

Diane Mulligan (00:00):

For many people living with lung cancer, palliative care can be a beacon of hope and support. I'm Diane Mulligan.

Mitch Jelniker (00:08):

And I'm Mitch Jelniker. The goal of palliative care is to alleviate suffering and to nurture comfort and promote understanding at every turn.

Dr. Sherri Cervantez (00:18):

Palliative care is really focused on patient-centric things and how do we help make you feel the best for the longest as you're going through critical illness care.

Mitch Jelniker (00:29):

Most insurance plans cover it and it is designed to provide comfort and relief for the patient. For many living with lung cancer, palliative care is really worthy of exploring.

Sally Cain (00:40):

I just cannot stress the importance of having palliative care, somebody in the palliative care team to help you through this.

Diane Mulligan (00:50):

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.

Mitch Jelniker (01:00):

Advances in lung cancer treatments over the last few years have made it possible to live with lung cancer for years after diagnosis.

Diane Mulligan (01:08):

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.

Mitch Jelniker (01:29):

Welcome to another edition of Lung Cancer Foundation of America's Hope With Answers podcast. Today, we're going to delve into palliative care and its profound impact on the quality of life for those navigating living with lung cancer.

Diane Mulligan (01:42):

This is a holistic and a compassionate form of care designed to alleviate all types of suffering, whether or not it's associated with lung cancer treatment. Think of it as a team of medical professionals who are focusing on providing relief for symptoms, pain, and stress.

Mitch Jelniker (02:03):

We'll begin with Dr. Sherri Cervantez. She's the director of palliative oncology at the UT Health San Antonio MD Anderson Cancer Center

Diane Mulligan (02:14):

Dr. Cervantez, how do you define palliative care?

Dr. Sherri Cervantez (02:19):

Yeah. That's a great question. I think a lot of people are confused about what palliative care is and what it means. For my patients, I really try to express to them that palliative care is about making you be as functional as possible for as long as possible. We really focus on symptom support and control. We focus on what's valuable to a patient, what gives them meaning and drive and motivates them, and we try to incorporate those things into their medical management and plan. Palliative care is really focused on patient-centric things and how do we help make you feel the best for the longest as you're going through critical illness care.

Mitch Jelniker (03:08):

Yeah. About quality of life, essentially. Sometimes, when people hear the word palliative care, they confuse it with hospice care, but they're not really the same, are they?

Dr. Sherri Cervantez (03:18):

Right. They're actually sort of an overlap between palliative care and hospice care, but they're definitely distinct entities. Most palliative care physicians now go through a training, a fellowship program, and part of that training teaches us how to both care for people as they're diagnosed with critical illness. How do we take care of their symptoms? How do we help learn about them and prioritize their goals through the end of life? A small portion of palliative care is hospice care, but hospice care is not all that palliative care is. Palliative care can be any time throughout the duration of an illness, whereas hospice care is usually closer to the end of life.

Diane Mulligan (04:08):

Let me make sure that I've got this right. I want to know who exactly should be considering palliative care and when, but is it more of a life-limiting illness? Is it when your illness is impacting the quality of your life? Is that how we should think about it?

Dr. Sherri Cervantez (04:26):

LCFAmerica.org Page 2 of 12

Yeah. It's both is what I would say to that question. One of the key things for palliative care services are that the anticipated course of an illness would be life limiting, okay? Because, oftentimes, those have a lot of psychosocial distress or symptom burden associated with them and that's what we focus on. That's what a palliative care team would help care for, whereas the functionality and the quality of life is one of our goals, one of our priorities. Patients that have maybe chronic illnesses that may not be life-limiting wouldn't be the ideal patient to receive palliative care services. We certainly focus on that for patients who have these critical illnesses, but there's only so much that we have the capacity to do in palliative care, and there's a lot of patients with these illnesses that we try to help support.

Diane Mulligan (05:32):

I want to follow up. If you have someone who has lung cancer, would you most likely be thinking of people who are at stage four or is it more impacted by the symptoms that they're having?

