Navigating Intimacy Challenges in Lung Cancer Transcript

Diane Mulligan:

Intimacy, whether it's sexual, emotional or intellectual, it's essential for all relationships, but now add lung cancer into the mix. Hi there, I'm Diane Mulligan.

Jordan Sherman:

And I'm Jordan Sherman. A lung cancer diagnosis can impact you emotionally, physically, financially, and mentally. So how does that affect your intimate relationship with your partner?

Diane Mulligan:

We're going to talk about that on today's Hope With Answers podcast. We're going to talk about the intimacy connection, sex and lung cancer. What should you expect? How should you talk to your partner and what should you be talking to your healthcare professional about?

Annabelle Gurwitch:

My doctor said, "Well, just stop having so much sex." And I was like, "Wait, sex is part of my treatment program." I was single when I was diagnosed. I get the great fortune to start a relationship and is really important to me, to my sense of identity, to my sense of purpose, to the quality of life. And these issues come really important when you're dealing with a long-term issue.

Jenni Daniel, BSN, RN:

The most important thing that I could communicate to anyone dealing with lung cancer or any chronic illness, honestly, it's just to try so hard to communicate with your partner because no one can read a mind.

Diane Mulligan:

Lung cancer is a tough topic. It's a disease that affects patients, families, friends, co-workers, 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:

A diagnosis of lung cancer does not have to diminish the significance of your sex life and intimacy.

Diane Mulligan:

But it does require communication with your partner and doctor. So today we're going to hear about maintaining intimacy from a cancer patient and a cancer coach. Our first guest is Cancer Coach Jenni Daniel. She's a registered nurse and founder of My Nurse at Home, a cancer support resource center.

Jordan Sherman:

Sexual side effects of lung cancer diagnosis can be physical, mental, or emotional. Jenni, let's break down each of those individually. Starting with the physical impacts, thinking in terms of energy level, maybe exposing a partner to chemo, radiation, pain issues, what can you tell us about that?

Jenni Daniel, BSN, RN:

You have to realize that sexuality in general is really a very fundamental aspect of somebody's identity. So it's never limited to just solely sexual intercourse. It can cover a whole spectrum of affectionate acts. And I think that those are important to include, like cuddling, intimate conversations. The experience and expression of an individual in their sexuality, it's so more involved than just the physical, right? There's thoughts, there's emotions, there are actions.

Lung cancer treatment, certainly along with the emotional turmoil of just being diagnosed with a cancer certainly can impact many aspects of a person's sexuality. Physical side effects. You can have the treatment side effects that they may have shortness of breath that was either by treatment causing or just from their initial diagnosis, depending on where that tumor is sitting, how large the tumor is. Fatigue is a huge concern for folks physically.

Body image issues, a lot of us become uncomfortable with changes going on. So imagine any surgery scars or things like that, or you may even have a tube coming out of your chest at different points. There's erection issues, there's vaginal dryness or just total loss of sexual desire.

Lack of hormone levels is another thing that can be linked to pain and discomfort during sex. Your physical attraction, energy level, honestly, fertility issues also come in there and medication side effects. All of these have such a large amount of physical impact and it's just so different depending on what some of those, or all of those are covered by each individual. Right? Who's experiencing what?

Jordan Sherman:

Really not a one size fits all, is it?

Jenni Daniel, BSN, RN:

There's never a one size fits all in cancer treatment for anything, anyone. But I think too, the emotional burden plays right into that, right? Because the emotional burden of being diagnosed with a cancer, couples will often kind of pull away from each other. They tend to stop showing affection almost for fear of hurting their partner that's going through the treatment.

But there's also the inner emotional turmoil where there's so much concern about what's going to happen, what the future holds that to me, a lot of it is the cancer patient's emotional state that affects the desire, the sexual desire. And some of the problems can definitely be worse for couples that don't have an open sexual communication as well.

Diane Mulligan:

Jenni, you were just talking about the emotional impact of partners getting together. Talk a little bit more about that. How can people deal with those emotional impacts and what does that really encompass?

