.

Diane Mulligan:

Dr. Carbone, we've talked a lot today, but I'm interested, you work with so many patients. What else should these patients know about that's really important when they get this diagnosis and they're like, "I don't look sick." So it's so difficult to be able to explain to people how I'm feeling and what's going on inside.

Dr. David Carbone:

Well, the cancer treatment and dealing with cancer is incredibly complicated, and it involves the whole patient in all aspects of the patient, but it also involves their family. And as a cancer survivor myself, I can confirm that the diagnosis of cancer impacts dramatically the entire family, especially children and the spouse. And it's hard to underestimate how trips to the doctor and surgeries and procedures can be viewed by children who don't really understand what's going on. So I think it's also important for us to be sensitive to the patient's home environment in general. It can be financial issues that we can help the patient with that impact the family and sometimes medical care results in loss of the family home or spending the entire college fund for the children and children need this support as well. And offering or having available psychological counseling for children in the home I think is important, and making sure that patients understand that that's normal and acceptable and not a sign of weakness, for example.

Diane Mulligan:

Great information. And I'm sure that will also give solace to a lot of cancer patients and their families out there because they need to know that these are very typical concerns that impact just about every family when they get the cancer diagnosis. Thanks so much, Dr. Carbone. We really appreciate it.

Dr. David Carbone:

Well, you're very welcome.

Jordan Sherman:

We've heard a doctor's perspective on this. Now let's hear from someone who's living with lung cancer.

Diane Mulligan:

Aurora Lucas lives in Chicago. She's no stranger to people being shocked that she is living a vibrant life with lung cancer.

Jordan Sherman:

Aurora, thank you so much for joining us today to talk about a topic a lot of people may not have thought about. Sometimes when people learn that a young vibrant person like yourself is living with lung cancer, they're really taken aback. They get caught up in this stereotype that lung cancer patients must always be this old, frail person who is a chain smoker, and that's just not always the case.

Aurora Lucas:

Yeah. You're totally right. And Jordan, thank you for having me on the podcast. I think when I was being diagnosed, I would've been like, "Oh my God, all defensive." But now that I've had time to unpack it, I say, yeah, I get it. Exactly. Because that is the reason why there's delayed diagnosis, especially my story. It took about three to four months. Because even licensed doctors, they weren't very concerned that I could possibly have lung cancer. They were thinking it may be other things, anything but cancer.

Jordan Sherman:

Yeah. I mean, so few people our age have been diagnosed with lung cancer. You can certainly understand that stereotype. That doesn't mean that it's something that shouldn't be addressed. So when people are trying to be complimentary and say something to you like, well, you don't look like you have lung cancer. How does that make you feel?

Aurora Lucas:

I know how I'm supposed to respond, but feeling wise, it makes somebody like me who's a lung cancer patient sometimes it could make me feel isolated. It really depends who's saying it. But this past summer, I actually had insurance complications, so I had to go to another team that didn't really know my case. And for about an hour, the oncologist was like, "You look really great. You don't look sick at all." And for an hour, I had to really keep advocating for myself and say, "I have lung cancer. These are the tests that I need to get done."

But when it's a regular person who's not in the medical field, I tell them thank you, because I think it also goes into culture. I was thinking about this and I was raised never to really show pain. So I think I'm doing it right, showing that I look okay, but knowing that there's something else going on in my body.

Jordan Sherman:

When people are shocked that you have lung cancer and say something like, you never know by looking at you, what is your response? You mentioned, or rather I should say, you referenced how you needed to advocate yourself at the doctor's office. But what do you tell people who may be friends or acquaintances who are just learning for the first time?

Aurora Lucas:

Yeah. It takes me about a minute. I breathe and I'm like, okay, this could be an educational moment because I think it goes into survivorship as well. Looking, okay, as a lung cancer patient and not the stereotypical one, people tend to say, "You look good now, you're fine." But when it's someone that I'm just meeting, I try and take the opportunity to educate them and say, "Yeah, this is what lung cancer looks like now. People like me are surviving, but it's still the leading cause of cancer death around the world."