Dr. Sherri Cervantez (05:45):

Yeah. Another great question. I think this is where a lot of people get confused about palliative care. Even in early stage cancers, there's a potential that that could be a life-limiting illness. Patients that come in with high symptom burden, specifically for lung cancers... Maybe they have an airway obstruction or something like that and they're short of breath or they're having chest pain. Those would be patients that are appropriate to see palliative care, even if they're planning to undergo curative treatment, so surgery or radiation and chemotherapy. Those are patients we can still assist with and help with. It may not be that we follow you indefinitely; you might graduate from palliative care services once you complete your treatment. There's sort of a spectrum to what we do, but especially in cancer care, the earlier the better, I think. The more symptoms you have, the more helpful we can be through your treatment course and helping you be successful in that treatment course.

Mitch Jelniker (06:52):

It sounds like palliative care would offer great comfort to the patient, so how does it work exactly?

Dr. Sherri Cervantez (06:59):

Yeah. With palliative care, oftentimes we're notified by the oncologist or if a patient is hospitalized by maybe the nurse that a patient would be appropriate for us to see. The most common way people are referred to palliative care services would be on an inpatient basis. You're hospitalized for some reason, you're hospitalized to provide symptom relief or you're needing to have a surgery, potentially you're being diagnosed with your cancer, and palliative care would be called in by your team to come and help with managed symptoms. Okay.

(07:40):

Occasionally, there are outpatient structures for palliative care medicine and that is growing. More and more systems have outpatient or ambulatory palliative care services. Now, oncologists can refer directly. The other way that sometimes people get engaged with palliative care services is they have a family member or they have a personal experience with palliative care services. Once they find out about their diagnosis, they ask their physician, "Hey, I'd really like to see palliative care. I think it would be helpful for me."

Diane Mulligan (08:17):

This is fascinating. Do you have stages in palliative care?

LCFAmerica.org Page 3 of 12

Dr. Sherri Cervantez (08:25):

Sort of a difficult question. We don't formally say that there are stages for palliative care, but we try to meet patients wherever they are. Okay? On the inpatient side, palliative care can be involved as a consultative services. There are some hospital systems that actually have inpatient units for palliative care. You might consider that as a phase or a stage.

(08:53):

The outpatient setting, there's both clinic-based palliative care services, as well as home-based palliative care services. They're, again, just trying to meet patients where they are. How can we be the most useful and helpful to patients and their families? And then, that last portion or the next phase of palliative care is really that transition to hospice. Again, it's included in our palliative care training. It's considered palliative care in a sense, but it's really reserved more for people who we think are closer to the end of life.

Mitch Jelniker (09:32):

You mentioned at-home Services, also outpatient services. Give me an example of the kinds of services that might be included with palliative care.

Dr. Sherri Cervantez (09:44):

Most palliative care programs are designed to be an interdisciplinary team. It's not just you walk in and you meet with the physician. The hope and the design of palliative care is to be able to care for the whole person in one place. You'll have access to the social worker, the chaplain, the nurse, sometimes physical therapy or occupational therapy, most of the time some type of social support with a psychologist or psychiatrist.

(10:17):

We're really trying to care for the whole person all at the same time. It's a team-based approach, so the expectation when you come to meet with us is that we're going to be there for you to listen to what's going on, to try and really get to know you, to try and really get to know your family, and how does that impact your care choices or your decisions that you might be making.

Diane Mulligan (10:41):

So are all palliative care services basically the same? I mean, what questions should you ask and what should you be prepared for when you have your first consultation?

Dr. Sherri Cervantez (10:54):

I would say most often, people come into the palliative care office, especially if they're referred from their oncologist, and they really don't have an understanding of why they're there. You ask, "What do you know? Why did your oncologist... Why did your cancer doctor send you over to see us?" And they go, "I don't know." There's this pause, and so we will commonly go, "Well, that's okay. Most people don't really know what palliative care is and how we can help. Let me describe a little bit for you and talk to you about how we might be able to assist you as you're going through your cancer care." We talk a little bit about what resources are available to them as far as our team members. So we do an introduction, so you should anticipate that you're going to meet the team.

(11:42):

LCFAmerica.org Page 4 of 12

We also do a full assessment of, "What is your symptom? What are other symptoms that you might have? What are your worries or concerns? What questions do you have? What's your understanding of your illness or your treatment?" And really try to learn more about them. Typically, you can anticipate that these appointments are longer. Most of the time, the first time you meet one of your doctors, it's maybe a 20 to 30-minute visit if that. For our new patients, most commonly they're somewhere around 45 minutes to an hour and a half, so they're pretty long visits. And that's because we need to get to know you to be able to help care for you moving forward.

