“Mental Health and NETs” with Dr. Karen Kersting
Released on February 15, 2023

Lisa Yen:

Welcome to the LACNETS podcast. I'm your host, Lisa Yen. I'm the LACNETS, Director of Programs and Outreach, as well as a caregiver and advocate for my husband who is living with NET. In each podcast episode, we talk to a NET 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.

Lisa Yen:

I'm excited to introduce Dr. Karen Kersting, a licensed clinical psychologist who provides counseling and psychotherapy to patients treated by surgeons in the Division of Surgical Oncology at the Medical College of Wisconsin. She completed an undergraduate degree in journalism at the University of Wisconsin Madison, a PhD in Counseling Psychology at Virginia Commonwealth University in Richmond, Virginia, and a postdoctoral fellowship in clinical health psychology at the Dayton Veterans Administration Medical Center in Dayton, Ohio.

She joined the faculty of Medical College of Wisconsin in 2016. And on top of her clinical duties, she's also raising a three-and-a-half-year-old son. Dr. Kersting’s research interest includes the development and assessment of integrated psychosocial services for people coping with cancer diagnosis and treatment, with an emphasis on patients diagnosed with the cancer of the pancreas. Additionally, her work aims to highlight issues related to social determinants of health and Acceptance and Commitment Therapy interventions.

I learned of Dr. Kersting from NET surgeon, Dr. Callisia Clarke, who has joined our LACNETS community for our annual conferences, and Dr. Clarke and I have collaborated on patient centered care panel discussions. When Dr. Clarke shared with me that every single one of her pancreatic NET patients sees a licensed psychologist during their very first visit with her, my mouth literally dropped open and I almost fell out of my seat. It sounded too good to be true. I then learned that Dr. Kersting was going to speak at the 2022 NANETS Symposium, and I really enjoyed her mental health in NETs talk. This was a symposium for medical professionals. But I enjoyed it so much that immediately after her presentation, I invited her to join us for a podcast episode, because as I said, I loved her presentation, I felt the information needed

to reach a wider audience. So welcome, Dr. Kersting. And if you might, just tell us a little bit about how you got involved with NET and what really attracted you to this population.

Dr. Karen Kersting:

Yeah. So, thanks so much for having me, I'm grateful to be here. Let me say a little bit more detail about my background that kind of explains my story. My PhD program had a focus on health psychology, which is a well-established field that puts psychologists in healthcare settings to address the specific issues that arise from all kinds of different health problems. So, from there, I actually worked in primary care mental health, which is another established kind of modality. And, you know, worked with patients, again, with a wide range of medical problems, but I've also had some specific training in cancer. So when this position opened up in the Division of Surgical Oncology, and it was an opportunity to bring this same highly integrated model that we use in primary care mental health, to the cancer center setting, it just was a perfect match.

And in particular, you know, I, as a psychologist, my preference has never been to work with patients with serious mental illness like schizophrenia or bipolar disorder. So, I really love the opportunity that I have in health psychology to meet patients who have maybe not had too many mental health problems over the course of their lives who are hitting their moment of crisis, and provide them with support that gets the medic on track without having to struggle into a mental health problem. So, pancreas cancer has been an excellent area for me to get started in. And I've been particularly interested to learn a whole bunch about NETs.

Lisa Yen:

Thank you for that background and for distinguishing what health psychology is, because it's a field that I know a lot of people probably haven't heard of. Yeah, that's really encouraging to hear that there's a field like that out there that integrates what I know our population, our community is going through.

Dr. Karen Kersting:

Yeah, it's a great area. There are currently more jobs than people to fill them. So, I recommend it to anybody too.

Lisa Yen:

Wow. Well, thank you. And we're so glad that you're in that field and helping our community.

Dr. Karen Kersting:

Thanks.

Lisa Yen:

So, let's dive into the questions, shall we?

Dr. Karen Kersting:

Sure. Sounds good.

Lisa Yen:

So, the first question is, how common are mental health issues in NET patients? And what are the most common mental health issues you see a NET, and what can be done about them?

Dr. Karen Kersting:

Sure. So first, let's talk about what a mental health issue is in this context. So, I'm not necessarily talking about a diagnosis of anxiety or depression. We're talking about difficulty adjusting to this life altering diagnosis. So, you know initially, when someone is diagnosed with a serious cancer like this, there is a moment of panic. It's a really scary time, being in a car accident and getting T-boned. All of a sudden, this thing happens, you might walk away from it, but your world has changed. And it's a very difficult moment. So, at first, there can be a lot of shock, difficulty understanding what's happening, taking in all the information at once, a lot gets thrown at patients when they are finally diagnosed.

