Episode 22
Navigating the New Normal:
Transcript

You can find information about subscribing to this series at netrf.org/podcast, where you’ll also find helpful infographics, and videos that expand on this material.

If you’re new to NETWise, we strongly recommend you go back and listen to the series from the beginning, starting with episode one. It will give you a solid grounding in the basics of neuroendocrine tumors and how they’re treated. You can find the whole series at netrf.org/podcast and wherever you get podcasts.

Do you have a story to tell about your own NET journey? If you’re a NET patient who would like to participate in a future episode, please email us and let us know! podcast@netrf.org

---

Welcome to NETWise. This is a podcast for neuroendocrine cancer patients and caregivers that presents expert information and patient perspectives. My name is Jessica Thomas, Director of Patient Education from the NET Research Foundation.

In the last episode of NETWise, we talked about a moment of transition – the time right after someone receives a diagnosis of NETs and the feelings of grief that can follow. In this episode we are going to start to understand and talk about the next part of the journey - how to navigate through the emotions, symptoms, and treatments of NETs while managing all the responsibilities and relationships that fill your life. How do you create and navigate your new normal?

> ***Banerjee:*** *"The first few months or perhaps even a year or two, are a shock. You're not only adjusting to a new diagnosis, you're adjusting to the treatments that you're taking, you're adjusting to all the side effects and really your body and your mind. It's figuring out how you're going to be living in this new normal."*
>
> ***Johnson:*** *"We are given that diagnosis and it takes time just to accept the new reality, to research and to Google and to talk to people, and to plan a methodology."*
>
> ***Lister:*** *"And I think it's that transition from receiving the diagnosis and coming up with that action plan that seems to produce the most anxiety during the whole course of the disease, because there's so much unknowns. And as with most human beings, the known is much more comfortable."*

But that transition is, of course, only the beginning of your NET journey. In today's episode, we're going to talk about what happens after that, and then after that. Some people live with NETs for many years, and we want to help you learn to navigate this journey with confidence and grace, no matter how long it continues.

Here's Dr. Chandana Banerjee, a hospice and palliative care physician at the City of Hope National Medical Center in suburban Los Angeles:

> ***Banerjee:*** *"I think what does happen is when patients are a little bit more familiar and comfortable with what the treatments have been like, when they start understanding through their research or even with the discussions with physicians, what the course looks like, I think that's when they can shift into the mode of really looking at the present and looking into the future.*
>
> *I call it almost doing a 360 in terms of, 'that's the life I knew before my net diagnosis, this is the life I know now as it stands, and now with enough knowledge about the tumor and the treatments and the support of my family, I can see what my future looks like, whatever the outcome of that disease is."*

And here's Greg Johnson, an interfaith chaplain who serves as Chief Advisor for Family Caregiving at EmblemHealth:

> ***Johnson:*** *"None of us knows how the story is going to be written. None of us does. Nor do we know our expiration date. I haven't found mine yet. I keep looking. Remember, you are in charge of your disease. You are in charge of how you are going to handle it. You're not in charge of did you get it or didn't you get it? You've got it. That's a given, and here are options."*

In this new normal, you will very likely be undergoing some kind of treatment for your NETs. So let’s start by looking not at the treatments themselves but at how they might incorporate into your life as a whole.

With the more common low-grade forms of these tumors, there’s sometimes an acute treatment, like surgery or interventional radiology, which might have a period of intensive recovery, but then the long-term, medical treatments that follow are often administered very slowly, with long periods between doctor’s visits. Here’s Michael Lister, a clinical nurse with the outpatient oncology group at the University of California, San Francisco.

> ***Lister:*** *"With patients that have low-grade, dota avid disease and their treatment option is Lanreotide, Octreotide, Sandostatin, and they can be on this for a very long time, years of getting these monthly shots. They'll probably see their local oncologist, some of the smaller offices, they'll see them every month with their shot, or they'll see them every few months and they'll see us, after imaging most of the time. So they'll see us between every three to six months, probably, and sometimes extended all the way to a year's point if they're very stable. So their one big commitment is these monthly shots and, and these six to 12 month visits, after imaging, to confirm that they've remained stable.*

> *And then some patients, perhaps they're not responsive to Octreotide, Lanreotide, or maybe they have such a small amount of disease and such stable disease that they don't require any treatment. Then those, that's a very minimal amount of interaction."*

This creates a kind of pendulum in many patients' lives, where there are short periods of intense attention to the fact that they have cancer, separated by long stretches where it's very much in the background. This can lead to times for some NET patients when they almost forget they have NETs at all.

> ***Lister:*** *"Even some patients with metastatic neuroendocrine cancer, when well differentiated and very targetable and treatable, can have it for a very long time without incredible interruption in their life. A lot of them, over the course of the time, see this as a chronic condition rather than an acute condition that requires treatment regularly.*
>
> *And they're still able to do the things they love. Like, we've had patients that we care for many years that are marathon runners or scuba divers or… you name it, they do it."*

And when you can, it can be perfectly thing to ride that pendulum all the way to the end, and allow yourself to feel healthy for a while. Here's John Kerns, an interfaith chaplain at Beth Israel Deaconess Hospital in Plymouth, Massachusetts:

> ***Kearns:*** *"You want a break from it and that putting it in a box on the shelf. I think it can be a good thing because I think to live in that state of high alert all the time isn't feasible. It burns us out and it keeps us from enjoying life or, appreciating... and gratitude is one of the biggest things and priorities of what's most important in your life, and so that's what I'm going to focus this time on.*
>
> *I know that's there and I'm doing what I can to take care of it. I have my next appointment set up. I have my next scan. Unless something like flares up, I'm going to live my life, knowing that the medical stuff is set up if I need to. I'm only going to talk about it when it hurts or when I have… when the problem shows up. But otherwise, I just want to live as if it doesn't exist."*

But please keep in mind that this is still cancer, and the nature of cancers is to grow, so please do allow the pendulum to swing back when it is time for a treatment or a scan or a check-up.

