Living Beyond Cancer

The Short and Long Term Effects of Lung Cancer

Guest: Adrienne Duckworth

Lauren Hixenbaugh: Welcome to Living Beyond Cancer. I am Lauren Hixenbaugh, the coalition manager for Mountains of Hope. Living Beyond Cancer is podcast created for cancer patients, survivors, and their caregivers. This series is sponsored by the West Virginia Cancer Coalition, Mountains of Hope, and is produced by the West Virginia Cancer Institute's Cancer Prevention and Control. Today's topic is the short and long term effects of lung cancer and our guest is Adrienne Duckworth, a nurse practitioner in the Department of Medicine at West Virginia University Cancer Institute. We are thrilled today to have Adrienne with us. First off, just tell us a little bit about your job at the Cancer Institute.

Adrienne Duckworth: So, like you said Lauren, I am a nurse practitioner here at WVU Medicine in the Cancer Institute. I specialize in seeing lung and head and neck cancer patients with one of the physicians. Here at the Cancer Institute we see patients in a team setting, so even though in other specialties nurse practitioners practice maybe a bit more independently, at the Cancer Institute we really take a team approach to this because cancer patients have a lot of needs, and we can better meet those needs if we have a team working with the patients. So it is myself, a physician, a nurse, and usually a medical assistant that are involved in that team and know the patients really well and can make sure that patients get the appropriate care and resources as they are moving through their journey.

Lauren Hixenbaugh: We are really glad to have you today as a part of our team to talk about survivorship. What does the term survivorship mean to you?

Adrienne Duckworth: Okay, so survivorship is a term that is really difficult to define. So there's a lot of definitions out there, I believe the American Cancer Society's standard definition is that once you're diagnosed with cancer, you are a survivor. I think that that's a great definition in terms of letting people know that we are really trying to help them as they are moving along and every day that you're living with cancer you are really surviving and thriving, hopefully. But I think that in terms of lung cancer, it is a difficult thing for a patient to be considered a survivor. Patients do not always look at it the same way and physicians in cancer are not always sure when to call a lung cancer patient a survivor. Because in surviving, you think, oh, you've moved past that cancer, a lot of patients think "Oh, I do not have to come " to the Cancer Institute any more. "I do not have to go to my local oncologist any more to get treatment," in order to consider themselves a survivor. We had a program here that was sponsored to help with lung cancer survivor patients and we had a really difficult time getting referrals to it when we were calling it a survivorship program because the physicians just weren't really sure when to send the patients to see us. So we started calling it the Bridge Program and terming it more we are bridging you back to your local community or back to your primary care doctor for more of your acute needs in terms of your other health problems and in terms of your cancer we would still be here to support those things. So, I think it might be a little bit easier to define in some other cancer types, but in lung cancer, it is a hard thing for me to know what we should really say.

Lauren Hixenbaugh: Right. That's understandable. So one of the things that these survivors, I guess we'll use the term a little bit more loosely here, but they do deal with some short and long term effects after they've received treatment. Can you talk a little bit about that?

Adrienne Duckworth: Yeah, so the short term effects, physical effects, can be something as simple as shortness of breath right after finishing radiation or after having surgery. Some patients have a chest tube in place whenever they leave the hospital, so you might be dealing with some physical pain after having surgery. Long term effects, shortness of breath can still be there, a lot of patients become weak or physically deconditioned whenever they are getting these treatments if it involves radiation and chemotherapy. Some of the patients who have like a stage three lung cancer are getting chemo, radiation, they may have had surgery first, they may get chemo radiation and then go for surgery. They may get immunotherapy afterwards. So, it varies a lot by what type of treatment you received. But the big things to look out for would be shortness of breath, if you have a cough that's not getting better after a couple months following the treatment. The radiation can cause long term effects as well. And the chemo has some long term effects. Numbness and tingling in your fingers and toes, balance issues, it really depends on what type of treatment you received. What I would say is that if you feel like something happened after you got this treatment for the lung cancer, after you received the treatment, then you should really discuss with your oncologist is this something that's related to the cancer? When I say oncologist, I really mean your surgical oncologist, your radiation oncologist, your medical oncologist, any of them would be an appropriate resource and then if they kind of say "No, I wouldn't expect this," then it might be something more to discuss with your primary care doctor.

Lauren Hixenbaugh: Wonderful, so that way folks can talk to their oncologist, and they can even talk to their primary care provider and kind of deal with some of those special needs that they might have after treatment. So you talked about the treatment effects, but what are the common needs after people receive treatment? Maybe not just physical but just in general.