And then, you know, obviously, there's a lot to worry about in the context of coping with cancer and planning for treatment. So, for some patients who've had an underlying, you know, tendency towards worry in their lifetimes, maybe they would have said, "I'm a worrier." At this point, it can really spin a bit out of control, there's a lot to worry about with a cancer diagnosis. So, people can start falling into habits like not sleeping at night because of worry. Of not being able to be present with their friends and family in a meaningful way because their mind is on their cancer. Feeling nervous or anxious all the time. And that's where we start to see something that's called an adjustment disorder with anxiety.

Similarly, some patients, kind of the other side of that coin is some patients become depressed. This is really sad news, it's very unfair to get a diagnosis in a fundamental way. And for some people, it looks more like depression. And that can be wanting to sleep all the time, feeling really cranky or irritable, which pops up in men especially. And just feeling down all the time. Those are some of the symptoms of depression or adjustment disorder with depression. So those are some of the initial pieces, I think, in the first few months after a diagnosis. And then additionally, with NETs patients, they've often had this incredibly long journey to their diagnosis, full of frustration and anxiety. And I think that puts you in a prolonged state of anxiety for a long time. And then you get to the diagnosis and it's really kind of a traumatic experience. You might have had genuine issues of distrust with the medical system and all kinds of things that are really important to talk about, I think, as you finally get your diagnosis right.

Lisa Yen:

Wow, you really named so much of what we've seen personally, in our community. And I think even just naming it helps. It helps at least me, have a sense of relief, to say, "Wow, that *is* what I experienced!"

Dr. Karen Kersting:

You're onto something with that we actually know that when you name the emotions that you're having your executive function center of your brain has a better ability to deal with them, you can have more control, so you can decide what you want to feel panicked about more often than not.

Lisa Yen:

That's a common experience as you're just explaining it and I think many people can relate to it. So, you know, you've already started touching on anxiety. The second question is, how does anxiety impact NET patients? And why is it so prevalent? When do I know I need to reach out for support with anxiety and what that treatment maybe look like?

Dr. Karen Kersting:

Yeah. So how does it impact patients, you know, multiple ways. But I think the big one is, being anxious is its own form of suffering. It's just miserable to be inside of a mind and a body that can't stop worrying. It's painful. And I think on top of everything else that cancer patients go through, they deserve some support and not having to be in that sort of pain, as well.

Let me talk a little bit about the basics of anxiety. Anxiety is helpful to us in many ways, it keeps us paying the bills on time. It makes it so we don't step into the street in front of a bus. So, it's very useful. However, when your anxiety is about something that you can't immediately take an action on, there's nothing to do about it, it just gets kind of stuck in panic mode. Or it results in behaviors like googling all the time, or obsessively willing your cancer away, or putting all of your energy into very rigorous diets. Any kind of these sort of slightly obsessive behaviors can be a product of that experience of being really scared and not having anything to do about it. So, you know, cancer really in the way that treatment rolls out where there's a timing to it, you move forward, there is relief in moving forward through treatment, but it happens at its own pace, and you don't know what the results are going to be. It's a breeding ground for anxiety.

Lisa Yen:

And when you talk about this, I know as a caregiver myself, I'm thinking, I sensed this I see this, not just you know, patient. And so, I'm wondering how this also speaks to caregivers.

Dr. Karen Kersting:

Oh, absolutely and in some ways they have even less control, right? Because they're not in the body and they're not in the experience of it. They're certainly experiencing their own suffering and difficulty because of their loved one's diagnosis and maybe the requirements that puts on them, but they're also, you know, experiencing all the fear and worry, and maybe even more so, about some of the exterior details about how other family members are coping, how finances will work out. All of that can get very intense for caregivers.

So, in my clinic, just actually in the last six months, I've been given the okay to also take on family members as patients. I don't do it too often, because I try to reserve as much time as possible for the patients themselves, but I think that's often very appropriate. And it's always appropriate for a family member to come with to a therapy session, especially if there are communication issues to address, which there often are.

Lisa Yen:

Wow, thank you for addressing the needs of caregivers as well. So, when do I, either patient or caregiver, know I need to reach out for support? And what does that treatment maybe look like?

Dr. Karen Kersting:

You know, I think there's two ways to think about this. I think being diagnosed with a serious cancer is enough of a life stressor that everybody should talk with a therapist and kind of just have a preliminary conversation, even if the result of that is for the therapist to say, "Holy cow, you're actually coping really well." You know that is a really meaningful thing to have said to you by a professional. And so, I think

everybody with that kind of traumatic diagnosis should have a conversation with a therapist. That said, how do you know when there's a problem? You know, a good way to think about that is when the anxiety, the worry is preventing you from doing the activities you normally would do, or you would want to do. So you're already potentially prevented from doing activities due to physical limitations during cancer. But if you're not able or wanting to do the things that you usually would do, then we know there's an issue. Additionally, if you find your mind racing all the time, if you're not sleeping well because of that, that would be a reason. And if you're just cranky all the time, you know, and I think an internal experience of that is, honking at traffic more than you would before or not being able to wait in lines. All of those can be a tip off that anxiety is surging, and you might benefit from some support.