Mitch Jelniker (12:31):

Yeah. So prepare for some time and you need to take the time so you get to know the team and they get to know you and what you're going through. As a patient, can you seek out palliative care on your own or must it be recommended by a doctor?

Dr. Sherri Cervantez (12:47):

Absolutely. You can be referred by anybody, including self-referral. We certainly encourage that, especially for their lung cancer patients. We know that palliative care can be very impactful in lung cancer diagnosis, almost as impactful as a treatment line. The initial palliative care study that really brought palliative care to the forefront, especially in cancer patients, was the Temel study. In that study, they looked at patients who were diagnosed with advanced stage lung cancer who received early palliative care at the time of their diagnosis, versus patients who received standard oncologic care. There was a three-month improvement in overall survival. That's as good as a line of chemotherapy. That's really impressive and one of the reasons why we encourage people, "If you find out that you have a cancer diagnosis and you want to talk to us, let your doctor know. Tell them you want to go see palliative care and we're happy to see you."

Mitch Jelniker (13:54):

That's great.

Diane Mulligan (13:55):

This is great. Three months, that is outstanding. Is this covered by insurance?

Dr. Sherri Cervantez (14:02):

Yes. Most insurances cover palliative care services. There is sometimes a distinction between the palliative care services and hospice services, and so that's why I say most of them cover it because they sometimes have some different coverage for hospice services. But pretty universally, insurance companies will cover it. One of the reasons is because it's holistic, it's looking at caring for the whole patient, looking at all of these different things, and trying to connect them with appropriate resources and supports. As much as we can do to help keep people functional and help keep them out of the hospitals, the insurance companies really like that, so they cover the palliative care services.

Mitch Jelniker (14:54):

I am gathering that there are really no bad questions here. In other words, I can picture a lung cancer patient thinking, "Well, my legs hurt, but I don't want to bother my oncologist with it," but you could share that with a palliative care team. They might have some things that would make your life easier.

Dr. Sherri Cervantez (15:12):

LCFAmerica.org Page 5 of 12

Absolutely. I always encourage our patients to do that. We tell them that, "we partner and we're going to team with your oncologist, but we're here to talk about the things that maybe you feel you can't share with them or you're not ready to share with them or you didn't have time to." Sometimes we just are a safe space. It could be that they're discussing a change in treatment plan, but they didn't really understand what their oncologist or their radiation doctor explained to them. We have a chance to sit down and explore it a bit more, maybe talk to them about it, and explain what does it mean for them, what does that look like, and really just help ease their mind about what are the things that are being offered to them and is it in line with what they want for themselves.

Diane Mulligan (16:02):

If you had a lung cancer patient, are there any special considerations that a lung cancer patient might come to you with, whether it's coughing all the time or the stigma issue of the self-blame "because I was a smoker," those types of things? Are those handled in palliative care as well?

Dr. Sherri Cervantez (16:21):

Absolutely. Those are really great points. For the different disease processes, we might focus on different things, but the common things that we see in lung cancer patients would be concerned about their cough, sometimes chest pain. The other thing that we see is their fear of shortness of breath, their fear of air hunger. We do spend a lot of time talking to our lung cancer patients about how do we help manage shortness of breath or cough. We also spend quite a bit of time helping with the stigma of smoking and cancer patients with never smoking history. Sometimes, they feel this guilt associated with it because there's this long history of that association.

Diane Mulligan (17:08):

Dr. Cervantez, how many patients use palliative care? Is it well-known? Is it underused? Where are we with this?

Dr. Sherri Cervantez (17:19):

I think the most direct answer to that is it's underutilized. I think that because of the association and stigma with hospice services that people don't utilize the full extent of palliative care early enough. That's one of the big efforts of the palliative care field is to really help people understand, help educate both providers and patients and the community about what services are available.

(<u>17:56</u>):

I can speak from our experience in our cancer center here. Unfortunately, less than 1% of patients get referred to palliative care and that's in any cancer group. You can imagine in cancers that maybe are less common, fewer people get referred. I'm a huge advocate for palliative care as an oncologist. Most of my patients get referred probably earlier than most, but I think from the standpoint of understanding what it is and being able to educate the community, sessions like this are so vital and critical to helping people understand what we can do. It really does help people live longer.