Jenni Daniel, BSN, RN:

Yeah, there's a lot that it encompasses. I mean, when you're dealing with the emotions, it can be different second to second, minute to minute and certainly day by day. But if you think about from a mood perspective, there's anxiety, there's fear, there's a whole host of words that we could use, but the lung cancer diagnosis itself can lead to a very heightened anxiety and fear, which certainly affects one's ability to actually engage in an act of intimacy.

So the fear of the disease progressing or just the uncertainty of the future can just certainly be emotionally challenging and obviously again, put some real strain onto an intimate relationship. Depression, just to cope with an emotional burden of lung cancer. Again, you're contributing to other feelings, sadness, anger, depression. There's so many again, right? I always call this the emotional rollercoaster because it literally could be anything and everything or multiple things all at one time.

But the emotional distress, again, can reduce the desire for intimacy and the ability for an individual to connect on an emotional level as well. You think about body image issues and surgery, chemotherapy, radiation, all of those therapies can certainly result in physical changes, scarring, hair loss, weight loss, fatigue or weight gain.

I shouldn't say just weight loss. But those changes to the body images, that affects your self-esteem and your confidence when you're in that intimate situation. If we think about physical symptoms, again, you've got a lot of lung cancer patients experience pain, fatigue, shortness of breath, nausea, all of those would certainly interfere with one's ability to engage in a physical intimacy situation.

Diane Mulligan:

So I'm guessing that when you're talking to men versus talking to women, I mean, you have to kind of break the ice on all of this. How do you go about that?

Jenni Daniel, BSN, RN:

I'm just very matter of fact. I can be a little blunt, which I really try not to be, but sometimes people just need the information. It's not about kind of dancing around it. Intimacy affects all of us in a different way. It means something different to everyone. And the most important thing that I could communicate to anyone dealing with lung cancer or any chronic illness, honestly, is just to try so hard to communicate with your partner.

Because no one can read a mind. And again, because things change from a patient perspective, especially on a minute by minute basis, they may decide, "Hey, I'm in the mood." And then you get into the bedroom and things start happening and all of a sudden, "Oh wait, I'm having this horrible pain attack" or "I can't breathe in that position. We need to figure this out."

Jordan Sherman:

Jenni, how important would you say sexual health and or intimacy is to the wellbeing of people who are living with lung cancer?

Jenni Daniel, BSN, RN:

I think it's really important. I think it's just as important as having a connection with anyone. It is important, but we also have to remember that changes in sexual health and identity are very common and are also very distressing. So it can really put an impact on and making intimacy either kind of help

promote or kind of further the ability for the patient to get to where they're recovering and they don't have the anxiety, especially as it concerns their physical changes and their physical bodies and activities.

The patient has to be very aware and allow themselves to explore the mental side of the pleasure and desire, which can in turn help improve their level of intimacy. And certainly there's professionals that are out there that their providers can recommend that would be wonderful in being able to aid in helping the person kind of deepen that mind body connection.

Jordan Sherman:

Do you find in your experience that it may be men versus women or women versus men that are experiencing more so sexual issues either physically or mentally that comes following a lung cancer diagnosis? We know it's not a one size fits all, but just based on your clinical experience.

Jenni Daniel, BSN, RN:

That's a tough question. I definitely think there are differences and different ways that as providers, we can support men versus women. But I like to be a lot more general just because there's comorbidities, meaning other medical issues, other things that are also involved in all of these things. And unless you really know the kind of behind the scenes of an individual, you can't give specifics, if that makes sense.

Jordan Sherman:

Yeah.

Diane Mulligan:

So what we do know is that sex is all about, and intimacy is all about emotional connection. I mean, it doesn't matter whether you're a man or a woman, it is that emotional connection.

Jenni Daniel, BSN, RN:

Yeah.

Diane Mulligan:

But when you get that lung cancer diagnosis and you're going through treatment, the needs of the partners can really change. How do you talk to them about that and what do you suggest and give to them so that they can work through these changes?

