

EPISODE 56: NEUROENDOCRINE CANCER STRAIGHT TALK (Part 2)
Dr. Diane Reidy-Lagunes

[00:00:00] **Lisa Yen:** Welcome to the Neuroendocrine Cancer Foundation Podcast. I'm your host, Lisa Yen. I'm the Director of Programs and Outreach, as well as a caregiver and advocate for my husband, who is living with neuroendocrine cancer. In each podcast episode, we talk to an expert who answers your top 10 questions. This podcast is for educational purposes only and does not constitute medical advice. Please discuss your questions and concerns with your physician.

[00:00:31] **Lisa Yen:** I'm really excited to introduce our guest for today, someone that many of you may already recognize and appreciate, Dr. Diane Reidy-Lagunes. Dr. Reidy joined Duke in 2025 after many years at Memorial Sloan Kettering Cancer Center, where she held numerous leadership roles. She is now the Chief of the Division of Medical Oncology at Duke University and has been recognized for her clinical excellence and commitment to teaching and mentorship across her many decades of service in the neuroendocrine and cancer field.

[00:01:02] **Lisa Yen:** As you know, she specializes in neuroendocrine and adrenal tumors, and she's actively involved in national efforts to advance care, including work with the National Cancer Institute and NCCN guidelines. Her work has consistently focused on improving care coordination and supporting patients and families navigating cancer, something that closely aligns with the conversations we aim to bring to this community.

[00:01:24] **Lisa Yen:** She's also the creator and host of Memorial Sloan Kettering's Cancer Center's award-winning podcast, "Cancer Street Talk," where she brings honest, evidence-based conversations directly to patients and caregivers, which is exactly why we are so glad to have her here today. Dr. Reidy previously joined us for episode 42, which was incredibly well-received by our community, so we're really glad to have her back for this conversation.

[00:01:48] **Lisa Yen:** Dr. Reidy, thank you so much for being here again.

[00:01:51] **Dr Diane Reidy:** Thank you so much for having me. It's really an honor to be here, and I just love that I'm invited back again. I've been at Duke for a year now, which is really exciting, and having a really great time. I miss my patients in MSK and in New York and New Jersey, but it's certainly where I belong, and I'm thrilled to have such amazing faculty, colleagues, and patients in North Carolina.

[00:02:12] **Dr Diane Reidy:** It's so wonderful to have you, and we know that your patients in the New York area miss you, and those in the Duke area are really excited to have you there. So, Dr. Reidy, would you also share a fun fact about yourself? I know you have many fun facts. So, fun fact is that I am here in North Carolina. I sort of joke around that my son is also a freshman here at Duke, so I kind of followed him to college unexpectedly.

[00:02:36] **Dr Diane Reidy:** He got accepted before I took the job, so it's really nice. But my daughter is still in high school, so I actually commute back and forth between North Carolina and New York for one more year until she finishes. So it's great that I get best of both worlds, but it's a little bit crazy sometimes. Yeah, that sounds crazy.

[00:02:54] **Lisa Yen:** It is fun that Duke is a family affair right now.

[00:02:58] **Dr Diane Reidy:** Exactly, yeah. We're Blue Devils. We bleed blue in my family.

[00:03:01] **Lisa Yen:** You bleed blue. Well, if you don't mind, we can just jump into some of the questions. I know that there's a lot that we could ask you, so we narrowed it down to some just general questions, if that's okay?

[00:03:13] **Dr Diane Reidy:** Absolutely. I am ready.

[00:03:14] **Lisa Yen:** Okay. So, you know, one thing that's been coming up a lot, we're hearing more and more about the rise in cancer rate, especially in young adults, including neuroendocrine cancer. What are you seeing, and what should patients understand about this trend?

[00:03:30] **Dr Diane Reidy:** Yeah, Lisa, that is real. The cancer in younger adults is definitely rising, and we know it's not from genetics passed down from mom and dad, meaning that it's probably something in the environment. We really don't know why. Actually, here at Duke, we have a really big program that's testing whether microplastics, you know, something that we're all potentially worried about, might be culpable. But there are probably not one smoking gun, but probably multiple things that are causing that. They call it a birth cohort effect, where around the nineteen fifties and sixties, we start to see this trend rising, uh, suggesting that maybe as early as in utero we might be exposed to things that could be increasing that risk.

[00:04:14] **Dr Diane Reidy:** There was a fascinating recent study that was just published in Nature Medicine, and what they did is they actually took the NCI Genome Atlas of a lot of

different data on different types of what we call signatures in tumors. So they looked for patterns that we know might be associated with different types of chemicals and exposures.

[00:04:33] **Dr Diane Reidy:** And they actually found that a certain type of herbicide called **Picloram** was actually-- or sort of the signature in that pesticide, which is a known carcinogen, had been seen in patients with early onset colon cancer. So really a kind of fascinating type of science that we're doing for the first time to actually be able to look at what we call genetic footprint and ask the question: Could we actually identify that needle in the haystack?