> **Lister:** "Because I'm sure that there is a temptation… if this is indolent, this is slow growing, this is something I don't want to have right now, I don't want to pay attention to… but there's a lot of value in regular care. It's very valuable to have (all) the information you can to empower you to make decisions. You'd still be able to live your

> life, do the things that you love, and hit your goals while still making sure that you're paying attention to a chronic condition that you have, so that you can manage it and stay ahead of it.
>
> Because at the end of the day a treatment decision is a recommendation from the doctor and a decision by the patient. So it will always be the patient's decision, but having that information will empower the patient to make those decisions."

But not everyone's NETs are quite so invisible. To start with, some NETs – especially functional NETs that produce hormones – can cause symptoms, sometimes ones that can be quite intrusive in your life.

> ***Lister:*** *"The real common one is diarrhea, and it can be multifactorial for a lot of the patients, so not just related to the hormone production. Because something to keep in mind about patients that are NET patients, they sometimes have had a resection at the beginning of their disease. And so for that, they may have a shorter GI tract, so that will affect motility as well. And it's hard to decipher all this, especially if you haven't gotten much education on diet – to know what really speeds up stuff and what slows things down. it is sometimes a real mind shift for folks."*

"My name is Hector Perez. I am from Utah, just around the Salt Lake City area. And I am 37 years old now. Just turned 37 last month. I was diagnosed with neuroendocrine tumors back in 2017 and so a lot of stuff leading up to that. My primary location was in my mesentery and that went eventually to my liver. So the two structures specifically and only structures that have any tumors or lesions are in those two areas.

So about a year before that I started to just very faintly have little flushing types of episodes. When I eat specific types of foods and what it feels like I thought I was just sensitive to, to something and so I thought there was just allergy related. I could never really nail down what it was, and they were happening sporadically.

I had an episode, while we were just out eating, my wife and my kids where it got really bad, started feeling heart palpitations. My face was all flushed. My upper body was all flushed and for a few minutes I was in the state of just being really uncomfortable. Heart rate was going, started feeling tingly and, my extremities at that point, I figured that there was something else that was going on and it was at that point where I went to my just my general doctor and let him know what was going on. He referred me immediately to a gastroenterologist, and so he then had me do several things to try to identify what was going on in my digestive system. And so amongst those things was a CT scan. They found some lesions. He was pretty sure that it was what he at that time just called carcinoid syndrome.

Right? and so he referred me to an oncologist. My initial thought when I got the diagnosis is what's next and how's this going to change my life? Is it going to turn it upside down?

One of the things that I was surprised about is like when you get a cancer diagnosis, usually it's okay chemo are you going to start. And lanreotide is more or less a hormone type of treatment, right? And so that's been the biggest thing is it's every four weeks. So every four weeks I'm having to go to the doctor to get the medication. With time I did start having to add a couple other medications into the mix, but the biggest thing has been, planning around this four week, moment, right where I have to go and get this medication. So we, we plan vacations, we plan events and things like. Usually a week or two after I get this medication because usually that's where I feel the best and more stable. I don't, the symptoms don't really bug me as much. So that was the biggest change. It hasn't really turned my life upside down in relation to how I feel afterwards.

After the first few months, like there were some side effects and I would feel a little more fatigued, things like that. But from it just bringing me completely to a halt, it hasn't, a luckily it hasn't because I have a young family, a couple little boys, and we're very active . We like to be doing stuff outside. And I've been able to lead a pretty normal life in relation to physical things such as *hiking, going to Disneyland, all that kind of stuff, I've been able to do all that with all of this all in the past five and a half years. It hasn't really held me back in that aspect.*

It's known that the benefit of symptom control with lanreotide decreases over time. And so about the three and a half year mark, around three weeks after receiving the dose. I started to feel a little more sensitive, right? I started to feel flushing when I was eating and things like that. And so, one of the adjustments was I started to, I was prescribed, short acting Octreotide, which then became the norm of filling the gap between, when my Lanreotide started to wear off. And then I got my next dose. At this point, five and a half years later, I start to feel a little more sensitive at around the two, two and a half week mark after getting Lanreotide. And it's just been the adjustment of if I start to feel a little more sensitive, then I start taking octreotide and usually I feel pretty good. In my case I only take one dose of octreotide a day, around lunchtime, right before I eat. Cause again, that's my biggest trigger is eating. And so after just doing it, then I'm able to eat lunch and I typically won't, won't take another dose, later on the day before dinner, either I'll usually feel okay.

My day to day was a lot of visiting clients and there were a lot of local clients here in Salt Lake City. What has happened a little bit is, and in the course of, I don't know if it's just the doctor's visits, the scans, the, just all of that, over time, anxiety started to become a thing for me and probably for three years. I would, I have to interface a lot with like CIOs, executives, in some of my projects. And so when I'd go visit with them, there's always a little bit of nervous butterflies, "Hey, I'm gonna go present to this particular group of people" that kind of normal stress of the day to day job. But it started to turn into something else, which was, a little more of the anxiety, not just like stress and a little bit nervousness, but anxiety.