Jenni Daniel, BSN, RN:

Yeah, good question. So it said that your biggest sex organ is actually your brain, not your genitals. So I think that recognizing that you can have an experience of arousal or even climax, like for a man without even having an erection, is something that a lot of men aren't even aware of. Right? So I think it's important again, to bring that mind-body connection together. But an orgasm is happening as much in your brain as it is in your genitals.

So allowing yourself to explore the mental side of pleasure and desire can then help improve your intimate life overall. And again, if you struggle with that, there's professionals that help to deepen that mind-body connection. But I think often it's pleasurable for men to pleasure their partner, so and that's something that you could do whether you have an erection or not. Right?

So being able to pleasure your partner can still be a turn-on for both men or a woman. And I think that there's more ways to be sexually active than certainly what we see in the movies or on a TV screen. Being creative, having open dialogue, the communication that allows you to explore non-penetrative sex is incredibly important. It doesn't have to just be intercourse.

Sex is that emotional connection, but it's also communication. So being able to vocalize your desires, your needs, along with your expectations from a partner. Actively listening to each other during conversations, physical affections, kissing, hugging, cuddling, holding hands, these things can be very comforting to a partner along with intimate and quality time together.

Jordan Sherman:

So what tips do you have for couples who are living with lung cancer on raising that issue of sexual health with their healthcare professionals?

Jenni Daniel, BSN, RN:

Yeah. Yeah. So that's an excellent question. And you're right, it's a very uncomfortable topic for not just patients, but honestly there's a lot of providers that have a whole lot of difficulty talking about these things. So I think addressing sexual health, it remains integral to the patient-centered care that we as providers should be giving our patients. As a cancer diagnosis itself, it certainly does not automatically negate the fundamental aspect of human sexuality. Right?

So we have to normalize the sexual health component of cancer care and asking permission to continue addressing the patient's concerns. This should be done by doctors, by nurses. Anyone that's caring for the patient, they need to also recognize that these conversations can be uncomfortable. And that's okay. Not every conversation is an easy one. As providers, I think we need to allow patients the space to really come in and share concerns, ask questions, and address their sexuality as non-judgmentally as possible.

That to me is key. And really that conversation I think should start at diagnosis and it should be then periodically reassessed as a patient progresses through treatment and then into follow-up, right? But I do believe that sexual health should be addressed, whether it's a provider or a patient that starts that conversation, doesn't matter. Somebody needs to initiate it.

And also that people who do discuss and receive treatment for sexual dysfunction, they do. It's important to note, report an improved quality of life and better communication with their partners. Some of the better conversation starters that I've worked out kind of to just for a patient to finally just say, "I've read that sexual health issues are common in patients with lung cancer, and I would like to talk a little bit about this," leaving it a very blanket statement.

The other one is to mention that before the new start of treatment or the start of a new treatment, how might this affect my sexuality, is just an easy question to ask to start that conversation too. Recognizing that it's hard to talk about. So I'll tell people, you can tell your provider if they seem a little standoffish. "I know it's hard to talk about this subject, but I do want to discuss how my cancer has affected my intimacy."

Another one, my libido has decreased. Can we discuss this? My physical relationship with my partner has changed since my diagnosis of lung cancer, I would like to discuss this with you and find solutions. That way they're making sure that they're saying, "Not just talk about it because I'm not trying to just vent. I need help to resolve this and move forward." And then the last one would probably be, what can we do to regain my experience of intimacy with myself or my partner? Because patients have to remember too, they are part of their healthcare team. They should play an active role in initiating conversations even when they're difficult.

Diane Mulligan:

I think those are great conversation starters. They're great ways to have conversations even with your spouse or your partner and kind of open up that discussion. So thank you for those. I think those were fantastic.

Jenni Daniel, BSN, RN:

Thank you.

Diane Mulligan:

And I guess the bottom line here is that if you've had a close intimate sexual relationship before cancer, there's really hope that you can have that after cancer. And also what I learned is that you could actually have a better relationship if you learn how to increase that communication. So it's kind of interesting in talking to you about how not only can you have a relationship, but you can increase it by talking, getting more emotionally connected, and that it's not something that you have to say, "That's just not part of my life anymore."