Jordan Sherman:

For you, Aurora, this is far more than an annoyance. It's a lot more than just, got to take a deep breath and try to figure out if this can be a teachable moment. This was an integral part of your lung cancer story. This is not something to do with fitting into a real or a perceived stereotype of a cancer patient. This is something that actually delayed your diagnosis. Can you tell our listeners a little bit more about your story and why that attributed to the delay?

Aurora Lucas:

Yeah. So by profession, I am a teacher and teachers need to talk the whole day. And I could not even finish a whole sentence. And this was the time that COVID was still around. I mean, it's still around today, but it was still rampant back in 2021. And actually I was just trying to fight through the cough, but my students were like, "Ms. Lucas, you can't even finish talking or your lecture." So I went to go see a doctor, and the first thing after I told the doctor my concerns about coughing, he said, "Everything is okay. Go boil some water and add some honey to it." And I think I left that office like, what? I just didn't feel heard.

And him being the doctor, I bullied him at first. I didn't have that much of my advocacy self now, back then. It took another two to three weeks for me to actually go to the emergency room because a new symptom had shown up and it was a deeper chest pain, and I didn't understand. And this chest pain lasted for about 48 hours. Then I checked myself in, and then they were trying to do other tests such as tuberculosis. The word cancer, the C word just didn't come up for the next two or three months.

Jordan Sherman:

Wow. That's interesting because COVID was certainly a concern back then. But what really struck me with your story is you felt that pain that you're like, wait a minute. This is not normal.

So eventually, how did you break through to get the diagnosis? How did you advocate for yourself to say, "Listen, this is probably more than just a cough?"

Aurora Lucas:

Well, I had to learn to show pain. That was one of the biggest lessons because I would go in and they would ask, "Oh, how is the pain?" And I would say maybe a three or four, and then I would be waiting in the emergency room. And I would tell my sister, what's going on, she's like, "I think you need to tell them you're really in pain." So I would say six or seven, and then they would have a little bit more agency. But even then with that hospital, I had to go back to my primary care doctor and my life was in her hands because I had to wait for her to give me a referral for a PET scan, which took so long. So another part of my story is having that type of insurance and having to wait for the doctor to give me that referral.

Jordan Sherman:

What's interesting, Aurora is you talk about the cultural aspect of having to keep your pain silent, and I think that that's something that a lot of lung cancer patients endure on a day-to-day basis. The premises podcast, and our listeners I'm sure have already understanding here is you don't look like you have cancer. But the truth is that a lot of the therapies that lung cancer patients are on are going to have a lot of side effects that the person that you see or people that you see every day just aren't going to see. And maybe pain, it could be other side effects. What are some of the things that you've experienced now that you're on a therapy that you may be experiencing day-to-day that somebody who sees you just may not see?

Aurora Lucas:

Yeah. That one has been a roller coaster ride because in the beginning I'm given this magical pill and the side effects were pretty minimal, but I had to learn how to stay out of the sun or adding lotion to my scalp. But then I learned being with these advocacy groups that these side effects can go away, but then new ones can come in. For example, in the present day, the bottom of my feet hurt, and I don't want to be seen around limping. I think it's just a part of me that I'm learning how to accept. But first thing in the morning it hurts to walk. Those things that are also affected by stress. I remember because I could text my oncologist, I'm like, "Hey, it really hurts to walk." And he said that could be linked to lung cancer. And I think for me, I've had to really assess my stress as well, like my stress levels, and see when there's a lot of stress in my life, there's a lot more side effects as well that goes with it.

Jordan Sherman:

That's really interesting feedback too. And I hope that some folks who are listening can walk away and say, "Thank goodness that's not just me that are dealing with these issues." You mentioned stress, and I think something here that's just not talked about enough in the lung cancer community is you may be on a targeted therapy and it may be helping you now, but there's always the stress, the scanxiety, it's known that there could be progression around the corner. So even though you may look okay, you're still dealing with that in the background. How do you deal with that and what advice would you have for those who are also dealing with the scanxiety?