Lisa Yen:

Wow, that's really helpful. I'm just going to share that I know for me after my husband was very suddenly and dramatically diagnosed, and on life support, and I was like, “how did I miss this?” I found myself having difficulty driving. Because I wondered, I really doubted my ability to make that judgment to make that, you know, unprotected left turn.

Dr. Karen Kersting:

Yeah.

Lisa Yen:

And that's when I knew my anxiety was, was more than I can handle.

Dr. Karen Kersting:

Yeah.

Lisa Yen:

And that it would be helpful to find some support.

Dr. Karen Kersting:

I think you also asked, what does treatment look like? You know, anxiety treatment is often a combination of working on the thoughts in your head, and how they can be repetitive and kind of bring you down, but also the sensations in your body. So, anxiety is kind of a conversation between mind and body, with your mind, thinking worried thoughts, it sends a signal to your body to be nervous or tense. And that physical tension actually sends a signal back to your brain to stay scared. So treatment for anxiety is very much about identifying the thoughts and working towards other thoughts, to say it in a simple way, and figuring out ways to help your body relax, to you know, use your body as a tool to tell your mind that you're safe in that moment.

Lisa Yen:

Wow, that does sound like that would be very helpful. Yeah. And let's tackle depression in a similar way as well. How does depression impact NET patients?

Dr. Karen Kersting:

You know, I see less depression than anxiety. But I think depression tends to come on months into a healthcare crisis. When you're exhausted by the process, probably exhausted by the treatments, frustrated, you're starting to feel like when will I ever get back to my real life? Is it even worth living like this? When questions like that start to come up. That's when I think people kind of can settle into a, like a fog of depression, of feeling like they're going through the motions, feeling sad all the time. I think more often than not, this kind of depression does not show up as crying all the time. It's more tired and soft and low energy and sad than it is hysterical or crying. And actually, the combination of feeling down and being tired all the time is really tough because fatigue is actually a symptom of depression. And at some point, it's hard to figure out which comes first depression or fatigue.

So, with depression even more than with anxiety, I do often first you know right away recommend that patients seek out medication support for depression, especially this low energy kind of depression is really quite significantly helped when a patient starts on an antidepressant medication. And those are completely compatible with cancer treatment. There's really no contraindications there. It's nice to be able to find a psychiatrist that works with cancer patients specifically, but honestly your primary care doctor can prescribe this kind of thing in one phone call. Because if they know you have cancer, they know there's a reason and it's reasonable to start on an antidepressant. So that's often my recommendation when I diagnose depression. And then you know, it's a process of having more support both through myself and finding it through social support, that helps with depression a lot. And identifying those repetitive thoughts that are sad or down or negative, and working to see if you can shift your perspective.

Lisa Yen:

So, it sounds like some changes in your thinking or trying to shift thinking. And then also maybe some of the calming behavioral techniques that you were talking about.

Dr. Karen Kersting:

Yeah, exactly. When I mentioned those kinds of calming techniques, breathing exercises are a go to. There's a reason why everyone wants to do meditation and yoga. It helps. But it can also be painting or prayer, or walking. Or if you're not able to go hiking or go walking, it could be driving by the lake or driving by the ocean. There's a whole range of things that meet that need of physical calming, and it doesn't have to be sitting on a yoga mat for a half an hour.

Lisa Yen:

Yeah, well, that's helpful. Thanks also for demystifying the medications, antidepressants a little bit and saying it's okay to take those.

Dr. Karen Kersting:

Yeah, I think, again, these are often patients [who] have not had any mental health problems in their lifetime and it's a bit of a shock to be in that position. And there can be some stigma attached to the medications. But just like any other, you know, side effect of treatment, or even your disease itself, you would treat it. In this cancer process, you would do what you needed to ameliorate the effect of what you're going through. And I think that medications are no different.

Lisa Yen:

Yeah. And that's one thing that you and I talked about, right? Just lessening the stigma around all this. I mean, you just showing up [for] the very first appointment, makes it more normal. That people see psychologists and people need to talk about these things, and how helpful that is.

Dr. Karen Kersting:

Yeah, I think every patient, pretty much at some point, needs to hear from me, this is normal. It makes sense that you feel this way, that you're not doing it wrong by struggling to cope. And you know, there's a lot of the word now is, “toxic positivity.” There can be in cancer populations of, “be strong,” (you know what does strong mean?) just stay positive, and that's really problematic because it's not that easy. And it's important to know that it's normal to feel down to feel sorry for yourself. I mean, how can you not feel sorry for yourself when you're going through this kind of thing? And to feel those things and then move through them is the goal of therapy?