Jenni Daniel, BSN, RN:

Yeah, absolutely. I think keeping in mind that the diagnosis of a lung cancer does not diminish the significance of your sex life and intimacy. Sexuality is intertwined with who we are. It's our sense of self. It's our connection to others. It's a means of communicating with someone that you feel very special about in your life. It's crucial to engage in these conversations with your healthcare professionals regarding how to actually preserve this aspect, which I think is super vital in everyone's life of your well-being. Because that's really what it is, it's part of your well-being when you're living with or recovering from a lung cancer.

Jordan Sherman:

Our next guest is New York Times bestselling author, actress, lung cancer survivor and tireless advocate for lung cancer research.

Diane Mulligan:

We know her well. She's Annabelle Gurwitch, and she is frank and funny, and she has always been talking with informative discussions about what it's like to live with lung cancer. So we recently asked her to share her experiences about lung cancer and intimacy.

Jordan Sherman:

Well, Annabelle, thanks so much for joining us on this podcast. The first question for you today is can you talk about the unseen side effects of a lung cancer diagnosis? And they could be physical, mental or emotional, can't they? What was it like for you?

Annabelle Gurwitch:

Yeah. Jordan, I think one of the things that I think is really challenging, and it's also the same thing that's an amazing opportunity, is for people who are diagnosed. At this point in time, I was diagnosed in 2020, is that with the advent of biomarker therapies and the improved research. So we are in this territory where it's a lot of unknowns for the patient.

In the past, there were these sort of known pathways you would follow, maybe surgery if that was indicated for you, chemotherapy, radiation, these kinds of treatments that we all become familiar with because we've had friends, family, we've seen the movies where people get cancer. But this world that we're in right now is so different and it has so much... Look, here I am three years into biomarker targeted therapy, and it's been stable. I've been so fortunate on that therapy, but it's a lot of unknowns.

And so when you're talking about, as we talk today about the kinds of toxicities you experience, whether it's emotional or physical or financial, from that stem, from a lung cancer diagnosis, one of the big issues is that we don't have models to follow. And one thing I want to really encourage anyone who's recently got a diagnosis is to reach out to groups like this, to find groups. If you have been fortunate enough to test positive for a mutation, there's all kinds of patient support groups.

Your patient advocate base is really the best support for this. And so as a patient advocate, I'll talk about first the emotional impact. One of the things that is very challenging when you get a lung cancer diagnosis is that at the moment, lung cancer is an incurable disease, particularly when you're diagnosed at a late stage like I was, stage four. And so this idea that you are going to be in treatment for the foreseeable future until science changes is a very challenging existential crisis that many of us face.

How are we going to live? How are we going to negotiate that? And I think the very first thing is to acknowledge that this is a very unique challenge. It's very different than being challenged with a kind of disease or illness where you say, "Here's the beginning, middle, and end of our goal for your treatment." This is an ongoing treatment, an ongoing conversation you'll be having. So that is the very first thing. I want to talk about the kinds of toxicities, Jordan, if it's okay to move to that now, that you experience physically.

So physically, again, you're in some unknown territory. And one of the things that happens is that when you start, for instance, biomarker target therapy, which is really what I have focused not only my lived experience, but the research I've been doing and the writing I've been doing. As you know, I just published a piece in the Oncologist's Journal about the [inaudible 00:23:30] study, which was done with the support of EGFR resistors and Dr. Narjust Florez at Harvard and at Dana-Farber, which looks at intimacy issues.

But these issues, for instance, are often so surprising because your caregivers don't know about it. So in addition to things like you might have gastric issues or you're experiencing some fatigue, what we are really going to talk about today is that you could have issues that deal with sexual dysfunction. And that was a complete surprise to me because I didn't see that.

And so I was getting UTIs with this incredible frequency, and my doctor said, "Well, just stop having so much sex." And I was like, "Wait, sex is part of my treatment program." I was single when I was diagnosed. I get the great fortune to start a relationship, and is really important to me, to my sense of identity, to my sense of purpose, to the quality of life. And these issues become really important when you're dealing with a long-term issue.