And then I had a couple of episodes where it actually turned into a full fledged type of episode, the flushing, at a client's office and things like that. And so the stress, the feeling of nervousness, adrenaline in those moments or episodes that I had. And yeah, heart palpitations and all of a sudden it got flushed and, and so it started to affect a little bit of that at that time.

It's changed a little bit of the dynamic of my job where, a lot of what we do, a lot of the clients we work with, are just happy to do work projects remotely. And so I've been able to, more or less, 95% of my time, is really just remote work at home. And so that's been the shift and it's been fine. It's very accommodating, obviously, for my

> *situation. There's moments where I just, you know, after a particular meeting, I can just lock my computer, go take a few minutes outside. Take a breather, relax, even lay down sometimes, right? So that's been helpful for me.*
>
> *There's good times and there's rough patches. Early on, I think, the first few weeks especially, there's a feeling of numbness, whether it came from just not understanding the extent of just the disease, and not understanding what was going to happen. But, over time, I think it just depends on what's going on in life.*
>
> *The word hope, it's just always in my mind. And as I think about the first few days after getting diagnosed and just being scared and just not having a good feel of what was gonna happen and so much unknown. But just knowing that there's a lot of options.*

Of course, not all NETs are low-grade. Some are very aggressive, and that disrupts someone's life to an entirely different degree.

> ***Lister:*** *"A high grade tumor, that sort of diagnosis prognosis is scary. I think it's unavoidable for it to take over a lot of your daily life, just because you're going to have symptoms, you're going to have frequent appointments, and you may even have some unexpected appointments. Letting that happen, just will happen… there's no way around that.*

> *But also, taking a step back when you can to look at what, where you are, where you're. What you would like to see changed, what your goals are, what your wants are, and making sure that you can prioritize some things in your life that don't necessarily revolve around your disease.*
>
> *So if there's things that bring you joy, making sure that you don't lose those things that you can keep, that bring you joy, and making sure you make time for that and telling your team that's something you want to make time for. Telling your team that you need to adjust a date for something, or that you need this break, or that you've had these symptoms, because anyone who's treating you wants the treatment to be something that's sustainable, something that can continue, and the only way to do that is to adjust treatment to be something where you have a quality of life that you can enjoy while on treatment."*

But no matter the specifics of your diagnosis, it's really important to communicate with your care team – be direct about telling them how you're feeling and what you need and want for your day-to-day life to be better.

> ***Lister:*** *"As a nurse, I only know the information that I get, and I rely on patients to tell me how they're doing. And even if I've been a nurse for a while, I don't know what it's like to go through cancer treatment. And so I rely on the patient to tell me what their needs are and what their struggles are, and what their problems are. So*

> *it's really valuable to understand that those around you, that are there to support you, don't know – and the only way they'll know is for you to tell them."*

And it's equally important to communicate with yourself. How are you really feeling? What do you want and need? What does quality of life mean to you? Keep in mind that quality of life is as much emotional and spiritual as it is physical.

> ***Johnson:*** *"Feelings aren't facts, but we need to honor that they're there in order to deal with them."*

> ***Banerjee:*** *"At the end of the day, depression and anxiety are two real important concepts that anyone with chronic disease or something like cancer will face."*

And anxiety can be a real present force in your life, and perfectly normal, even at times when your disease state is relatively calm.

> ***Kearns:*** *"It's that low grade simmer on the stove that, okay, they're going to watch it. But how closely? What does that mean? So it's great that I don't have something that's so awful right now, but there's something happening inside me all the time, and when is the point when it's going to change? Or are they going to catch it? Is that something they're going to be on top of?"*

Banerjee: *"I know I have cancer. What if it just comes back? I know that my next treatment is months away, but what if something happens in between that I'm not aware of, right? What is growing inside of me?"*

Kearns: *"Will I be forgotten in the system? Yay… but I think I'll be living with this constant anxiety and worry."*

Lister: *"It should not take over your… take space in your mind when it doesn't need to. Easier said than done, I will admit, for a lot of things in life, but just meeting it where you need to meet it and then letting yourself live your life and have the quality of life that you desire, is important."*

But how do you achieve that kind of balance?

Banerjee: *"The first thing is, I think, to understand and recognize anxiety. A lot of people that actually don't even recognize that they're going through anxiety, and it may come off as them being upset or irritable, or they may have sleep issues or loss of appetite.*

I think people also need to communicate more about anxiety. I think that's what doesn't happen with a lot of patients because when they're thinking, perhaps, that they don't want to burden the loved ones with talking about this, or maybe they say that talking about the anxiety will make them less resilient than they should…than they are.

> *but I think people have to understand that anxiety is normal. It is something that is accepted and it's something that you should not just hide underneath the carpet, because once you start suppressing your anxiety, your physical and emotional state will take the toll, and your relationships will suffer. Your quality of life will suffer, and ultimately you won't make the appropriate decisions that you have to make, with your treatments and your day-to-day."*

Once you've identified your anxiety, and named it, there are a lot of things you can do to tackle it.

> ***Banerjee:*** *"I think it's really important for a couple of things to happen. You should not give up your hobbies and your social life. I think that is not a healthy situation. It can make anxiety worse when you're isolated. It's important to seek medical help when you have to, when you know that anxiety is getting in the way of your functioning and the relationships that you have with your loved ones. You know that it's time to actually seek help from a professional, and whether it's cognitive behavioral therapy or medications that are needed, it's time to address it, because if you ignore anxiety, it's just going to take you down a very bad spiral and depression might actually be very harmful to your disease in general."*

> ***Johnson:*** *"I don't know about you, but one of the worst places to spend time is between my two ears. It's better to*

get it out, do some journaling, whether it be 20 minutes, 30 minutes, whatever it is, each day or every couple of days – setting that time limit to allow ourselves to say, 'Yes, this is emotionally how I'm feeling' and writing it down."