Lisa Yen:

That's really reassuring to hear. I know, even for me hearing you say those words, eight years into this, it's really comforting…

Dr. Karen Kersting:

Oh good…

Lisa Yen:

Makes me feel, feel like, “Oh, okay, that's okay. “

Dr. Karen Kersting:

Yeah.

Lisa Yen:

So, shifting into sleep.

Dr. Karen Kersting:

Yeah.

Lisa Yen:

This is a common one, I know. What kind of sleep problems do you see in NET patients?

Dr. Karen Kersting:

So, I mentioned before that anxiety can turn into sleep problems. Anxiety, it makes it difficult to fall asleep at night, if you have racing thoughts, some people find as soon as they turn the distraction of the TV off, they can't rest because their mind is so active. So that can be a problem. Anxiety can also wake you up in the middle of the night. It interferes with getting through sleep cycles. But in addition to that, NETs patients may have spent time in the hospital where it's very difficult to sleep. And that kind of messes with your relationship with sleep, which I'll explain a little more. Additionally, if you're

experiencing pain, that can mess up your relationship with sleep. So even after the pain is gone, you're still maybe struggling to sleep as well as you did before.

So, there's a bunch of reasons. I think it would be strange to not have some struggle with sleep. Oh, one other big one is, if you have suddenly retired from your job because of the diagnosis or taken off work, and you don't have a regular daytime schedule, that shift or lack of regular daytime activity or having to be somewhere in the morning, also really messes with sleep. And I find patients often end up staying up to 2 am every night, and getting out of bed at 11. And there are consequences to that, both socially and actually, that kind of sleep is not as high of quality as sleep that is more attuned to the night day cycle.

Lisa Yen:

Sounds like so many reasons to not sleep well.

Dr. Karen Kersting:

Yeah.

Lisa Yen:

So, what does the treatment look like for…?

Dr. Karen Kersting:

So, I'm just going to briefly explain a little bit about how insomnia develops, because that speaks right to the treatment. So, like I said, there are lots of things that come up, that make sense that they would interfere with your sleep. Now these are not insomnia, just like you know, parents of a newborn not being able to sleep at night. That's not insomnia, that's the baby crying. So, it's a sleep problem per se, but it's not insomnia. So, when you're going through something, for example, even if you just had a cold that might keep you up at night coughing and sniffling. When you're in that position, you end up spending a lot of time awake at night. And that's just fundamentally miserable. So, you start essentially being miserable in bed. Same with pain. Same with being woken up at the hospital. You're just having all these negative experiences with sleep, and you're feeling super tired during the day because of it. So, after a while, you start to have what we call compensatory behaviors to try to ameliorate that.

So, for example, you might be very anxious about sleep and start believing that you can't get to sleep unless you take medication, or you can't get to sleep unless you go to bed really late. Alternately, you're tired all the time, so you might be spending a whole lot more time in bed, but not necessarily asleep. So going to bed at 7:30 because you're tired, but that doesn't necessarily help you to sleep well or sleep more – more quality sleep. And then once a cold has passed, once you're recovered, you're not in pain anymore, you've still got these behaviors, like spending too much time in bed, lying awake, you know, just feeling an uncomfortable relationship with your bed, in a sense, because you've spent so much time in it miserable. And all of these things can contribute to a sleep problem.

So, when I work with a patient, I will, in a detailed way go through their sleep pattern and try to figure out what is causing the issue. We'll go through some basic sleep hygiene, like you know, avoiding caffeine before bed, avoiding alcohol before bed. Passing out drunk is not sleep, by the way. So that's not a good way to fall asleep. Additionally, how much activity are you doing right before bed? For some people looking at a screen in the hour before bed is a problem. Not actually for everybody, so that's one

to experiment with a bit. You know, is there an underlying anxiety problem that's causing it, and we work to address those.

And then for folks that have sort of developed this negative relationship with sleep, we work on that specifically through actually spending less time in bed. That's called sleep restriction. And we would pick a wake time and stick with that every day, same time to get out of bed and pick your time that you go into bed, maybe starting with six hours ahead of that wake time. And that might lead someone to be going to bed at midnight and getting up at six. But, if they were to sleep that whole time, if they were able to sleep that whole time, they'd be getting six full hours of sleep, which they may not have in the past. So, like I said, a psychologist, specifically one that is trained in something called cognitive behavioral therapy for insomnia, CBTI is trained to take kind of all the principles that I just spoke about and integrate them into a treatment plan for patients to get their sleep back on track. And work with a therapist like this has better long-term results than any sleep medications.