[00:04:59] **Dr Diane Reidy:** Could we start to think about what chemicals we're exposed to? Could they potentially be at least in part responsible? So, we call that causation. Really, you know, it's correlated. Whether that's actually the reason or not is unknown. But I do think with this technology that we're now able to have, we're gonna be learning more about what types of environmental exposures might be playing a role here, so that really importantly, we can prevent the cancer from starting in the first place.

[00:05:28] **Dr Diane Reidy:** Now, that's colon cancer. It's different than neuroendocrine malignancies. But what is it that's causing the damage in these cells that are causing the cancer to occur much earlier in life? We don't know. But there's thankfully a lot of investigation into that very question.

[00:05:43] **Lisa Yen:** Yeah, it's very interesting that you brought that up, that it might be something environmental, and I've recently heard people say to me, "Hey, I just learned that someone else from my high school," so two people in this small town- [Yeah] -or three people in this small town have the same neuroendocrine cancer. Could it be environmental?

[00:05:59] **Dr Diane Reidy:** Exactly. And I think we know that there are certain, what we call gene mutations or damage to the DNA that are more associated with neuroendocrine cancers. The good news is those mutations seem to-- I'd like to use the analogy of a bingo card.

[00:06:15] **Dr Diane Reidy:** It's the accumulation of a couple of mutations, and then unfortunately, bingo, you get it when you have more than one, and usually four or five, and sometimes more that can cause that cancer cell to turn on. In neuroendocrine, there's something called tumor suppressor genes, and what that means in English is thankfully those genes when damaged typically would be turning the cancer on, but not as aggressively as other mutations that you see in other types of cancer.

[00:06:40] **Dr Diane Reidy:** So the good news is that might be at least in part the reason why our tumor tends to grow a little slower than other cancers. The not so good news is that we have not been able yet to really define our therapies based on the gene mutations that our patients with neuroendocrine have. So we don't have those so-called, quote, "**targeted treatments**" that are going after the genes like other cancers have, and that's probably in part because of the mutations that are damaged.

[00:07:05] **Lisa Yen:** Yeah. That's the kind of bingo we don't wanna get.

[00:07:08] **Dr Diane Reidy:** Yeah. It's like usually it's a, it's a fun game. It makes me sad to, to even, you know, sort of correlate it with that. Yeah. But it's that, you know, each piece on the bingo card can often take years to develop, and so that's why typically cancer is a disease of aging, that it usually occurs over many decades.

[00:07:24] **Dr Diane Reidy:** But it is scary that kinda combination is happening much earlier to turn that cancer cell on.

[00:07:30] **Lisa Yen:** That's a really helpful overview and understanding- [Yeah] ... of why there are more and more cancers. This is really of interest to the general public and population, of course. Thank you for that.

[00:07:41] **Lisa Yen:** Let's talk a little bit about misdiagnosis, and I know this comes up a lot, and you've done some work in this as well.

[00:07:48] **Lisa Yen:** How does gender influence who gets taken seriously and who gets missed?

[00:07:52] **Dr Diane Reidy:** Yeah. It's such a huge issue, particularly in our disease with neuroendocrine tumors, because the symptoms are often vague. Our patients don't necessarily have weight loss, which is a typical thing of cancer, or, you know, severe pain, which is a typical sign of cancer that a doctor would be worried about, but rather sometimes it's flushing, sometimes it's diarrhea, sometimes it's just fatigue or abdominal discomforts, and people sort of brush it off as, "Well, that must be menopause," or, "That must be anxiety," or, "That must be irritable bowel syndrome," because often those symptoms can be attributed to those real problems also.

[00:08:28] **Dr Diane Reidy:** But it can delay our diagnosis, which is incredibly unsettling, 'cause it's like our patients are saying, you know, they're screaming for so long like, "I'm not well," and nobody's listening, and I don't, you know, I think people don't wanna listen. I think that they just miss it, you know? And I think that's why trying our best as we can to advocate for recognizing our disease and, you know, listening to those zebras, that kind of thing, is really, really important. Because we're not as rare as people say we are, right? There are many, many people living with this disease, and so we need to be able to hopefully get that diagnosis earlier so we can prevent symptoms and obviously improve lives.

[00:09:04] **Lisa Yen:** Yeah. It's so hard because those symptoms are vague and thank you for acknowledging that struggle to just be acknowledged, even though it is disappointing and frustrating for those who are living it.

[00:09:16] **Lisa Yen:** And the other part of the struggle is that a lot of times after diagnosis, and I know that at least conversations from family members, many patients will ask or family members will ask, "What did I do to cause this?" So, if you could be really honest, is there something that patients did to cause it? And if yes or no, well, how do you address that?

[00:09:37] **Dr Diane Reidy:** All right. So the first thing I tell a patient and their loved ones when they come to talk to me after I get a, you know, understanding of their history and I

examine them and we're talking about the disease is every single time is probably if, if patients are listening, I will say there is nothing in the world you did or didn't do to get this disease.