Diane Mulligan:

I think they do. And I think that's a great point, Annabelle. I think also on the other side, sometimes some of our patients talk about issues with body image and issues with lack of desire. Tell me your thoughts on that.

Annabelle Gurwitch:

There are a number of reasons why you can experience sexual dysfunction. One of them might be body image. One of them can be fatigue. I mean, there's a number of issues. I think what is really important is

to A, to know that that's a possibility. And that's one of the reasons why I've been writing about this, is because when it's happening to you, you feel really alone.

And if your doctors aren't aware that this is an issue for whichever reasons, you don't get any support with it. Because I think saying, "Just don't have sex," is not really a good answer. And of course, as we know for people, for males who are going through prostate cancer treatment, no one ever says to a man, "Just don't have sex." We're like, "Well, let's help you with that." And in terms of what the issues are, I just want to say, when we think about gene targeted therapy, one of the connections, it actually makes a lot of sense.

The reason why this is happening is because your skin can be affected on a TKI, a targeted therapy and skin dryness, skin cracking. So imagine the inside of your vagina having that experience. But that connection isn't always made with doctors. And I think it's really important to be able to separate, and I mention that in specific because it's important to separate there's emotional issues and then there's physical issues, and they each have to be dealt with in a different way.

And I think one of the pressing reasons why we're talking about this Diane is because as we know, more and more, and the majority of people who we diagnosed with lung cancer this year in America will be young women, issues of fertility, issues of sexual function. This is really important. I mean, I'm 62 and it's important to me. And I know that it's really important to young women to preserve their fertility if that's an area they want to pursue.

And also the quality of life issue becomes really important if you're diagnosed in your 30s or your 20s. And one of the distinguishing factors of lung cancer treatment is this longevity of the treatment. And that is something really important to understand when you're talking to your doctor that you might be speaking to someone who spent a lot of their career in this old paradigm of treatment, which was much more short-term because of low survival rates.

Let's just say that. Now, the great opportunity and challenge that we have is as we are living longer, these survivability issues, these survivorship issues, as we call them, become much more important. And they just weren't an issue. And so your doctor just might not be used to that kind of conversation. And also, when you're dealing with things that are over a long period of time, like fatigue, fatigue sounds like one thing when you're fatigued for a couple of days. When you're on a treatment for years, that causes fatigue. That can really wear you down.

Jordan Sherman:

And I think a point that you made earlier, Annabelle really stuck with me. You said, "Hey, sex is part of my treatment plan. You can't just tell me not to do it." So for couples, and you bring up young women in particular, as we're seeing those diagnoses rise, unfortunately, who may not be as comfortable broaching the subject, do you have any advice for them? How to even just start that conversation so that people can still have a good relationship sexually, but also feel good about talking about it.

Annabelle Gurwitch:

There are guidelines that are used in other kinds of treatment. There was a model called the Explicit Model, which is a guideline for talking about broaching the subject that can be taboo for some patients of how is your sexual life? Because we don't want to leave that up to patients to bring it up. This is very difficult when you're in the room with your doctor and they're asking you how your medicine's being tolerated. You do not want to be taken off the new biomarker targeted drugs.

And one of the issues that is very pertinent to this subject is under-reporting. So a lot of people won't tell their doctors about this because of fear being taken off the medication along with, "How do I talk

about my sex life with my doctor?" And I think one of the things that LCFA is interested in as well as I'm interested in is helping caregivers to be aware of these things.

And just even our talking about this, for someone watching this who says, "Well, my partner is going through this treatment. I hadn't thought that this is, maybe there's a physical issue, or maybe it's an emotional issue that is making it more difficult for us to have intimacy." And so I think if we can give as much support to the person in treatment, that's fantastic.

Diane Mulligan:

I think that that's so important. But I'm also interested, and I know that you have personal experience with this, is what if you don't have a partner and you're single and you're kind of out there and you want that part of your life to continue? How did you broach that? How did you handle that type of situation?

Annabelle Gurwitch:

That is a great, great question, Diane. And in our little cone of silence meetups that I have with other patient advocates, it's a very interesting topic. So one gentleman who has been in treatment for many years, he said to me, because he was in that situation as well, we were talking, he said, "How did you do it? What do you do?" And he said, "I have a rule now. I don't bring it up till the third date because I had dates with women who were seeming to be interested and then scared away."