Adrienne Duckworth: Yeah, so a lot of patients have anxiety or fear that their cancer's going to come back or they are going to get another cancer. We really address that by trying to remind patients that just because you finish your treatment doesn't mean that your oncology providers are going anywhere. If you have a question, we certainly want you to call us. If you live a distance, that's where the telephone can be very helpful. I'm happy to call patients back and address their concerns. That is also part of the reason why we try to give treatment summaries to patients and make sure that they get to primary care providers. Because those people are in your local community, they might know better the resources for you in those local communities - where you can really get in touch with the people that can help you best where you live. I also think that patients get so the fear is there, but then also there's just anxiety in general; you finished this treatment, where do I go from here? When is my next scan going to be? So if you have questions about the timing of scans and those kind of things, that would definitely be better addressed by your providers wherever you receive your cancer care. Your PCP may not know exactly when your doctors would want to time scans and it really does depend on which type of treatment you received as to when the scan should be completed. So if a patient has a stage one lung cancer that was surgically removed, complete with negative margins, with no what they call high risk features, things that may qualify you for chemo or radiation afterwards, you usually need a scan about every six months. But it is very hard to know exactly; every case is different. We have guidelines that we follow that are put out through different societies but it really is patient dependent, and should be tailored to the patient.

Lauren Hixenbaugh: So they really need to work with their team and kind of keep a close eye on those things.

Adrienne Duckworth: Yes, that's what I would recommend.

Lauren Hixenbaugh: So, kind of going back to that team. I've read a little bit about some folks that have expressed frustration with the link or with the lack of link I should say between their PCP and their oncologist. What would your recommendation be for those folks?

Adrienne Duckworth: So, I think that this is where those treatment summaries are actually very helpful. I do not know if the people out there listening have received one of these, but we are really trying to do our best to get them out to our patients who are stage zero through three across all cancers. In lung cancer we do not really have a stage zero, it is either stage one, two, or three that we would consider patients who are being treated with curative intent. We are sending these treatment summaries when patients complete their treatment to their primary care doctors to try to give them an idea of all of the treatment that the patient has received.

Lauren Hixenbaugh: That's great.

Adrienne Duckworth: Yeah. At least here at our Cancer Institute and I know that a lot of places throughout the state are really trying to do these treatment summaries. They are required by some of the accrediting bodies, I know they are required by the breast cancer accrediting body, there's another one that's across the board for cancers called the Commission On Cancer or the CoC and they are required through that. So we are really trying to get that information out there. Also, there is a way, at least in our system at WVU, that we can send our notes to the primary care doctor. And a lot of our physicians do that automatically so that each time a patient is seen, a message is routed to that primary care provider. I keep saying doctor. A provider, nurse practitioner, PA, whatever your primary care provider is who can receive these messages. And that way they can kind of keep up as we are moving along. I know it might be a little frustrating for the PCP because some of my patients I have to see every week. Getting a note every week might be a little bit overwhelming but we are doing our best to try to keep PCPs in the link, or in the loop as to what's going on.

Lauren Hixenbaugh: So do these summaries go home with the patient or do they go directly to the PCP?

Adrienne Duckworth: So the patient gets a copy of the summary in person and then it gets sent to the primary care provider.

Lauren Hixenbaugh: So would that be helpful to a caregiver?

Adrienne Duckworth: I would also think that that would be helpful to a caregiver. A lot of the times actually the patients hand the paper to the caregiver whenever I hand it to them to like put into a book or binder so that they can keep ahold of that information. It gives a brief summary of what you received, and we try to put it in terms that the patient would understand, but also meet the crediting guidelines for what we need to be putting in there. I think that it is important to keep in mind that yes sometimes we as providers feel like this is an extra thing for us to do, but it can be very beneficial to the patient, to their caregiver, their PCP, other people across the patient's journey.

Lauren Hixenbaugh: I think another one of those things that they can kind of take home, put in their binder if you will is a resource. And you sort of touched on it a little bit about talking to their PCP in their community, but are there resources available for caregivers and patients?

Adrienne Duckworth: Yeah, so I know here at the WVU Cancer Institute we actually give each new patient a guideline for caregivers, or a book for caregivers in addition to the binder that they receive with all of the resources that we have. I'm not as sure about the resources that are available throughout the state. I know that Mountains of Hope does have a resource guide that you can find on the internet I believe.

Lauren Hixenbaugh: Yes, Mountains of Hope does have a webpage, and you can check it out at moh.wv.gov.

Adrienne Duckworth: A lot of the times it would be trying to find out what resources are available where you were seen for your oncology care or through your primary care provider. Because sometimes it is hard for me, if there's a patient who's in the southern part of the state nut chose to receive their care here in Morgantown, to know where I should refer them to physical therapy. So sometimes what I actually do is have them meet with a physical therapist here in the Cancer Center and then that physical therapist does have contacts throughout the state and tries to help them get established with somebody closer to home. But at least then they've met with somebody here too that has a little bit more experience with oncology because our physical therapist here is actually an oncology certified physical therapist. Sometimes patients go to an outside facility and they are just not really sure what to do whenever you have cancer and if they should be doing certain things, because do you have a clean scan that shows that you do not have cancer? I know that we are getting away from some of that mentality, but it still is a difficult barrier sometimes for patients when they go closer to home. So, if we have a little bit of a link, then I think that that can be helpful.