[00:09:56] **Dr Diane Reidy:** And I mean that. I'm not trying to make people feel better. It is we truly do not understand what in the environment can cause neuroendocrine malignancies. It is not associated with the traditional exposures that we would worry about. Obesity, alcohol, smoking, illicit drug use, you know, things that we know aren't the best for us really have no correlation with our disease.

[00:10:18] **Dr Diane Reidy:** And I think importantly, like we talked about before, we don't know what causes those damage over time, but we know that it's not something that the patient could have prevented. And really, really importantly, like we just discussed, because patients don't have the classic symptoms, they often will feel badly that they brushed it off and they should have said something earlier.

[00:10:39] **Dr Diane Reidy:** But again, we all have abdominal discomforts or a little diarrhea from time to time, and that is often benign and not thinking about this diagnosis, especially when you're not a clinician and you're not even understanding what this cancer is. You know, so many of my patients have never even heard the word neuroendocrine before this diagnosis.

[00:10:57] **Dr Diane Reidy:** So how would you know to recognize symptoms? So, I think that I find it really incredibly important to address that, and also the loved ones. There are many loved ones who feel like, you know, "I should have noticed," you know, "I knew that he was going to the bathroom a lot, and yet I didn't say anything," or, "Maybe I should have been pushing her to go to the physician earlier," or something like that.

[00:11:20] **Dr Diane Reidy:** I will say in a, in a little bit of an unsettling way, most times when we have the symptoms, it has already spread. In fact, it's the metastasis themselves that often cause the diarrhea, the flushing, and the symptoms of abdominal discomfort. So that's also very, very unsettling that when it's in its primary place, in its localized place, when it's most silent is when it's doing the most damage by starting to spread.

[00:11:43] **Dr Diane Reidy:** And that is, again, very unsettling, but a reality of where we are, that when those symptoms developed, it was probably metastatic. And so, I don't know if that helps, but sometimes it can help our patients to know that they didn't miss a window per se, because often, unfortunately, the window is when you don't have the symptoms.

[00:12:01] **Lisa Yen:** Yeah, it's tough. It's a really tough thing, and not all of the tumors cause symptoms as well. I know that, I mean, myself as a medical professional, I'm a nurse practitioner, and I missed it. Yeah. I felt like I missed it. My husband had widely metastatic disease by the time he was diagnosed, had never been in the hospital and never had any medical issues.

[00:12:20] **Lisa Yen:** And really hearing that over and over again from the doctors and processing it in my own journey- [Right] ... was important for me to go through and be like, "Okay, there's nothing I missed."

[00:12:31] **Dr Diane Reidy:** Absolutely.

[00:12:32] **Lisa Yen:** Yeah. It's a tough thing, for sure. Another challenging part of it, perhaps the most challenging part, is living with uncertainty.

[00:12:41] **Lisa Yen:** And patients and their loved ones describe it as living on edge, waiting for the other shoe to drop, or wondering if they're doing something wrong or missing something along the way or should be doing something. What is your straight talk for them here?

[00:12:56] **Dr Diane Reidy:** And this is also really tricky, right? Because we can go both ways.

[00:12:59] **Dr Diane Reidy:** Sometimes patients have a higher grade tumor that can behave more aggressively and is starting to grow, and we have to have a conversation there on what that really means with transparency and honesty and hope, because we never really know how long patients have. And then some patients can get an incidental diagnosis and they say, "I just want it out," and I want it out too, but the pattern of disease doesn't allow us to make it go away.

[00:13:24] **Dr Diane Reidy:** And so, you're bringing up one of the most, I think, challenging parts of our diagnosis, which is how do we get our minds wrapped around this diagnosis and somehow deal with the anxiety and that uncertainty? I don't have an answer to it, but I will say that particularly in patients that have the lower grade, more indolent treatments, the, the first scan is usually the hardest, right?

[00:13:45] **Dr Diane Reidy:** I say to patients, "It would be exceedingly unlikely that it grows, but let's watch. And if, God forbid, it grows, we'll get on with multiple treatments that we now have, thank heavens." I say half-jokingly to my patients, "You gotta run faster than the bear," and we are, you know? And often running faster than the bear is not using the treatments and options that we have in the bag because we want to save them.

[00:14:05] **Dr Diane Reidy:** So how do we think about this disease as something that's, um, part of us? And for many, many patients, it can absolutely be considered like a chronic disease. I can't cure diabetes, you know, in young children, but they can live many, many years and decades, and that's still possible with our disease too. So learning to sort of understand the pattern of disease and the, what I say, the, the behavior of that disease can be very helpful for a patient and their loved ones to understand.

[00:14:34] **Dr Diane Reidy:** And so the first couple of scans, if they're stable, that's a lot easier. And the patients will say, "Okay, I kind of put it behind me." But for patients where very, very often it may grow a little bit, but it's like two millimeters in six months or maybe a couple more millimeters in six months, and what does that mean, and when do we need to pull the trigger?