And I think that's an experience that can happen. And I know for me, I did not expect to be able to start a relationship when I was in treatment. And I think there's a couple of things that are important here. One is that we're living in a different world in terms of the kinds of outcomes for lung cancer. We are so fortunate.

My oncologist said when I came to see him the first time, "There's no better time in the history of the world to be diagnosed with lung cancer." I thought that was a little over the top, but I understood what he meant. And that is true. So first of all, I think that we are living in a time where it does seem possible that one can begin a relationship. And I think everyone has to do this in their own way.

Diane Mulligan:

I think lots of times people have a hard time bringing this up with health professionals. We talked about that a little bit earlier. Do you think, especially if you're a wife or the female partner and you're not the one with lung cancer, that it's really helpful to go and you should feel comfortable, especially it depends on, you have to have this conversation, obviously with your partner first, but that maybe you're the one, as you said, women have an easier time talking about this sometime, that brings it up with the doctor. What do you think about that?

Annabelle Gurwitch:

Well, as I said, Diane, I think that what's much more helpful is when your care team brings it up for you, because that really takes the onus off the person in treatment and the partner of the person in treatment. And I think that, I mean, that's one of the reasons why I published in an Oncology Journal is I think we need to educate not only patient base, but also provider base. We, like I said, we have so much on our plate already, having a difficult conversation, what might be a difficult conversation is really hard to bring up. And also part of the issue is the under-reporting. So if your doctor is not aware of this issue, it's going to be dismissed very easily.

Diane Mulligan:

And I think it's also important if you have a doctor who you really like but hasn't brought it up, that it's okay to have this conversation. I mean, that's I think one of the things that people need to hear that this is part of life and that your whole life has been turned upside down. And the same for the caregiver, their whole life has been turned upside down.

Annabelle Gurwitch:

Everyone has their own metric of what a quality life looks like, and I think that includes being sexually active. It includes wanting to look attractive, whatever that means to you, and have the ability to be here for the important things that we each consider important in life.

Jordan Sherman:

Annabelle, you talk about how there's just so much more to intimacy. It's not just sex. Everyone has different things that they're doing. It could be with their caregiving team, not necessarily have to be a partner that gives them a feeling of good. And sex is just one part of that. So kind of an all-encompassing question here is, what do caregivers need to know about that?

Annabelle Gurwitch:

Oh gosh, that's a really good question. What do caregivers need to know about this all-encompassing set of intimacy? Well, I think that one of the really important things to talk about is the kind of vulnerability that a person in treatment feels. And it's really the kind of empathy that we all need for everything in life just sort of souped up. Because we know that someone in treatment might not want to immediately say how they're being affected, it can take just a little bit more of listening.

One thing I think is really interesting is that I think the greatest thing is to be treated like someone who doesn't have cancer. One of the great things a care team, your support team can do is to treat you as if you and your identity are still intact. I mean, we all know we have been transformed. Our lives have been transformed. But it is a great thing when I'm not treated with kid gloves.

Diane Mulligan:

I love that. And that's a great way for us to end the segment.

Annabelle Gurwitch:

Well, thank you. And it's my pleasure. I want to say that LCFA was my first destination after being diagnosed, and it's because of LCFA that I got connected to the larger lung cancer world. And I feel so grateful to be part of the community and supportive of the work you all are doing and giving me a chance to reach people. And the community is very important to me, and it's very important to me to get to do that with you guys.

Diane Mulligan:

What a great conversation with Annabelle Gurwitch and registered nursing cancer coach Jenni Daniel. Both provided great insight into the world of intimacy for patients who are living with lung cancer.

Jordan Sherman:

If you're enjoying the Hope With Answers: Living With Lung Cancer Podcast, consider donating to help LCFA produce this resource. Remember, it's for patients or anyone else who are seeking answers, hope and access to updated treatment information, scientific investigation and clinical trials.

Diane Mulligan:

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