Lisa Yen:

Wow, that was amazing! That was really, really helpful. And I think you explained that really well. And I think that'll be helpful for everyone. And I know that resonates in our household as well. I'm wondering, I mean, you talked about fatigue as well... How do you work with patients who have had long periods of fatigue, which is so common with NET?

Dr. Karen Kersting:

You know, this one's really hard. And I sometimes feel that I don't have excellent strategies for helping people cope with it, especially for people who are still having physical problems that prevent them from trying to increase their exercise. Because our number one strategy for combating fatigue is exercise, is movement and activity. And the more you do that, the more you tend to build up fatigue during the day, so you sleep well at night. And that helps you to have better energy. But, at the same time, when you're tired all the time, and maybe still having some pain, the last thing you want to do is get up and move. So, this is really difficult. So, I work with patients on baby steps on making sure that they're eating and drinking enough to have enough energy to move. Also work on finding some joy in whatever movement they do. You know, if they used to love running marathons, they're kind of out of luck, right? So, we have to find something new that's more compatible with their current body, that is actually joyful for them to do in terms of exercise. And, you know, I have a patient who decided to learn how to play the ukulele to try to get through this at least, you know, something he's excited about. That really helps to move through the fatigue as well. Even if it's not a very active thing, at least it's sitting up and using your mind. And then additionally, there's absolutely help through an antidepressant medication for this as well. There's a whole class of the medications that actually help with energy. And, you know again, in that question, is it fatigue? Is it depression? It makes very much sense to try something like that if there's an ongoing fatigue problem.

Lisa Yen:

Yeah, and I've heard about several people picking up ukulele and maybe ukulele sales will go up after this…

Dr. Karen Kersting:

Maybe that a thing. Yeah. Fatigue is so hard. I think that's just another one where it's also really important to say it's normal to be exhausted for six months after a Whipple. And I don't know that people always hear that from their physicians, because the physicians want to paint the more ideal picture, which is the case for some people don't have that level of exhaustion. But when I tell folks, “This is normal, there's still an end in sight, this is not the permanent condition for the rest of your life,” that makes a big difference too.

Lisa Yen

Yeah, just hearing those words from you. And again, thank you for destigmatizing medications. Well, you talked about eating and how difficult it is to eat sometimes. So how can a psychologist help people who are struggling to eat after treatment or surgery?

Dr. Karen Kersting:

Yeah, eating is really hard too. A couple of the things that can happen is, if you've had a lot of vomiting, or stomach and GI discomfort, or even, you know, diarrhea, and constipation problems, eating has been potentially a very painful, very difficult thing for you, either leading up to your diagnosis or because of treatments.

And, I mean, is there anything worse in life than vomiting? It's the worst. It's a miserable, miserable experience. And so, it makes sense that people can become kind of avoidant of eating, because they don't want to experience that. In addition, you know, the surgeries that some folks have and chemotherapies genuinely impact the way their hunger works, and the way their mouths taste food. So those are very real physiological issues that come up. And those are very hard to overcome with will. And as much as you're trying to eat, those can be very difficult to overcome. And it's an awful thing to have to force yourself to eat when you don't want to. I think for anybody who's not in that experience, it sounds lovely to be able to eat as much as you want. But it's really not something that is easily doable, to force yourself to eat more than what your body is telling you you want.

So, number one, again, this is something that's normal. And I think some empathy and normalizing around this is important. For all the patients I've worked with, if they can get through a certain amount of time by eating as much as they can, this does get better. And I think it's that idea that it's never going to get better, is one of the things that's so upsetting about not feeling able to eat. But when someone is being pushed by their team to eat to maintain their, their life, it's so important and there's so much pressure associated with it, it's just such a hard thing.

So, in terms of what I work with patients on, there's that normalizing piece. If there is this conditioned experience of disgust towards foods, because of the fear of vomiting, we'll talk about that and try to figure out some ways to do essentially exposure therapy to eating different foods to kind of retrain your brain to think that it'll be okay to eat them, and that they won't cause you problems. And then one other thing that I think is really important to talk about with the eating issue is the conflict that can develop between a caregiver and a patient when the issue is eating. The caregiver wants so desperately to help the patient, helping someone by making them food is, is everybody's go to, right? This is what we want to do. And it's really scary to see someone wasting away or losing weight because they're unable to eat. So, the caregiver is then in the position of pressuring the patient to eat. The patient is miserable, and that's the last thing they want to do. And that really drives a lot of conflict and

discomfort in a relationship. So, I think it's really important to name that. And for many patients, I encourage them to just let it go for a little bit. So, you know, to think of it as you've been in this tug of war for a while. And now it's time to probably drop the rope and relax and take this pressure off your relationship and see what happens. And I often find patients find they're just naturally eating a bit more when the pressure is off. So, this is a really complicated piece and I think it can be very helpful to talk through with a therapist.