[00:14:50] **Dr Diane Reidy:** It's hard, and I want to acknowledge that it's hard. I don't want to pretend that it's not. My mantra is the most important thing I can do for any one of my

patients is to get more time. Time is our most precious gift for all of us. I always, every morning I get up and I say a little prayer that I can get more time for my patients, but for all of us.

[00:15:08] **Dr Diane Reidy:** But I do think it's critically important that that time is Precious and high quality. So many of my patients are like, "I have to get the surgery. I have to do this treatment. How can I just let it sit and not do anything?" But when I really try to articulate the why, why I'm saying we can wait, because the biology of the tumor allows us to wait now, and that's a beautiful thing, patients start to understand.

[00:15:32] **Dr Diane Reidy:** But when I say, "No, it's time to, to do treatment," they also understand. So I do think that, importantly, you've asked before, which I think is so smart on, on the partnership of, of understanding. And I do think that I wanna make sure my patients know that they're empowered to help me make the right decisions, but I also believe it's my responsibility to give my best recommendation.

[00:15:52] **Dr Diane Reidy:** 'Cause sometimes patients wanna know the, the different side effects, and there may be two options that we can decide together. But what I don't think is fair is telling patients, "Well, you decide." You know, you're not an expert in neuroendocrine. You're a patient. And it is my responsibility to give my best opinion on what I think should be done and why. The why is super important.

[00:16:11] **Lisa Yen:** So beautifully said. I love that you say that thing about running faster than the bear. And with that partnership, it sounds like, well, number one, some people aren't runners and may have to learn how to run, and then you're learning the pacing. Like, do I run fast? Do I run slow? And learning to pace your running based on the biology.

[00:16:29] **Dr Diane Reidy:** That's beautifully said, yeah. And the good news is, like, I couldn't say this five years ago, but as that's happening, technology just keeps advancing, and we do keep getting new therapies, thankfully. And I think that's the hope and excitement around, you know, whether it's Cabozantinib or Lutathera earlier on or now we have, for higher grade tumors, the possibility of what we call antibody drug conjugates for those potentially more aggressive cancers.

[00:16:55] **Dr Diane Reidy:** So I do think that we're in an era and an opportunity for more clinical trials and more, uh, therapies, hopefully sooner rather than later. You know, it took us a decade to get a lot of therapies, and then all of a sudden we got a lot of treatments, which is great.

[00:17:09] **Lisa Yen:** Yeah. Those of us who have been around for more than 10 years, like my husband was diagnosed more than 11 years ago, we can see this explosion. For those who are just diagnosed since COVID, it's harder to see when you're in it.

[00:17:21] **Dr Diane Reidy:** That's exactly right.

[00:17:22] **Lisa Yen:** Yeah. They don't see how it's changed so quickly- [Right]… and how hopeful that is for all of us.

[00:17:27] **Dr Diane Reidy:** That's right.

[00:17:27] **Lisa Yen:** That is hopeful. Thank you for that. You know, you touched on this word cure, and I think it's important to talk about. What does that word mean in neuroendocrine cancer?

[00:17:37] **Dr Diane Reidy:** That is a great question. You know, I think we like to always say that we won't stop until we find the cure, right? I don't like that my patients have to live with a chronic disease. I wish I could make it go away, too. I think we all are blessed that that does give us the gift to understand that every day is a gift and that many of our patients can live for many years and often decades, thank heavens, depending on the type of neuroendocrine that they [00:18:00] have, but some can't.

[00:18:01] **Dr Diane Reidy:** And so I think cure traditionally is you have no evidence of disease for at least 10 years or more is when we think you're cured. But the reality is our disease, like breast cancer, can pop up and surprise ourselves 25 years later, right? So we think that there are no microscopic cells left when we can't find it for more than 10 years.

[00:18:21] **Dr Diane Reidy:** And the NCCN guidelines say you should follow for 10 years, but are we truly cured? It's hard to say that for any type of cancer, but I think after 10 years it would be exceedingly unlikely that these diseases would come back for most of our patients.

[00:18:36] **Lisa Yen:** So it's really different from other cancers, and no evidence of disease is what we're aiming for.

[00:18:42] **Dr Diane Reidy:** That's right.

[00:18:42] **Lisa Yen:** So we often hear about miracle cures, and patients are told about alternative treatments online from ivermectin to coffee enemas.

[00:18:54] **Dr Diane Reidy:** Right.

[00:18:54] **Lisa Yen:** What's real, what's not, and what's your honest guidance on all of this?

[00:18:58] **Dr Diane Reidy:** Yeah, so this is actually the] reason why I started my podcast, The Cancer Straight Talk, when I was at MSK, because patients are being flooded with alternative therapies, and I get it. Like, I would too if I had a devastating diagnosis, that you want to find anything that might contribute to a better outcome. The problem is that there's so much out there and people have so much conviction without any data whatsoever to drive that. And ivermectin and coffee enemas are a beautiful example of that.