Lauren Hixenbaugh: They have a lot going on and a lot to think about.

Adrienne Duckworth: Right.

Lauren Hixenbaugh: So, giving them that to take home is a great way that they can kind of go back and look after everything, after their appointment and everything has been happening. So, my next question for you is kind of a loaded question. What are some common questions that you get from your patients?

Adrienne Duckworth: So, I will say that a couple weeks ago two patients asked me the same question on the same day, it was a little bit like "were you guys talking to each other?" But one was in the morning and one was in the afternoon. So, I think these patients ask me, their cancer is actually doing quite well on the therapy that they've been receiving. But they were diagnosed as a stage four cancer, which stage four lung cancer means that it went outside of the lungs to somewhere else in your body or that it is in both lungs and we think that it is the same cancer. Typically these are cancers that can't be treated with a curative intent. Or it is more difficult. By curative intent, I mean we are probably not going to be able to get rid of this cancer. This is probably something that you're going to be dealing with throughout your life. Every now and then we do have patients who have a stage four cancer that are cured but that's relatively rare. We are hoping that those things will become a little bit more common in the future but we aren't quite there yet. So both of these patients just wanted to know, "Well, I'm doing so well, "do I still have a stage four cancer?" I think the important thing to know for staging a cancer is

that the stage that you're given when you're diagnosed is the stage that you remain. So if you're diagnosed as a stage one lung cancer and then your cancer comes back, you do not have a stage four lung cancer, you have what they call recurrent disease.

Lauren Hixenbaugh: As we begin to wrap up today, I just want to take a moment and revisit some points for our listeners. Adrienne, if listeners remembered one tip out of today's podcast, what would you want that to be?

Adrienne Duckworth: So, I think that it is really important to know that lung cancer is not the diagnosis that it used to be. For some patients, yes, things still can progress quickly and they may not have very long to live with this diagnosis. But there are other patients that there are very good treatment options for, even if you're diagnosed at a stage four, so you should definitely be worked up completely by an oncology team rather than just, and it is not to say that primary care providers aren't doing the right thing and telling patients, but we are getting new data that immunotherapy really has been a game changer in terms of lung cancer treatment. You may have seen commercials for Pembrolizumab, which is Keytruda. Usually they are interviewing a few older patients about this that are saying like "I'm living with lung cancer." There used to be a lot of commercials for a drug called Opdivo, or Nivolumab and usually in those commercials the sun is coming out from behind like dark buildings. These drugs have really changed what we've been able to do for some patients. Again, not everybody responds to these treatments, but they are something that is an option for a lot of patients. There are patients who have lung cancer who have never smoked. 20 to 25% of lung cancers are diagnosed in never or light smokers. In West Virginia, that number might not be quite as high because our smoking rates are still pretty high. But it definitely is something that if you have one of these mutations, you can live for many, many years on these pills, and without significant side effects from the treatment. So it really is something that, if you're diagnosed with lung cancer, I really really strongly recommend that you see at least an oncologist, whether it be a surgical oncologist, radiation oncologist, medical oncologist, somebody who gets your foot through the door so that you can have this different testing done so you can have a biopsy to see what type of lung cancer it is, and then you can move forward with the treatment. Or you can at least move forward with your decisions having all the information. You know, they say knowledge is power, and in terms of lung cancer, it really is the thing that provides the most power to patients. Having the appropriate people involved in your care.

Actually, last week, we just received new information from an analysis done by the American Cancer Society that cancer death rates in the US are falling and they have been falling over the last three decades by about 1.5% points a year. This past year, and this data is old data, the data has to be looked at, but between 2016 and 2017 cancer mortality rates fell 2.2% and that's primarily driven by lung cancer and melanoma. But lung cancer is the big one. When you look at the data, from what I had read, cancer mortality rates would have only fallen by about 1.4%, which is the typical amount that they have fallen by, if you took lung cancer out of the equation. These new treatments and the screening that is available are really changing the game as well. So if you have questions about screening, you should definitely look into the resources that are out there, discuss it with your primary care provider, and I could give you the screening information, but I think that it would be a lot more to add. But there are resources, just Google lung cancer screening guidelines, and it'll tell you exactly who's eligible to be screened for lung cancer. (For screening information visit https://www.cdc.gov/cancer/lung/basic_info/screening.htm.)

Lauren Hixenbaugh: It is great to know that there are some opportunities out there for folks with lung cancer; that's wonderful, wonderful news. To find out more information about Living Beyond Cancer, you can visit moh.wv.gov or you can visit wvucancer.org. We also have a Facebook support group for caregivers, survivors, and their families. To join our Facebook support group just visit Facebook and search for “Living Beyond Cancer”. Living Beyond Cancer would like to thank Adrienne Duckworth for talking with us today as well as our listeners. We hope that you will continue to join us in the future.