Lisa Yen:

I'm so glad you brought up the thing about the caregiver because that was one of the questions that came to my mind. So, should they keep asking or making food? Or what can they do understanding that may be normal and have empathy, so where can they direct their empathy and their efforts if they want to support their person?

Dr. Karen Kersting:

That's a great question. I think it's really hard and it's different for each individual. The patient genuinely doesn't know what they want to eat. And so, asking them, "What do you want, what can I make for you?" can be a very antagonizing question. At the same time, of course you're asking them what they want to eat, because you want to give them food they can eat. So that's a tricky balance.

Patients who go through cancer treatment, and in particular for NETs, they lose a lot of control in their lives. And even though your instinct is to make food for your person, it might actually be more helpful to hand it over to them and to ask them to start spending some time in the kitchen, if they can. That could potentially be, you know, the kind of lightweight activity, that would feel good, too. So, it's going to be different for everybody. But I think being creative, being flexible, not taking it personally, which is so hard. All of these things are some of the strategies to think about when you're trying to work through that.

Lisa Yen:

I think the key thing you're saying about easing off the pressure, that seems to resonate and make sense, right? Yeah, all that pressure is like, you know, maybe stopping the flow of eating.

Dr. Karen Kersting:

Yeah, I should say, if the patient seems to not understand the importance of eating, then that is its own mental health problem, at that point. But I think most of the time, patients are well aware of the stakes related to eating and taking the pressure off tends to help.

Lisa Yen:

And speaking of these, you know, maybe differences in perception, how can a patient or a loved one or physician tell the difference between a symptom such as fatigue or anxiety caused by the NET tumors versus a psychological trigger? And does it even matter?

Dr. Karen Kersting:

Yeah, I think I'll answer the first part second or second part first. I think it probably doesn't matter that much, that the resolution will be the same. It will be talking with a therapist, potentially thinking about

medication, sometimes there's a diet change, that can make a difference there, too. The research on what NETs, tumors do to mood is still kind of fuzzy. So, they may be sort of indistinguishable. That said, if there was some significant shift in personality ahead of the diagnosis, it might be easier to point to as a result of the tumor itself. However, you know, stress from being sick, stress from looking for a diagnosis stress from being diagnosed, is probably going to have more impact on your mood than anything the tumor is doing directly. And stress can make you depressed, it can make you anxious, it can make you tired, all of these things. And for some people, I think the question is, what is a normal reaction to cancer versus what is something that requires intervention? And, again, I'm not sure it matters. Cancer is just really hard. You deserve support. That said, it does make sense to be sad, it does make sense to be worried. Again, there's that line of is it interfering with your otherwise ability to do activities that really comes into focus there?

Lisa Yen:

So, a follow up question. I've heard this from patients or caregivers who are concerned, how does one's mental health impact one's NET disease or the effectiveness of treatment? So, I guess, worried about are they being too anxious or sad, and maybe not getting the effectiveness from surgery or impacting their recovery?

Dr. Karen Kersting:

Right. So, I think there's two ways to think about this. One is physiological activation, you know, being in fight or flight, release of cortisol, all of those things that come with panic and anxiety. Again, the research is fuzzy on this, but we definitely think there's some impact on your actual physical well-being. Your resilience, your ability to heal, ability for your immune system to help out, all of these can be impacted by stress. And that's absolutely another reason to work on your stress and anxiety through strategies for relaxation, maybe through medication. Absolutely, it can affect things.

Probably the larger piece of it is when anxiety or depression interfere with your ability to comply with your treatment, with your inability to recover, to rehab yourself, if you've had a surgery, to get moving, to eat, to sleep, to want to get better, to rejoin your social relationships, you know, all of these things are really important for your long-term healing and well-being. And they are significantly impacted by anxiety and depression. So, it's those two different pieces. And honestly, I think the second one is probably a larger concern than the direct impact on biology, although that is absolutely something to consider. But yeah, it's essential to attend to your mental health in one way or another.

Lisa Yen:

Yeah, thank you for that just shining the light on the importance of this. Let's talk about young adult NET patients. As we know there are a significant number of young adult patients affected by NET, if you could just share a little bit about how NET might impact young adults.

Dr. Karen Kersting:

Sure. You know, I think in a lot of ways, there's similarities to any other patient. But you've got these additional set of concerns. It's more expected, it's more normal for a middle aged or older adult to have cancer. So you can really feel like you're the only one, and you have gotten such a raw deal. So, it is easy to fall into a depression of, “I can't go live my life. I can't pursue my dreams. Everyone else is moving

forward, and I am not able to do that right now." So, I think that experience itself can create a lot of depression and kind of lack of motivation to keep moving towards regular life goals. If you're facing a difficult treatment, you can't continue, you know, finishing your college classes or moving up your career ladder. And there's a risk of people getting stalled out permanently even if they are able to recover from their NETs.