[00:19:27] **Dr Diane Reidy:** And coffee enemas can be drastically dangerous, particularly in our patients that may have hormone-secreting tumors where diarrhea is an issue. So I would say ivermectin, for many reasons, became very political during COVID, and in preclinical models in the lab, there was evidence that ivermectin might kill cancer cells.

[00:19:47] **Dr Diane Reidy:** We have killed cancer cells in the lab gazillions of times, so we've cured cancer multiple times in the laboratory, but that's not in us. There are studies, there's a study with triple-negative breast cancer where they're testing ivermectin with pembrolizumab. I mean, I think people think, "Oh, no one wants to test it," you know. Like, drug pharmaceutical companies don't want us to know. And again, I would do anything to help any of my patients. You know, I wish marijuana cured cancer. It would make my job very easy. And, and ivermectin is pretty well-tolerated as comparison to some other therapies that we have, but there's just no data whatsoever that those things can be helpful.

[00:20:22] **Dr Diane Reidy:** MSK has an integrative medicine website for people that really do want to explore other possibilities. That's a place that's a nice resource to check it out. I think things like curcumin and ginseng and maybe they could help. They probably don't harm. I do think that there's things in Eastern medicine that we probably can learn from, it's just they've never really been studied in a rigorous way, so we just don't know.

[00:20:45] **Dr Diane Reidy:** But I think that there's a misunderstanding that doctors don't want to try these things. It's not that we don't wanna try, it's just that we're so data-driven and we care so much about the safety of patients that we say, "Don't do it," because we just don't know if it could be harmful, [00:21:00] and that's what we worry about the most.

[00:21:02] **Lisa Yen:** Why is it that things could show up in the lab and, you know, cure cancer, and then it- [Yeah] ... can't be replicated with people?

[00:21:08] **Dr Diane Reidy:** Such a great question. It has to do with what we call the pharmacogenetics. So what that means is how does the drug actually get to where it needs to get to? So you can imagine if you take a pill, for example, it first goes through our GI tract.

[00:21:23] **Dr Diane Reidy:** It has to get absorbed. It usually, almost 99% of the time, it first goes to the liver. It gets broken down in the liver, and then it has to try to get to the cancer cells, which are often inside organs, in the liver, in the lung, maybe the lymph nodes. So there's a lot there that we have to sort of assume that it can do that, and many drugs just can't do that. So once it's in the human body, it doesn't work the same way as it does, like, in a test tube.

[00:21:49] **Lisa Yen:** And that's too bad. So I know you mentioned that some of these curcumin, turmeric, some of the things may be able to be used. Now, is there a certain timeframe that perhaps these complementary treatments can be used? Like, some people think that they want to use it when they're in the midst of treatment, like say getting chemotherapy or PRRT to reduce inflammation. What is your advice when people are in active treatment?

[00:22:15] **Dr Diane Reidy:** That is a great question. I strongly advise patients to try to think about integrative therapies after treatments, and the reason is because, again, we don't know if it could potentially interact with the treatments.

[00:22:30] **Dr Diane Reidy:** So for example, vitamins. You know, a lot of people like high-dose vitamin C and other things. I don't think that that's harmful to take in and of itself, but

most of the therapies that we use to kill cancer are by nature oxidants. So that means they actually go and they try to kill cancers by being this type of oxidant pathway.

[00:22:50] **Dr Diane Reidy:** Vitamin C is an antioxidant, and there are a couple of trials that actually show vitamin therapies plus chemotherapy actually shortens the outcome and the overall survival because it probably does interact with the ability of the treatment to work effectively. So again, I would say it's just not worth it to be on those types of therapies when you're on active treatment.

[00:23:11] **Dr Diane Reidy:** Once you're done with Lutathera, for example, or you're taking a treatment holiday, then I think you should certainly explore other opportunities. There are doctors out there that say, "Oh, no, no, I work in both ways, and I understand what can be interacted or not." I just have to be honest, I don't know how they would know that because there's no studies to prove it.

[00:23:27] **Dr Diane Reidy:** So you would really need to do clinical trials to show that some sort of integrated medicine plus Lutathera, for example, could be helpful, and there's just none out there right now.

[00:23:36] **Lisa Yen:** Thanks for your honest guidance. I think that we definitely don't want to be countering the effects of the treatment that we're on.

[00:23:44] **Lisa Yen:** Yeah. Now, with this uncertainty, without knowing that there can be a cure, how do you think patients can go about thinking about big life decisions after a diagnosis, like getting married, having children, continuing to work, especially if they have known metastatic disease?

[00:24:03] **Dr Diane Reidy:** Yeah, that is a really important question, and I think a very personal one.