Mitch Jelniker (18:47):

It's fascinating. Are there areas that we didn't ask you about that you would like to share more about?

Dr. Sherri Cervantez (<u>18:54</u>):

LCFAmerica.org Page 6 of 12

I just think the value of palliative care is so misunderstood. I think most people only come across it or introduce to it in an inpatient setting, very late in a disease illness course. And so we are not able to have the impact that we should be able to have on patients with lung cancer. When we talk about how many people are referred or how many people receive services, some of it's actually limited by the number of palliative care teams and the number of palliative care providers that are available in that region.

(19:40):

I think if you have access to it, utilize it. I can't stress enough how helpful it can be, not just for patients but also for their family members. We didn't really talk about caregiver burden and the distress that loved ones and family members might experience as their family member's going through cancer care. But that's another aspect of palliative care that we try and dig into and try to help support so that the patient can feel better and get the best care.

Mitch Jelniker (20:15):

Dr. Cervantez, this is excellent information. Thank you for sharing your expertise. We appreciate you today.

Dr. Sherri Cervantez (20:21):

Absolutely. Thank you so much.

Mitch Jelniker (20:23):

I love Dr. Cervantez's quote that palliative care is really supportive care. Palliative care is a team of medical experts providing added support that is available at any stage of illness.

Diane Mulligan (20:36):

It's not only about the patient's comfort. Palliative care can help patients be successful in their lung cancer treatment. Now, let's hear from someone who's actually experiencing palliative care. Sally Cain is living with stage four lung cancer and she is one of Dr. Cervantez's patients. Hi, Sally. It's so nice to meet you. I'm very interested in your lung cancer story. Tell me about it.

Sally Cain (21:04):

It just happened out of nowhere. I had an ache on my right side and this was last May of 2023. I got up the next day and drove myself to the emergency room. They thought it was a kidney stone. When none of the drugs helped that they gave me, they did a CAT scan of my lung. And then, the doctor came in and told me what they had found. They did a bronchoscopy where they go down through the trachea and into both lungs. After that was over, Dr. Hines came and told my family that I had stage four lung cancer and it had metastasized to my spine and to my brain and that I didn't have very long to live.

(22:22):

My team of doctors and one of them being Dr. Cervantez in palliative care have just been amazing support. I can't imagine going through this without my monthly meetings with Dr. Cervantez and her nurses. They're excellent. It's not that you're giving up. I think my husband was diagnosed with gastric cancer and he did not have palliative care for the last seven months that he was alive. I'm so sorry that we didn't have it. We should have, but things moved so quickly. But my daughter really encouraged me about this and certainly Dr. Taverna hooked me right up. I'm just eternally grateful for all the things that they do and have done and helped me with through this journey.

LCFAmerica.org Page 7 of 12

Mitch Jelniker (23:28):

That's fantastic. A lot of people don't exactly know what palliative care is and sometimes they can confuse it with hospice care.

Sally Cain (23:36):

Yes.

Mitch Jelniker (23:37):

Tell me why you chose to go this route. What was it about palliative care that appealed to you?

Sally Cain (23:44):

Well, it was explained to me by my medical daughter. She said, "Mom, this is where you go for every other little thing that's bothering you, because Dr. Taverna is just looking at your cancer in the lung and the base of the brain and on the spine. The pulmonologist, Dr. Habib is just looking at the lungs. Dr. Otchere is just concentrating on heart and cancer and muscle mass." And then, I go for IV infusions for Fosamax to strengthen my spine. This palliative care, you go for all the other symptoms and ailments that you have that are not related to any of those other doctors on the team and, oh, it's been wonderful. I can give you a couple of examples.

Diane Mulligan (24:45):

Great.

Sally Cain (24:48):

I had a really bad call during Christmas and my back started hurting. It felt like every time I coughed, it felt like the pain on my side when they first diagnosed me with lung cancer. I didn't tell anybody, but then I had an appointment with the palliative care team, and I told them about this because they noticed that I was coughing quite a bit. I said, "Well, I'm supposed to have a PET scan in about six weeks, a month to six weeks," and they said, "Why would we wait for that? You're worried." And I said, "Yes, I'm worried. I'm terrified." She said, "We're going to go right downstairs and have an X-ray of your lungs. We're going to check if they're inflamed, and maybe this is just muscular," which that's what it was.