Banerjee: *"What I often tell people is that you need to identify a couple of things that are important to you that make you happy, and when you go into that phase of being anxious, I think you need to turn to those things."*

Be careful, though, because not everything that makes you feel good in the short term is going to make you happy in the long term.

Kearns: *"There's higher and lower coping mechanisms. And that… so like alcohol, drinking would be a coping mechanism, but is that really going to help you though? Denial is one, but the cancer is growing all the while. And your bills are… your life could be tumbling down around you, but that's still a coping mechanism. And so how does one in that kind of way be able to say… or to even to look at how I cope with this? And is that coping really helping me or not?*

And as much as we pay attention to the bodily changes, I think, 'what are my behavioral changes? So am I still as social as I was? Am I as interested in life as I was? Where has my life changed? And my response to this life, or my *response to this illness, how has it been? How is it affecting me? And I don't think we necessarily know that until we ask that kind of a question, right? That kind of self-awareness piece. How can I be grounded? How can I live in a reality where the negative is acknowledged? But we don't go down the hole. We don't despair. And the way we don't despair is we look at what is around us and in us for which we're grateful, for what still is good in our life."*

Johnson: *"Quality of life is not determined by the circumstances, but by how you perceive the circumstances. So in other words, whenever we hear a diagnosis – and certainly the big 'C' word – where do our minds go? Planning the funeral. I have seen that again and again, with people coming into my office to talk. And I always say to them, 'We don't know when that's going to happen. What we do know is what's happening today.'"*

Kearns: *"Instead, gratitude. And I think the difference is gratitude is being able to hold the 'both and'… the boiling pot and 'I've got a great family'. Or, 'I'm feeling better today. Yes, I still have this, (this) is still happening', but, whatever things… my children, the beauty of creation, whatever it is, someone can hold onto that. That anchors them in."*

One thing about learning to channel these difficult emotions is that you don't have to deal with everything all at once. It's OK to take things step by step and save challenging conversations with yourself for times when you can best handle them.

> ***Johnson:*** *"I don't want to say compartmentalize or to deny, and we don't know when a feeling's going to come, but we don't have to deal with the feeling completely. I have found to learn to deal with that feeling and say, 'Yeah, that's tough. Okay, I'll get back to you later. This isn't the moment I have to deal with it.'*
>
> *We don't have to solve it. We don't have to do anything other than name it, because when we name things, we take half of the fear and power out of them. Because when it's still something that's not named, then we go into those wonderful judgment games: 'Oh, I shouldn't feel this way. I shouldn't feel that way.' And I always say to people, don't let anybody – now I'm saying this very carefully – don't let anyone 'should' all over you'."*

> *"I'm Mary Zeller. I live in Indianapolis, Indiana. I'm 65 years old. I was diagnosed with a neuroendocrine tumor in 2007. It was ileum primary with metastases to the liver at the time of diagnosis. When my cancer was diagnosed, it had already spread, and I was told at that time that it likely would come back. And so to me that meant I'm going to be dealing with this in some way, shape, or form for the rest of my life, either worrying about when that's going to happen or what to do with it after it does happen. And that*

was daunting and scary. And my initial large surgery was also very scary. So it's a long, bumpy road.

It's interesting when I look back on the 15 years, there are parts of those years - 3, 4, 5, 6 months here and there, and certainly the initial diagnosis would count for one of those - that were pretty intense. Times where my life was very focused on the cancer and what to do about it. Very focused on finding the information, seeking the right people, feeling confident in those people, but also dealing with the emotions surrounding that. And each time something new comes up, it's a very good question - how does this change your life? Because that's one of the biggest fears every time something comes up.

Is this the time where things start to decline and I really lose parts of my life that I'm no longer able to continue, whether that's travel or work, or gardening, which is one of my particular hobbies. And whether I'll still be able to be a caretaker for my mother, which is a very big part of my life, or help my daughter with her child, things like that. And so those periods, those months where something comes up and you have to deal with it and there are physical struggles and you're dealing with all things at once. Those periods are very intense and very focused.

I have learned in my 15 years walking with this disease that I go through those periods and then time passes.

Holidays come and go. Gatherings come and go. There's certainly times when I'm not thinking about my cancer. But I very definitely live with my cancer in that it is part of my psyche now and there… I can be very involved in life and doing fun things or playing with my grandchild, and it's not like you think about it every second. But there are times when things come up and in the back of my mind, I might be thinking something that no one else is thinking, and it's just because of my reality and my situation. It's not always overt, but it's always there.

In terms of my work interactions, these were all people who were not necessarily in my personal sphere, and so many of them never knew what was going on with me. It wasn't anything that was front and center with what I was doing. I'm actually, even though I'm speaking now, I'm a pretty private person.

Somebody asked me a question, somebody I've known for quite a while asked me a question. I mentioned that I am a support group leader for a cancer group, and then she asked me how I got into that, and so felt like I had to be truthful and say, 'I was diagnosed and I have the cancer, the type of cancer that this is a support group for.' She just was wide-eyed and she said, 'Wow, I just never knew that.' and I said, 'I don't usually lead with that.' And that's how I feel about it. If it's pertinent, I don't have any problems sharing it and sharing my experience and even advocating for this patient community I'm a part of. But if *it's not pertinent, I prefer to live life as it comes and what's present and before me and for me that works.*

I was speaking with a friend and she was griping about, I don't know, traffic or something, and then she says, 'Oh, I'm so sorry. I can't believe I'm just complaining about this stupid little thing.' And I said, 'Oh, please don't ever apologize.' I said 'I fight like hell so that I can just sit here on the phone and complain about stupid little things', so that's what I want to do. I want to live a normal life and that's complaining about traffic or getting irritated, being on hold on the phone for something or…or enjoying watching nature out my window. That's what I want most of my focus to stay on, if possible."