[00:24:09] **Dr Diane Reidy:** But I do want folks to understand that it is their choice. I have a couple of patients now who have had stage four incurable neuroendocrine tumors that have gone on to start families, both men and women. So women with stage four neuroendocrine that have had children. Thankfully, our tumors don't have estrogen and progesterone receptors that we're aware of that can somehow make the cancer behave more aggressively.

[00:24:34] **Dr Diane Reidy:** So at least in those patients, small numbers, but have not shown that somehow that could cause the cancer to wake up. I think that we have to be very thoughtful. I do think for anyone of childbearing years, both men and women, at the time of diagnosis, to really try to advocate to themselves to talk about planning and whether egg preservation or sperm preservation should be considered before any treatment, because they may not know right now if they want that decision, but having that option is critically important because there's certainly some therapies that could potentially affect fertility, and we don't want to withhold them because you didn't do it if we really need them.

[00:25:14] **Dr Diane Reidy:** So, you know, big life decisions like getting married, having children, continuing to work, they are not off the table. In fact, they're very much on. And so

again, it's very important to talk to your doctors about fertility, to see a fertility specialist before you start the treatment, even ideally before you start octreotide or lanreotide.

[00:25:32] **Dr Diane Reidy:** We believe it's okay during pregnancy, but the fertility specialists really want you off all therapies if you're going to try to do egg preservation and, and sperm preservation. So but I think that not everyone has the same goals, and sometimes patients do have more aggressive cancers that require treatment more urgently.

[00:25:51] **Dr Diane Reidy:** And then I say, "We'll figure it out later on if we need to." But I love this question so much 'cause I do think I find it ethically a little bit challenging to discuss these questions with other types of cancers that I take care of. But with neuroendocrine, I, I absolutely should have the conversations, and I will for women and men of childbearing age.

[00:26:10] **Lisa Yen:** And these are the questions people have, and they don't know- [Right] ... exactly how to ask. The thing about working that comes up is if I know that I'm only gonna live a couple years, should I just quit my job and travel the world versus, well, if I quit my job and then I live 10 years, then I'm out of money.

[00:26:26] **Dr Diane Reidy:** That's right, and we define ourselves so much by the work that we do, and the fulfillment that we get is often through that work. And so, I think these are really personal decisions. What I try to convey to my patients is check in every once in a while with your doctor. So, for example, you may have stable disease. It's helpful to touch base with your doc. You know, you might be thinking you're fine and two, three years in, and you know, just sort of say, "How do you think I'm doing? And anything change?" If you're not sure. Or if things do change, if the cancer does start to grow, are you worried about anything, and does that change my overall prognosis, and should I be thinking differently about measuring my life in many years as opposed to less than many years, or whatever that means?

[00:27:08] **Dr Diane Reidy:** You know, doctors don't know for sure, but we can give our best guess on what that means. Because what I think is one of the most tragic moments is seeing a patient in the hospital that didn't understand that their time was so much more limited, and they would have done things differently. And you know, we still have a cancer that we have to deal with, right?

[00:27:29] **Dr Diane Reidy:** And sometimes it allows us the gift of time without having to worry about it, and sometimes it can wake up, just like other chronic diseases. I mean, diabetes is life-threatening, right? Heart disease is life-threatening, and many of those patients will have troubles and often have to get hospitalized just like our patients.

[00:27:44] **Dr Diane Reidy:** And so, getting an understanding of, "Okay, something just changed in my disease. What does that mean?" Again, none of us know for sure what it means, but it may change the natural history, and I think that's important to have a, a conversation with your doctor to ask.

[00:27:58] **Lisa Yen:** Yeah, that continued honesty and kinda recalibrating.

[00:28:01] **Dr Diane Reidy:** That's right.

[00:28:02] **Lisa Yen:** So, I know you've touched on this, that whole topic of shared decision-making, and we hear this in the patient world all the time. So, in plain language, what does that really mean, and how should patients approach these shared decision-making decisions?

[00:28:17] **Dr Diane Reidy:** The idea is that it's really about a partnership. And I think that's why it's so important to pick a clinician, whether it's an APP nowadays or an oncologist physician, that understands the, the data, the options, the risks, and brings that to the patient and their loved ones to talk about what's important to them, what their goal is and their values. You know, I think it's rarely a one-size-fits-all in neuroendocrine malignancies, and often, thankfully, we do have a couple of different treatment options.

[00:28:44] **Dr Diane Reidy:** Again, as I alluded to before, I think decision-making is, is really important that we're aligning with the plan and the patient understands, and it's aligned with the patient's goals in life. But I also think that I want my patients to ask the right questions or that I'm as honest as possible so that they don't know what they don't know, that I'm, I'm providing the best available data and ideally the best available recommendation, 'cause that's part of my job. You know, you're coming to me for my recommendation and advice. So, I want patients to understand the why, but if there's more than one option, I will explain it so that that shared decision-making could be true.