(25:48):

That alleviated that fear because I really didn't know... I mean, I didn't know who else to turn to because I know Dr. Taverna is very busy in research four days a week and clinic on Fridays, but this was something that I just kept to myself because I didn't want to go there. I don't know how else to explain it. I didn't want to think that the cancer had spread. And then, there was another time I had real problems with my right ear and I collapsed when I was at physical therapy.

(26:34):

That's another referral that I got from palliative care because I'm a bit wobbly. I've lost about 30 pounds and I've lost a lot of muscle mass. When I went for the evaluation several weeks ago, I lost my equilibrium and collapsed. Palliative care, they've hooked me up with an ENT who will eventually send me to an audiologist, I would think, to check my hearing. But Dr. Cervantez said that possibly when they did the radiation at the base of my brain, that sometimes that messes up the eustachian tube. That made me feel a little better because there's something going on in there. I don't know what it is, a pulsing or a rush or a wave, listening to waves or whatever. These are things that I could talk to palliative care about that I wouldn't know who else to talk to. They've been a great help.

LCFAmerica.org Page 8 of 12

Diane Mulligan (27:42):

It seems to me that what you're talking about is that these people surrounded you with support and gave you the opportunity to talk about the other issues that maybe you wouldn't have talked to your doctor about because you're thinking it's not the same thing that they're interested in or they're too busy, whatever. Is that true? Is that what you would tell a patient?

Sally Cain (27:59):

Yes. Yes, I would. Because some of the meetings with Dr. Taverna are about 30 minutes, but with palliative care, you have an hour up to an hour and a half, sometimes two hours. I had an issue with my nails. Tagrisso, this immunotherapy drug I'm on, apparently does something to your nails. They split all the way down to the quick and it's not... I mean, it's a small price to pay for being on a drug that kills active cancer cells and certainly takes the inflammation away from the main mass. The spot on the base of my brain has gone from four millimeters to two millimeters.

(28:56):

But palliative care has made a difference in my life. I'm just so sorry that my husband didn't have that support, because the team... It's all of them, the oncologists, the palliative care, Dr. Cervantez, Dr. Habib, my pulmonologist, because I had to have another bronchoscopy because they were afraid that I had pneumonitis. And if that was the case, I'd have to get off of Tagrisso, so I worried about that. And then Dr. Otchere has just done a workup on my heart and we visited with the orthopedic because I have a cracked rib also in that same area where they found the original cancer. Dr. Taverna thought maybe they needed to put cement there, and they decided not to because it's not hurting as long as I don't pick up heavy things and make it worse.

(30:03):

I'm pleased that my daughter encouraged me to do palliative care. I just feel like there's hope. Maybe I'll get to see my granddaughter have her fifth birthday party. I've had a lot of support from my daughter and son-in-law and from my church. Father David came to see me in Austin right before I had the bronchoscopy and then got the diagnosis. the support is... It's a lot and you need it. I can't imagine people going through this without support, but the palliative care team has been just miraculous. I mean, because it was a nightmare when they tell you that you have lung cancer. I look at them and go, "I never smoked a cigarette ever in my life. Where did this come from?" So it's environmental.

Mitch Jelniker (31:14):

As we hear from so many people, if you've got lungs, you could get lung cancer. It can happen to anyone at any time. An excellent point, though, is you're living with lung cancer and your knee hurts or you've got an earache or your nails are splitting. Well, your family, while supportive, doesn't really know what to do. You feel bad bothering your oncologist about it. Well, here's where the palliative team comes into play.

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Sally Cain (31:41):
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Comes in. Absolutely.

Mitch Jelniker (31:41):

There may be something to it. If nothing else, it offers a higher quality of life. They can kind of soothe some of those things over. If someone out there is considering palliative care-

LCFAmerica.org Page 9 of 12

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Sally Cain (31:52):
Oh, absolutely.

Mitch Jelniker (31:54):
... you'd say yes [inaudible 00:31:56]?

Sally Cain (31:57):
Oh, wholeheartedly.