Banerjee: *"It's very difficult for a cancer patient, sometimes, to strip the disease out of their identity, and I think that becomes one of the biggest obstacles and barriers to their emotional and mental wellbeing moving forward. I think it's really important that, when you make choices, it should be based on what makes you happy. What in this moment is making you content? What are the decisions that you're going to make that are going to affect you and your family first in the future? I also often say that, you know, it's okay for you as a cancer patient to be selfish. You're absolutely allowed that, because that's the attitude you should take to make sure that you and your family and your loved ones are preparing the best way possible for whatever is coming your way."*

As we started talking about in the last episode, relationships with the people closest to you can be sources of both strength and also tension throughout your cancer journey. It’s important to remember that the people who love you and help care for you are on their own cancer journey, in parallel to yours, with their own fears and anxieties about your condition.

> ***Kearns:*** *"Cancer impacts every single person. I can imagine the frustration for the spouse of that person who is anxious about… and wants to plan everything and know everything, and is wondering every day when she wakes up whether it's, like, cooking again and whether we're gonna have problems soon.*
>
> *And so in a relationship, in a partnership, how do you navigate communication and sharing of information and processing of information together? How am I going to manage my reaction to your cancer and what it brings up in my life, and not expect you to take care of that for me? I think a lot of times conversations just don't even happen, that it's just such a hard subject to approach.*

And in that conversation, it is really challenging, but also really important, to be open and honest with everyone about what is and what is not, so you can work together to make the best of what will be. It’s important to remember that while cancer may be a bad thing, it does not make you a bad thing. It is healthy to create space to talk about cancer.

Johnson: *"The opportunity of talking about things that people don't talk about. Saying, 'Yes, it's frightful. I'm going to die.' Most of us do! You don't get out of here without that. We need to talk about it."*

Kearns: *"I think that the 'toxic positivity' is when one doesn't allow for, or permit, the facts - the reality of the situation and can't allow anything that is perceived as negative or as contrary to this positive thrust. Won't allow it in the environment and the conversation. And so almost like rules out negative emotions, tears, pessimism, or anything that would have any color that might be less than positive.*

Banerjee: *"So I really think it's important for patients to sit down with the loved ones, sit down with the physicians, and do what I call a sail board exercise. It's one of these psychology-based exercises where you're at the helm, you're the captain, and you're identifying which way the winds are blowing, where the sails are flowing. You're identifying what the waters look like, identifying what kind of obstacles you will face in this ocean."*

Kearns: *"Letting people know what helps and what doesn't help. What kind of responses are helpful or not?*
'Don't worry, it's going to be fine.', maybe I don't want to hear that! But be able to be clear about…
it's not ignoring it, but it's… I think having those healthy relationships where I can be open about what's

> *happening and I can even instruct my friends on what helps in their response to me."*

> ***Banerjee:*** *"And then once you identify that you come up with a core circle that becomes critical to your day to day. And that circle could be as small as your family, but it could be as large as your community support system and your medical team as well."*

The truth is that no matter how strong and capable we are as individuals, no one can do everything. If you were to become sicker you would likely need more help and support.

> ***Kearns:*** *"What are the resources you need as an individual? Going right down to the personality type… so part of it's knowing your strengths and weaknesses, knowing your limits and abilities. And if ever there were a time to be honest with oneself… and so who do I need to help me? How do I really identify what my needs are and my resources, and not feel bad because of them. I think there's a lot of shame sometimes involved in this, or there's a feeling that, like, 'I should be able to on my own'. So to be able to say, 'This has got me. I can't, I really can't manage this alone.' And what are the things I need to be able to deal with it?"*

Another part of your life that will no doubt be examined more closely as you move through your NET journey is your job. NETs are starting to be diagnosed much earlier and in many cases, people are living longer. However, there may come a point when you are unable to work. And even if you can continue working, many decide to change their priorities, focussing on something different, perhaps something more meaningful.

> ***Johnson:*** *"You are looking at life very differently, because when we think – or when we know – that we have a deadline, as it were… the finitude of life, whether it's a large number of years or a short period projected, what happens to every day we have? They become more precious, and we begin to live into life. We were trying to be that good citizen and that hard worker, do all those sorts of things, and so we wear all these masks… and then suddenly when we hit a roadblock, we say, 'do I really believe that?' And we begin to find the freedom to say, 'yes, that's been how I thought, but it doesn't serve me anymore. And shockingly, I can let it go now!' That's not the easiest thing, I assure you, but it can be let go."*

Others, of course, cannot do this. Many do not have the financial resources to stop working, and also many don't want to stop. Work can provide a lot of things other than money, and for many people it's a part of their lives they don't want to part with.

> **Kearns:** *"Work is so important for people, their sense of identity. Then there's also those people for whom work is the escape, and that… I'm just going to work more. That helps me be distracted from what I'm going through. I was even listening to something about people in retirement that the adjustment in retirement, even though they wanted to retire, they prepare for this moment their whole life, but then they're suddenly, 'Who am I without that job? How do I structure my life without… where's my purpose? Where's my contribution?" The thing around which they organize their identity and their life socially, psychologically, physically.*
>
> *And I imagine there could be with, say, someone like that… then they find themselves, well depressed, feeling useless, lost, and bored and even, 'Is there anyone around for me to play with?' So that, 'okay, now I'm not working, but my working buddies are still working and I've lost that social outlet.'"*

And for many, this isn't a time to stop working, but maybe it's a time to reassess the kind of work you do and who you do it with.