[00:29:19] **Lisa Yen:** Really having that open conversation. So, people come to you for second opinions, and they also may come to you first and want a second opinion. And in general, you know, second opinions can feel really uncomfortable. Could you honestly say, I guess, how you feel about it? And should patients get second opinions? Who should they go to, or how do they handle it? And then how do they handle if their doctors disagree?

[00:29:45] **Dr Diane Reidy:** So second opinions should never feel uncomfortable. They 1000% should get a second opinion. They should be standard, especially with a disease like neuroendocrine malignancies. Our disease is relatively rare. It is really heterogeneous, meaning some patients have one pattern of behavior and some could be very, very different, and I think that's critically important to understand. And sometimes those nuances are not understood by a general oncologist. So I really encourage patients to get a second opinion in a center of excellence where there are physicians and centers that specialize in this uncommon disease. We get one shot at a good plan, and we don't want to say, "Okay, it's time to come. Now I'm a couple years in and I'm not well." That's not the time. The time is to come early on to get a good plan, and hopefully that plan is a very, very long one. But I think I would really encourage our patients to do that. And I think where you get your care first matters, so it's very hard to make up for mistakes.

[00:30:47] **Dr Diane Reidy:** I'm not saying that, you know, those in the community-- I always say they're smarter than I am 'cause they have so many different diseases that they have to take care of. I only have one really. I mean, I take care of a lot of GI cancers, but neuroendocrine is my disease, and so that's what I do all day long. It's the outlier book. You just want the folks that just day in and day out see the disease, ask questions about the disease, do the studies about the disease, allow you to participate in those trials, which we think are hopefully gonna change standard of care. It matters.

[00:31:15] **Dr Diane Reidy:** I don't think you need three, four, or five opinions. You know, that can get a little confusing. And I will say even my own colleagues that I care a lot about in the neuroendocrine world, often there is a lot of conviction on what you have to do or don't have to do. I think this goes back to that shared decision-making. I believe I have a responsibility to explain why I wanna do something and then do it. But I don't think it's helpful to anyone to say, "I need to remove 60% of the tumors," without understanding why.

[00:31:43] **Lisa Yen:** So, second opinions are encouraged, and it can be really hard then for the patient then to have differing opinions. Som if they do understand the why but they're really opposite recommendations, how do you guide patients in making that decision?

[00:31:59] **Dr Diane Reidy:** Sometimes, again, it, it's the doctor that sometimes has a, a better delivery that wins, which is... That should never be the case, right? So, I don't have an answer to that except that for my own personal practice, I try my best to explain why I'm offering that recommendation I would say for this disease, there's often many different options. Not always. Sometimes there's only one option. I know it's hard, but to ask the doctor that feels so strongly, "Well, why do you feel so strongly, and why don't you think there's other opinions?" I also think that there is a responsibility for me as a doc to talk to that doctor, and I have done that. Patients that may be on here know I have no problem calling a doctor and saying, "I disagree with that, but this is why." You know? I always tell people what I think is better. "I don't think surgery's great right now because I wanna do chemo first, you know, and this is why I wanna do chemo first," something like that to explain it.

[00:32:49] **Dr Diane Reidy:** This idea that somehow our patient gets caught in the middle of two different doctors' opinions is just not good medicine, and it's not okay. I know it's hard for a patient to do, but I would ask both of them, "Can you please coordinate and communicate together so that I can get the right treatment?"

[00:33:04] **Lisa Yen:** I'm glad we get to ask you the hard questions. Thank you so much for being willing to answer them. We know that people travel long distances to see you in Manhattan, and now in Durham, North Carolina, at Duke. They're gearing up, driving long distances or flying in. What's your most practical advice for getting the most out of their medical appointments and setting realistic expectations?

[00:33:27] **Dr Diane Reidy:** I think this is a great question. You know, medical appointments are short, and so the key really is, as best as you can, to be prepared and focused.

[00:33:35] **Dr Diane Reidy:** And what I mean by that is be honest to share your symptoms. So many patients are like, "I'm fine," and then their wife is like, "What do you mean you're fine?" You know? Or their husband is like, "That's not true." You know, and so people, they don't wanna complain, and I get it, but we really wanna know what's bothering you. It's incredibly helpful for us to know that so we can take the best care. If you have a question, as hard as it is sometimes, I think it's to be open and transparent about it. And I think the goal is a plan. You know? Everybody wants a plan and to understand what we're doing and why. So, you owe it to yourself to walk away from that appointment knowing what the plan is. But being as open and honest about what might be bothering you is really important. Not only physical symptoms but sometimes the emotional symptoms, you know? Like, it's a big

terrifying diagnosis to get. And so, you know, we always say we take care of the whole patient.

[00:34:27] **Dr Diane Reidy:** I also think in terms of expectations, it's important to understand not every visit will end with a new treatment, thankfully, which is a good thing. Sometimes it's a warm hug, things are stable, and we're just riding the wave, which is wonderful. But sometimes it's deciding what not to do, that we don't have to change things, and, and that's good. That's progress. That's what we want. So that's a gift if we don't have to change things.