So another issue is fertility issues come up. Some of the treatments can impact fertility. And that can be really upsetting. You know, we have strategies for coping with that, you know, harvesting eggs, for example, and freezing eggs. And that is a good strategy. It's not usually covered by insurance. It's very expensive. Freezing unfertilized eggs is less effective than fertilized eggs. There's all these complicated issues around fertility and how to think about it with those patients.

And then finally, they're seeing a lot of old people in the treatment room, and they feel out of place, just feel awkward sometimes, and have to think about issues of life or death that we don't typically expect 30-and-40-year-olds to think about.

Lisa Yen:

Yeah, and they feel alone in this. And we know that people can have children. So, whether it's adult children, teenagers, or young children of NET patients, how do you see NET impacting the children?

Dr. Karen Kersting:

Well, you know, I think it's similar to any type of cancer. It's a difficult conversation to have with a kid. And I think there's a range. You know, a lot of kids maybe know that cancer is bad but don't really have an ability to understand more of the complexity of it. So, the stress on patients who have kids is often "How will I talk to them about this?" And it's hard because you want to protect your children from having to worry about your cancer. I think that's especially the case if you're chasing after a hard to diagnose piece. And there's that stress in the household of, "What is going on? When will we ever figure this out? Are we getting the right treatment?" That's the kind of thing that kind of intuitively seems like you should try to keep from kids. And it's almost never the right choice though. Because you got to think about specifically the developmental age of kids, but kids know when something's up in the household. And it's actually more uncomfortable for them to know something's up, but not be able to figure it out at all. That's really uncomfortable for kids. And it creates sort of a sense of not being able to trust their instinct. Their instinct is saying that something's off, but Momma's saying that everything's fine. And that's uncomfortable for kids. So, I think at whatever age-appropriate way you can let them in on what's going on. Let them in on your real emotions. I am scared, I am sad. You know, this is scary, and to trust those kiddos to be able to tolerate that discomfort with your support. I think that's almost always the right strategy. Certainly there can be extenuating factors, but you know, it is better to let kids in at the level that is appropriate for them, including to let them into your emotions.

So, with that, I would also say you just carry so much fear for your kiddos that they might lose a parent. And in some cases, you can call that anticipatory grief, thinking about the losses that could occur from losing your life or having your partner's life shortened. And that is just so desperately sad. And I think you have to face it and not pretend that it's okay. It's not okay. It's awful. And to sit with that and to know it and to figure out how to love those kiddos every moment that you have with them. And I think

that a therapist can often help with this. But these are hard things to face and the more you can, not manage your emotions, but be with them, the more you'll be able to be in your life.

Lisa Yen:

It sounds challenging…

Dr. Kersting:

Yeah.

Lisa Yen:

…and also potentially leading to something even more beautiful and healing.

Dr. Karen Kersting:

Yeah, there's so many interesting silver linings in the patients I work with, whether it's a deepening sense of emotion generally, that can be quite startling at times or, you know, a greater gratitude for life, or an ability to prioritize what matters to them. There are absolutely beautiful silver linings.

Lisa Yen:

Yeah. Wow. And we are grateful for those silver linings.

Dr. Karen Kersting:

Yeah.

Lisa Yen:

Well, you know, we talked a lot with you, and I wish we could just clone you. But I'm wondering who should see a psychologist? When might they see a psychologist? How does one even find a psychologist?

Dr. Karen Kersting:

Again, I firmly believe anybody who's going through this should have a conversation, even if it's just one, with a therapist. So that is the ideal.

When is it become important to seek someone out? I think when mental health symptoms, either depression or anxiety or interfering with treatment or making you just so miserable that the inside of your head is just as painful as any part of your body. I think those are good signs that it's time to look for someone.

Pretty much most cancer centers, at this point, do have supportive therapists, usually a psychologist, and often master's level providers like licensed professional counselors and social workers who are wonderful. They have just as much skill as psychologists in a lot of these things. So, first place to look is your cancer center. And then beyond that, you can look for a health psychologist or even one with a cancer specialty by going online and searching lists of therapists in your area. And this is challenging, it's hard to find the right therapist. I encourage folks to approach it like they would online dating.

You can pick all the things that you want to have be present in the therapist that you're looking for, but you don't know if it's a fit until you get there. And so, you may have to date around a little bit to find the right fit. I like for folks to know that that's okay. You know, if you walk out of a first therapy session, feeling worse, less hopeful, you should not go back. So, I would just empower patients to really be a little picky about the process. They may not feel like your best friend, but you should feel some comfort coming out of that first session.