> **Kearns:** *"If I'm going to be working, I'd rather use my time this way, something that has more purpose or meaning to them. And so maybe it means less of a commute. Maybe I want to adjust my work to suit my life so that I have more time, more free time, more available time for my family, for my*

friends, or even for self-care… to take care of myself to exercise , diet, meditate, and pray. And suddenly I have this other major demand in my life, and if I can, I'd like to make space for it, and be able to create more of a balance so that I have more time for what else has suddenly become more important to me than this work."

My name is Courtney Wilkinson. I am located in Dallas, Texas. I am 32 years old. I was diagnosed when I was 28 – so July, 2017 – with small cell neuroendocrine carcinoma of the cervix.

I've been very fortunate, God blessed me and I have been able to work full time through the whole six years of treatment. I also work with a great company that allows me to work remotely. When I was initially diagnosed and through my first surgery, I took a month off, because I just didn't know. I didn't know what to expect. I was diagnosed, going to have a major surgery, and at that time it's scary because they tell me like the surgery's going to be seven to nine hours. I didn't know how chemo would make me feel, and just a bunch of things. So I took a month off from that. And for me personally, it just wasn't a very good fit. I had a lot of time to think, dream up the worst of it. So I really enjoy work. I'm able to help people, and that's always been my main goal in life, through every aspect.

I do HR. It's all confidential. You don't have to tell, but I found it better, in my experience, with being open and honest about my needs, being transparent, what I can give to the company. Especially… I've been at another job before when I was diagnosed initially, and it was the same thing. I was open about what I was doing to my main boss, how we could work together and keep a solution, letting them know that I was still wanting to work.But definitely there, If you can't work – not everyone can work. I understand that – there's long term, short term disability that you can, you know, have. There's just a lot of things that can be done versus just quitting your job and, cause I know that's really scary for a lot of people that don't think they can work.

Unfortunately, when you have cancer and you're going through it, bills don't stop coming. you still have to eat, you still have to feed yourself. You still… the medical bills, the travel, none of it's… life doesn't stop just for cancer. And so there's definitely different ways that your company, depending on how big or small and what resources they have… So getting involved with your HR personnel and discussing that with them and not just quitting your job, I would definitely suggest that. Don't quit your job. Reach out to your HR group and discuss the possibilities that they have – available resources.

I share all my Facebook and Instagram and stuff to connect with people as well that are going through it. And that's *been my thing. If I could do one thing through this journey, it would be to help someone. And so that's… with work, I do enjoy it a lot. Some days, of course, I wish I would win the lotto and could stay and not work. But overall, I really enjoy it, and it's something that has kept me… and I think it's helped me through this whole thing, because it gives me a sense of purpose.*

And I actually was talking to my doctor the other day, and I was telling him the same thing, that I really enjoy work. And my dreams… cancer's never changed my dreams and goals. It might have watered them down some… maybe not gone out for a promotion because it has a lot of traveling and unfortunately my life... that's not in the plans right now. I go to treatment every two weeks. I can't travel for work. And so sometimes that gets hard, with cancer and being able to… having to put your dreams or goals on hold. But, I really do. I really enjoy work and like I said, it gives me a sense of purpose.

I catch my husband maybe crying when we've gotten bad news and. Some days are hard for them, I know. But everyone's… we all have the same goals, as far as we're going to fight this thing until the end. We're not going to give up until I say I'm done fighting. We're going to keep going and go any route that we need to go. And on days that I need a little bit more help, they all step in and give me that support. Some days we have to tag-team things because everyone still works as well. And so when I've had longer

> *hospital visits and stays, we've had to make different plans, or we've had to switch out in the middle of the week to get it done. But I would say they handle it as well as they could. And my mom's only child, so I know that's been hard at times for her and… I can only imagine. But overall we rally together. We cry when we need to cry. We pray when we need to pray, which is every day. And we celebrate the small victories and even the big victories.*

All-in all, the first thing you should realize as you navigate the new normal is that you are not alone. No matter the challenge you are currently addressing, there is someone nearby who is willing and able to help, if you reach out and ask.

For instance, getting your finances in order when you're dealing with a long illness is no small task, particularly in the United States, where the health insurance system is so overwhelmingly complicated. But look around, be tenacious, and don't be afraid to ask questions. Your care team is on your side, and you might be surprised by how direct they can be about navigating the costs of treatment.

> ***Lister:*** *"Pharmacy coverage is helpful, good pharmacy coverage, because sometimes there's an out-of-pocket expense for some of these medications that are specific to neuroendocrine. So that's… somatostatin analogs like Octreotide, Lanreotide, especially the short-acting Octreotide. That can sometimes be expensive. Pancreatic enzymes can be expensive. Telotristat or Xermelo can*

> *sometimes be expensive. And sometimes these things are cost prohibitive, and it's such a bummer to see someone have supportive medication treatment options that they are not taking because of the cost.*
>
> *So there's often a discovery process of trying to find if there's patient assistance programs and things like that for that. Because that's a thing that someone's going to take for a very long time, and that can be a pretty impressive monthly bill. So some recommendations I give, when patients are changing insurances to look into what the coverage is through their insurance company of some of the specific medications. They can also ask their team like, 'what are potential medications down the road that I could potentially see' so they can look them up. And then, what can be valuable sometimes is, some of these, the producers of these medications, they'll have patient assistant programs. So, an application process. Sometimes it includes disclosing some income requirements and stuff like that, and sometimes it also includes getting a signature from your clinical team."*

And as we've talked about before, most major medical centers have a dedicated palliative care team – an interdisciplinary group made up of doctors, nurses, chaplains, and social workers who exist just to help you find ways to improve your quality of life.