Aurora Lucas:

Yeah. That's a really good question, Jordan. It's something that I have to deal with every day. Now I'm 30 and I'm like, "Okay, anything could happen." So I think my body never fails to remind me that this thing is in my body. So I've learned how to make peace with it. But also, the other thing is being a part of this community, you never know if you have a close friend that you've just made that will pass. And this is an experience. One of my lung cancer best friend, she passed two weeks ago and we're the same age. So I think us carrying the grief with it. And then the scanxiety part... Usually I'm spoiled. Recently I get the results within a few hours, but the most recent one took more than three or four days, and I was just clicking on my chart. I was like, "Where is the result?" And that fear is always there.

But then in the beginning when I was just dealing with it on my own and with my family, I felt very isolated. And these thoughts, I could never make space for it because I didn't want to be a morbid person. Everyone's like, "No, you look fine." But being a part of a community, I could actually make space for this sphere of like, hey, what if there is progression? And the people that I've met, they've actually had progression and they've been able to comfort me saying, Aurora. But when that time comes or if that time comes, you'll be able to handle it differently because you have more knowledge now.

Jordan Sherman:

Well, talk about that a little bit more Aurora and the importance for you to connect with other patients on that level. They could be within the same biomarker group or just somebody else who has a lung cancer diagnosis through groups like Lung Cancer Foundation of America.

Aurora Lucas:

Yeah. LCFA being an example. I have friends there that have also had progression, and I think for me, observing, I know that they're strong, but I think I had that other layer of, I don't know how they feel behind closed doors. They are also doing the same thing I am. Looking great outside, but I know that they have those fears. But it's so important to have that community because you know who to go to. I love my husband and I'm able to tell him, but I know that the weight of this cancer is so heavy, and I know that other people could carry that weight with him. He doesn't have to be my sole person who I tell about... But there's a whole entire community, hundreds of people online, and it's pretty amazing.

Jordan Sherman:

So Aurora, the last question for you we have on the podcast today is when you're in the midst of a treatment plan, and maybe you're not feeling the best, you may be seeing your peers who are living with lung cancer that are doing really well. Maybe they're in remission or maybe they're showing as NED, no evidence of disease. Is that really hard to deal with? Talk us through your mental process and how you look at those situations.

Aurora Lucas:

Yeah. Honestly, my honest question is that I'm okay with it. I'm happy for them that they're doing better or that they're NED, and I'm here still having to deal with it. Because in the beginning of the journey, I really made peace with what was going on with my body. I talked to one of my

friends who she also dealt with cancer, but she has breast cancer, and she said, Aurora, I think what you need to work on is making peace with this thing going on in your body. And at first I was like, "What do you mean? I'm supposed to fight this thing." And she's like, "This is a part of your body now." So I think I have that mentality of putting my energy towards how can I make myself better and just be happy for other people who are on their own path, because you just never know. Even that person with NED or remission, it's still unpredictable.

Jordan Sherman:

And I think it further puts importance on just research, because we know that every lung cancer, it's like a snowflake. It's unique, and we know that how individualized treatments have become over the years. That research really matters to help all people who are diagnosed with lung cancer, not just ones that have approved targeted therapies on the market today or targeted that are in clinical trials. So Aurora, thank you so much for sharing your honest and candid feedback, and we certainly hope that your story is going to help those who are living with lung cancer and maybe feeling some of the things that you're feeling right now and have to day-to-day break through those stereotypes.

Aurora Lucas:

Thank you for listening, Jordan, and all of these meaningful questions. I know it's not always easy to talk about, but thank you for giving us space to talk about this.

Diane Mulligan:

What a great conversation with Dr. David Carbone and with Aurora Lucas, that gave us some great insight into what it's like to be living with lung cancer.

Jordan Sherman:

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Diane Mulligan:

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