[00:34:49] **Dr Diane Reidy:** And, you know, I think all of us recognize scanxiety. It's real. I even have a little of it when I'm scrolling through the images and I'm looking at certain patients' scans. So, trying to overcome that can be hard. But I think we're trying our best to make it as easy as we can for patients. But if you can come prepared with honesty of what things that might be bothering you, a question that you feel is really important that you want to make sure you have, and walking away with a plan that you understand is gonna be really important.

[00:35:15] **Lisa Yen:** Honesty and clarity and really taking care of the whole person.

[00:35:19] **Dr Diane Reidy:** That's right.

[00:35:20] **Lisa Yen:** So lastly, everyone's talking about AI. What is the hype and what is real, and how might it actually impact neuroendocrine cancer care and research?

[00:35:30] **Dr Diane Reidy:** So AI is real. Will it cure cancer? I don't think it's gonna cure cancer. I mean, I do think in today's world, what is real and practical is that AI is getting very good at pattern recognition. So what do I mean by that? So many of us went through, "Well, there's this little lung nodule. I don't really know what it is, but we have to follow it up in 12 weeks' time," or, "There's a little thing in the liver that may be something, and we have to follow it up with 12 weeks' time." And that's a lot for someone. I think AI is gonna tell us, "You don't have to follow it up, it's nothing," or, "Yeah, you do." I actually think AI will help us get to that understanding of radiology imaging in a better way that we have today. Not now, but soon.

[00:36:12] **Dr Diane Reidy:** Pathology as well. Our disease is tricky, and you want pathologists that are excellent in neuroendocrine to review those. I think with pattern recognition and pathology will be a lot easier to confirm the Ki67s and understand what type of cancer this is, the grade, the well-differentiated versus poorly differentiated. Sometimes we always get confused on what we call small cell or non-small cell. So, I think the pattern recognition on pathology will also be a lot better.

[00:36:37] **Dr Diane Reidy:** And I'm hoping that the impact on research is going to be real. So how do we combine all the data? And one question that I think many of us in the neuroendocrine world is fascinated by is, how do we really sequentially put together all these treatments for our patient in front of us? So can we use AI and big data to know this is a patient that should start with capecitabine and temodar, or this is a patient that should start up front with Lutathera? I'm hoping that with big data and with AI, we'll be able to at least think about the right sequencing of treatment, which we haven't really gotten to be able to answer

in today's world. But today we sort of say we want our patients to get all of them, and that it probably doesn't matter which goes in what order. But it may. It may matter maybe just for quality of life, but that matters.

So, I do think that the future of AI is really allowing us to be a tool, but probably not be the decision-maker. I do think that we still need clinicians for the judgment, for asking the patient about their values, for holding their hand, you know, when we go through these really important, difficult, challenging moments and being as honest as possible about where we are, why we're there, and how we can do our best. Because I think ultimately, this is a cancer that we're all trying to treat, and it gives us opportunity that our patients can live much longer than other diseases. But many of our patients will succumb to the disease, and it's our responsibility to be with them through that entire journey to the end as well.

[00:38:06] **Lisa Yen:** So beautifully said. And so hopefully it'll be a partner in helping us run faster than the bear. Nothing replaces compassion and that compassionate care that you give.

[00:38:17] **Dr Diane Reidy:** That's true.

[00:38:18] **Lisa Yen:** Any final thoughts or words?

[00:38:20] **Dr Diane Reidy:** I'm just so grateful to you and the entire Neuroendocrine Cancer Foundation and community for being advocates for our patients and for giving me the opportunity to talk.

[00:38:28] **Dr Diane Reidy:** I absolutely love coming on. And I think that the more we can empower our patients and teach our patients and their loved ones about the disease, the less noise from social media and other things of people claiming lots of things that really are not founded. And I think it's an incredible service that you're providing, so I'm just very, very grateful to you and for sharing your story too.

[00:38:51] **Lisa Yen:** We are so grateful for you. Thank you so much for all you do, for this thoughtful and honest conversation, for being so willing to have straight talk. I mean, you are so unique, and we have so much fun chatting with you as well.

[00:39:04] **Dr Diane Reidy:** Love to come back again.

[00:39:06] **Lisa Yen:** And we wanna thank our listeners for joining us. As Dr. Reidy said, we hope this conversation provided straightforward, meaningful insights to help you navigate your neuroendocrine cancer care with greater confidence and empowerment so that you can have not just more time, but more quality time. Thank you so much and see you next time.

[00:39:25] **Lisa Yen:** Thanks for listening to the Neuroendocrine Cancer Foundation podcast. We want to thank our podcast supporters, Novartis, Exelixis, Lantheus, ITM, Crinetics, and Boehringer Ingelheim. For more information about neuroendocrine cancer, go to ncf.net. We depend on donations to bring you programs such as this podcast. Please consider making a donation at ncf.net/donate.