> **Banerjee:** *"You have this interdisciplinary team in a palliative care team where you are not only addressing physical symptoms, but you're addressing psycho-social aspects of a patient's care, you're addressing the spiritual aspects and emotional aspects of a patient's care. And not only that, but you're also pulling in the other team members to make sure that the care that we are providing, the treatments that we are providing, are in sync with what the patient wants and needs. So I think it's really important to identify. As early as possible, even at diagnosis, a palliative care resource that can be available to you, so they can actually walk this journey with you and really be your advocate throughout the treatment course."*

And for many, the most valuable resource is the larger community of NET patients. By drawing on support groups and online communities, you can find invaluable help and guidance by talking to people who are going through the same thing you are, or who have been there and come out the other side.

> **Banerjee:** *"It's really important to identify other patients who have similar tumors, and perhaps connect with them so that they can be that resource and they can be each other's support system. Because it's much easier to speak to someone who actually is going through this alongside than someone who has no idea of what you're talking about when you're talking about this treatment and this tumor and the effect it has on you."*

Lister: *"I think that what's really fortunate about a disease like NET, although rare, has a very strong supportive community.Something that stands out to me as a hallmark of a neuroendocrine patient, they are educated. They have learned a lot about their disease. They've learned a lot about managing their symptoms. They've learned a lot about what to expect. And I think that this piece, this self-education piece, that comes with it and learning about their disease also provides a little bit more confidence in their treatment, a little less anxiety."*

Banerjee: *"I think it's really important for you to identify that resource locally and actually get plugged into it, because it is a tumor that is rare. It is a tumor that is not often understood by people. And it's one of those that people have rarely heard about. So you can tell someone that, 'Oh, I have a NET tumor' and they'll say, 'Oh, what's that?' There is no understanding of the tumors by the layperson. It's a very specific tumor. oftentimes they don't understand that this is a cancer that has a very different course at times from some of the other cancers. and until we educate and get plugged into these communities, we won't be able to spread the word of what's necessary about NET to make sure that everyone understands it for what it is, and then empathizes with the course of the treatment or the course of the disease that the patient has. If you don't understand anything about it, you're not going to be empathetic to it. That's just fundamental."*

My name's Bethany Ross. My pronouns are she/her. Located in Nashua, New Hampshire, so it's like an hour north of Boston. I am almost 35. My symptoms started five years ago, right around this time. Which is crazy to think about… I just said that.

So I had been sick for nine months. I was vomiting nearly every day and was getting misdiagnosis after misdiagnosis. I had doctors tell me it was all in my head. I was making myself throw up. I had doctors tell me it was anxiety, depression, IBS, you name it. I say it's because I'm a stubborn New Englander, I was like, 'I don't care what degree you have, I don't believe you. Something is really wrong with me.' So I always credit my stubbornness for still being here four years later, five years later from when my symptoms started. I got this diagnosis and I just knew I had to survive. That was my mindset. My life is just starting.

And it made me take a look at my life and say, 'What do I really want? What am I doing?' So when I first got diagnosed, I was managing a team of eight people spread across the globe. I was working an unreasonable number of hours a week. And first I just told people I had to get my appendix removed. I found out what it was and wasn't going to tell anybody. It was neuroendocrine tumors and wasn't going to use that word, wasn't going to use the word cancer, was trying to keep work and my health separate.

Once I got the diagnosis that it was in my pancreas and my liver, I did a lot of research on what is it like to disclose this information to your employer, and decided in order to get the protections I needed, I was going to have to tell people because I was going to be out of work for at least two months when I had my pancreas and liver surgery. So I ended up telling my team, I think I cried my eyes out when I told them and told my boss what was going on.

Am I going to be okay with future employers knowing that about me? And I decided that I was, because it's such a huge part of who I am, and shaped who I have become as a person, that I am okay with that information being out there. I've learned how empowering it is to myself to be vulnerable in that way. And I figure if a future employer looks at it as a bad thing that I am vulnerable and using my voice, then they're not a company I want to work for.

And then it was something that, like, would come up. I ended up looking at my life at that point and saying – this was around two years ago – saying, 'Why am I working an insane number of hours a week?' This is not what I enjoy doing.' Yes, I liked my job and my team, but the stress it was adding to my life - I was on the computer all the time, and I wasn't working on myself. It was always working on how to make everybody else's life better, and there was never that, 'What does Bethany want?' So I moved to security, and ended up working more of a nine to five, not frequently on-call job, and not managing people anymore, *because that was something I realized if you're a manager, you're not really focusing on yourself, you're focusing on everybody else. And a lot of my life had been focusing on everybody else, including professionally, and I took a step back and said, 'I just want to focus on me.' And I was like, 'Is this selfish?' I'm like, 'No, this isn't selfish, this is healthy.'*

Prior to this diagnosis, I was never called an adrenaline junkie ever in my life. Post-diagnosis, I have gone skydiving – that was my 'cancer-versary' present to myself last year – I've gone rock climbing, learned how to snowboard in Lake Tahoe. I joined my state's roller derby team. So I've done all of these things that were always in the back of my mind of these seem like cool things to do – got two tattoos – all the stuff that was like, 'I want to do this.' I decided, 'Why wait? What's the point in waiting? I'm going to do it.'