Mitch Jelniker (31:58):
Yeah. Their first consultation, what happens? What's the exchange? What do they ask you?
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Sally Cain (32:03):

Well, it's a long consultation. You have to fill out a form of everything that's bothering you physically and mentally. It takes a long time because they're just meeting you for the first time and they're getting to know you. It's not easy. It's not easy talking about it to strangers, I'll say that. I think I probably cried the first time I was there because all of that just brought back my husband's situation and losing him because we were so close. But they handed me a tissue and we moved on. That's what I needed. I needed them to say, "Okay, how do you feel and what's been happening? You've lost weight, you've lost appetite, your fingertips hurt." It's crazy things like that, but are you dealing with financial issues? Do you have support at home? Do you have groups that... I used to belong to an exercise group and I talked to the director.

(33:27):

She came over to see me and she said, "I just don't feel comfortable having you do what you normally did five years ago," and I appreciated that. Now, I'm in physical therapy and the palliative care took care of that and I have 11 sessions coming up. But that first meeting, it's long. Bring your family, have your family members with you so they can hear you. Tell them how you feel because they need to know how you feel. You know how they feel. They're sad and upset because it doesn't make sense because you look healthy but you're not. They need to remember that.

(34:24):

The first session is tough, but after that, you'll get to know all the nurses and Dr. Cervantez and all of the different nurses, and they're wonderful. I just cannot stress the importance of having palliative care, somebody in the palliative care team to help you through this and it's not hospice.

Diane Mulligan (34:50):

No, it's not. I want to ask you about that. I have one question. The first question is how often do you see them and then how do you see it as being very different from hospice?

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Sally Cain (<u>35:02</u>):
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I see them about every six weeks. If I'm having a good spell, maybe a little longer, but I check in with them about that long. I know to get there an hour early so I can find a parking space. I finally figured out exactly where I am and where I'm going in this maze of a building, Hospice, it's completely different. They take over. That's their job. They bring in a bed and they bring in people to bathe you and they bring

LCFAmerica.org Page 10 of 12

in ambulance to take you to your doctor's appointments. They're there to administer medicine or IVs. Bob was on IVs a lot and it's not the same.

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(36:03):
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Diane Mulligan (38:03):

You're not talking to a therapist, you're talking to a nurse that comes in to take care of you physically. It's not a mental... I mean, when you're on heavy narcotics for pain, it's supportive for the person who's taking care of... It was supportive for me taking care of my husband that someone was there administering that medicine, but palliative care is not that way. They all have smiles on their face and they're, "How are we doing today?" It's just a breath of fresh air. I think that says a lot through good times and bad times. I mean, you need that uplifting support. You're a person, too. I mean, you're not just a cancer victim, you're Sally.

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Diane Mulligan (37:06):
Living with lung cancer, which is a wonderful thing to be living with lung cancer.
Sally Cain (37:10):
Yes. My birthday is this month on the 17th. I'll be 70.
Diane Mulligan (37:15):
Happy birthday.
Sally Cain (37:17):
Yes. Thank you.
Mitch Jelniker (37:18):
Great advice for someone out there contemplating and just trying to figure out if palliative care is
something for them.
Sally Cain (37:25):
Right. Just have the best team care as you possibly can, because that makes you feel like there's hope
and that's what you want is hope to go on the next day. But thank you for giving me this opportunity. I
appreciate it and I just hope and pray that anybody who has lung cancer, that their journey is as positive
as mine has been due to palliative care.
Mitch Jelniker (37:59):
Good job.
Diane Mulligan (37:59):
That's lovely. Fantastic job.
Mitch Jelniker (38:02):
Yes.
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LCFAmerica.org Page 11 of 12

What struck me most during our conversations was that only about 1% of lung cancer patients are taking advantage of palliative care. We learned it can make such a difference during their lung cancer journey.

Mitch Jelniker (38:16):

Absolutely. Most insurance plans cover it and it is designed to provide comfort and relief for the patient. For many living with lung cancer, palliative care is really worthy of exploring.

Diane Mulligan (38:28):

It really is. If you are enjoying our Hope With Answers: Living With Lung Cancer Podcast, I hope you'll consider making a donation to help LCFA produce more of these types of resources.

Mitch Jelniker (38:39):

Remember, this podcast is a resource for patients or anyone seeking answers, seeking hope, and access to updated treatment information, scientific investigation, and information about clinical trials.

Diane Mulligan (38:51):

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LCFAmerica.org Page 12 of 12