One other piece is a lot of the philosophical pieces that I've been talking about about witnessing your emotions, being present with them, and then being able to make choices. That's called "Acceptance and Commitment Therapy." And that's another thing you can look for. It's called ACT.

Lisa Yen:

Ah, yeah, thank you for explaining that, since that was also in your bio. So, you're naming that maybe the hospital, our institutions, or locally, we might not find a psychologist per se, but it would be a mental health worker. So, what should a patient expect when they come for their first visit with a mental health professional such as a psychologist like you, or therapist or other, you know, licensed clinical social worker, or other?

Dr. Karen Kersting:

So, there'll be some brief assessment of background and previous experiences with mental health. I always ask my patients if they've had any mental health problems in the past. You know, we'll check in about if there's any substance abuse issues. And then we'll ask you about your family, maybe a little bit about your childhood or family of origin, but doesn't dig in too much there. It's not so Freudian, not like you see on TV. So, we dig in a little bit there to understand the context of their life. I like to understand, you know, what people see as their strengths. I like to know what their hobbies are to see if we can adapt them so they're still having joy in their life.

I always ask patients, even if I've had a chance to look at their chart, I always ask them to kind of tell me the story of their diagnosis and how they've coped so far to understand what kind of negative experiences they've had so far. And we talk about how much they're worrying currently. We talk about if they're feeling depressed currently. We talk about sleep, all of those pieces. We talk about how they're feeling about their interactions with the healthcare system. So, I'll ask questions about all of that. And then we'll work towards some, you know, with the patients I see, they're struggling right away. So, I try to offer at least one or two strategies to walk out of the room with to help ameliorate some of what they're going through. So, this is not the kind of long-term therapy where after six months you get an insight. That's not it. It's much more direct than that. And I think most people feel better after a single session. And most people feel a lot better after four-to-six-sessions.

Lisa Yen:

Wow, that's really hopeful and helpful because some people may have never seen a mental health professional in the past. So, to get an idea what it's like. Well, speaking of coping strategies. The last question we'll end with is what coping strategies or advice do you have for NET patients? And also, what coping strategies or advice do you have for family members or loved ones?

Dr. Karen Kersting:

Well obviously, seek out support whenever you need it. I think one funny one that I haven't touched on, is all the people around you – I think at some point, I'm going to end up writing a book called, "What Not to say to Cancer Patients." Because people, they just get it wrong. And they mean so well, they want to be there for you. They love to bring you lasagna, but they often get it wrong. But here's the thing, those people who want to be there for you in your time of crisis, all they want to do is be able to love on you and to be good to you. So if you give them even just a little bit of direction about what you need, they will be relieved.

So, for example, if you have too many people saying, "what's going on with your cancer treatment?" And you just don't want to talk about it, they're asking because they care, but also because they don't know what to say. So, if you say, "You know what, I don't feel like talking about it. Tell me how your kids basketball game went," they will be relieved to have some direction about how to interact with you. And you will also have a better experience. It stinks that that burden is on the patient to direct that at times. But 100% of time it goes well, when you redirect the conversation. And then you're still getting that social contact, social support, without having to struggle through the stuff you don't want to talk about.

So, that's one, I think universally, that kind of shift in attitude towards the people around you, is often very, very helpful. So, I'll leave you with that. And also seek out help. Try to talk with other people who are going through the same thing to have normalized stuff like the fatigue and the stigma and the stress and the crankiness and the, you know, honking in your car. All of that really helps to have it normalized. To get through all of this.

Lisa Yen:

Yeah, the normalization, destigmatizing it. I mean, those are the things that jumped out to me from your presentation from talking to you today. I mean, how many times did you say today, "That's normal, that's normal, that's normal."

Dr. Karen Kersting:

Yeah, yup.

Lisa Yen:

So reassuring. And then also some of the helpful strategies and ideas of how it impacts different people, and how to alleviate some of the pressure and burden around it.

Dr. Karen Kersting:

Yep.

Lisa Yen:

Thank you so much for the time, for all you do for caring for the NET community. I'm just really grateful and moved. And again, I wish I could clone you. I wish you were like my next-door neighbor. And I could just like, talk to you all the time. I think we would have a lot to talk about.

Dr. Karen Kersting:

Yeah, well, it's just a pleasure to get to know you and to get to know the NETs community more and I'm just excited about being part of all this.

Lisa Yen:

Thank you again, and we hope to see you again soon.

Dr. Karen Kersting:

Sounds good. All right. Bye-bye.

Lisa Yen:

Thanks for listening to the LACNETS Podcast. We want to thank our podcast supporters Ipsen, Advanced Accelerator Applications, TerSera Therapeutics, and Lantheus. For more information about neuroendocrine cancer, go to www.LACNETS.org. LACNETS depends on donations to bring you programs such as this podcast. Please consider making a donation at LACNETS.org/donate.