So I say I'll never say 'I'm thankful for cancer.' Definitely not one of those people. But I will say it made me look at my life differently. And made me discover meaning and figure out what was important at an age where most people… those thoughts don't even cross their mind. And it made me come to the realization that I didn't want to be married anymore. I didn't want to have children. I felt like growing up it's like, you're supposed to get married, have kids buy a house, all these check boxes, and cancer made me be like, 'Why? Says who?' I don't need those *check boxes in my life. Life should be what you want it to be, not what society or family or whoever says it should be. I have a Lego room that my nephew stayed in when he came to visit me, because I build Lego. So I don't need to be a quote 'adult', I'm going to do what makes me happy. Me and my pit bull in my Lego room is what makes me happy.*

And I was thinking like, what do I want my future - what's left of it - my legacy to be? So I say that what I think the meaning is, is to leave the world better than you found it. And through cancer advocacy and meeting other people who have various kinds of cancer, talking to my senators about cancer legislation, I feel like I'm on track for that. So that's it. It's definitely changed my life drastically having this, but it made me open my eyes in a way I don't think I ever would have, especially in my 30's.

I didn't think I would make it to even 35, because I remember getting diagnosed and looking at the five year survival rate, and at the time I was diagnosed with stage four, the five year survival rate was 27%. And I was 30, so I was like, 'Okay, I'm not going to make it to 35. And next week I turn 35. For the first time in a long time - and also through lots of therapy - I feel like I have a future again. It was something I really didn't think I would have. I did the Jimmy Fund walk a couple weeks ago, and I ended up talking to a couple people in my team - because I'm part of the young adult program team there - and I was like, 'So next year, when I do this…' And I didn't think about it at *the time, but then after all my drive home was like, that's the first time in four years I've said 'next year' without a qualifier. Usually it's 'next year if I'm still here' or I make a joke about 'If I'm still alive next year'… and that was the first time I've been able to say next year and think that I will still be here next year."*

Banerjee: *"When it's your time to leave this earth, whether it's tomorrow or 10 years down the line. That's a pact that we make between the superpowers up there and ourselves. But everything that happens in between, your decisions affect them, and how you decide to live will affect everything that you do. And so I'd say wake up every morning knowing that you're here and you're present, and today is what matters. And go to bed thinking that if I wasn't supposed to be here tomorrow, what are some of the things I could do so that my family and my loved ones are cared for and that I've made the right decisions for myself and for them. So live each day to your best, plan for the worst, and live like you would live if you didn't have the disease. That means that you take care of yourself emotionally, spiritually, mentally, and physically."*

Johnson: *"In the younger part of our lives, we build containers, we let the ego go wild. We set up all the material things and 'Yes, I'm going to do this. And yes, I got that.' And then suddenly, something comes in, like a diagnosis, a great trial in your life, those stumbling blocks that remind us we are not in charge. It's easy to*

get caught up, particularly with healthcare or 'if she'd done this or he'd done that', and you come up with all these sorts of things, but this is that point. And that's the gift of the stumbling block, the powerlessness, is it takes us from that human dimension into a spiritual dimension. Because, spiritually speaking, everything is unfolding exactly as it must at all times.
'It's a crisis! We've got to solve it now! Stop the world!'… I had a wonderful friend at Friends Indeed, one of the counselors, she used to say, 'look around at this moment. Everything is fine. Nobody's hair is on fire.'… It gives you pause. You know I like humor, but it's true. Oh, we can be so serious. Well why are we going to do that? That's only a pity pot. Poor me. Poor me… and we're better off if we can understand that nothing is going wrong! Given our culture. That's a difficult principle to understand.

We don't know how the story is supposed to go, and so it's with that moment of realizing the powerlessness… and I've had this conversation with so many people. I've had it in my own life, and that is… just maybe, even the most cynical, when it comes to a point of this nature, people become willing to say, 'let me explore.'

That's why writing gratitude lists… those are not things we don't normally do: journaling, getting out the things that are cluttering spaces, as it were, in our minds so that we can spend time enjoying the flowers, enjoying life, enjoying the moment. Because at this moment, everything's *okay. We don't know necessarily about the next moment. When we begin to connect like that, we begin to open up to possibilities that we never thought were possible."*

Mary (Patient): *"I think there were times I wasn't sure if I was strong enough to do this. And I guess what I would say to somebody is, with all of my doubts and all of my insecurities about whether or not I could weather this, I was able to. You can do this. You can make your way through this, and you have to hold on when things are busy and hard or painful and difficult to get through. That there will be… there will be another side, and there will be another week where you do feel like doing the things that you did before, whatever event or diagnosis or things happened. And that…find the best people to help you get there medically, and you will get there in every other way."*

–

Thanks for listening to NETWise. I'm Jessica Thomas, Director of Patient Education for the NET Research Foundation. Our Production Partner for this series is CitizenRacecar. This episode was written and produced by David Hoffman; Post-Production by Alex Brouwer; Production Manager, Gabriela Montequin (mon-ta-KEEN). It was made possible by the generous support of Ipsen; Advanced Accelerator Applications, a Novartis Company; TerSera Therapeutics; and Progenics Pharmaceuticals, a Lantheus Company. Special thanks to everyone we interviewed for this episode. We are grateful for your expertise. This is a

production of the Neuroendocrine Tumor Research Foundation. We're committed to improving the lives of patients, families, and caregivers affected by neuroendocrine cancer by funding research to discover cures and more effective treatments and providing information and educational resources. Please visit us at NETRF.org