NETWISE EP 54 — “SITTING WITH UNCERTAINTY” (TRANSCRIPT)

Jessica Thomas, LCSW, Director of Patient Education at NETRF

When someone is diagnosed with cancer, one of the first questions is clear: What happens next? But for many people, that question doesn’t come with a clear answer. Instead, it leads to something much harder to deal with… uncertainty. Uncertainty about what the diagnosis really means, how the disease may behave, what treatment will look like—and whether it will work, and what the future will hold.

Day by day. Scan by scan. And sometimes, just moment by moment. In this episode, we hear from patients, from a caregiver, and from a physician who is also a patient, about how they’ve found ways to cope, adapt, and continue moving forward, and how they manage *Sitting with Uncertainty*.

I'm Jessica Thomas, Director of Patient Education at NETRF, and you're listening to *NETWise*, the podcast designed to inform, empower and guide patients and caregivers through the world of neuroendocrine cancer.

Here, in my role at NETRF, I work alongside patients and caregivers that are navigating the neuroendocrine cancer journey. I'm deeply committed to helping people not just manage illness, but find a way to live well within it, and to advocate for care that sees the whole person, not just the diagnosis. I know from my own experience that we are wired for certainty and predictability. We are programmed for comfort. And when something like cancer enters the picture, that sense of certainty disappears. Suddenly, the questions get louder: What does this mean for my body? For my future? For my family? And how much time do I have? Can I live with this? And in many cases, there aren’t clear answers. And that’s where uncertainty begins.

And for some, that moment doesn’t come with warning. It arrives in the middle of a life that’s just beginning to take shape—when the future feels open, structured, and full of forward motion. Then, suddenly, everything is interrupted by a reality that doesn’t seem to fit or make sense. For Jackie Dong, that moment came at just 23 years old.

Jackie Dong, Person Living with Neuroendocrine Cancer

I graduated from Yale University around a year and a half ago, and I'm currently a software engineer working out of the financial district in New York. You would never really suspect a 23-year-old to have stage four neuroendocrine tumors, like, especially since how slow-growing, whatnot it is. Unfortunately, CTs and other scans show that it had metastasized to my liver, so quite prevalent. I just went through a 10-hour surgery to remove some of the cancer in my body. Good news only. Negative margins on the surgery– removed all the disease that was like, intended to go. So that's good.

Recovery has been a different story, kind of kicking me in the butt, but I'll – I'm getting through. One percent better every day. Getting up and walking.

I try to be rational, even in the most sort of emotional positions, just to, you know, ground myself. But yeah, a lot of crying. I was with my family, fortunately. So a lot of crying from them, also. But, yeah, it was… it's pretty world shattering at that point. The first sort of, like, I was also in denial. So, a lot of denial, and then grief, I guess, the five stages of, like, processing trauma, or whatever you call it.

Jessica Thomas, LCSW, Director of Patient Education at NETRF
Early moments, it's not just hearing the diagnosis, it's everything that comes with it– emotionally, starting to sink in.

Jackie Dong, Person Living with Neuroendocrine Cancer
I had really never imagined that it would come to the C-word, or, I don't really want to give power to that so to having cancer, you know. And I was just taken aback. I don't really, I can't really recall the exact thoughts that sort of, like, fluttered through my mind, but I was like, Oh my God. Certainly it took a lot of time to process, even in the hospital, and then it was like damage control– like, how is this going to affect my life.

Jessica Thomas, LCSW, Director of Patient Education at NETRF
What Jackie is describing… that moment of shock, of trying to make sense of something that doesn't feel real… that's something we hear from so many people living with neuroendocrine cancer. And one of the most important things we've learned is that the people living this experience—they're the experts in it. Their voices, their perspectives, what they're navigating day to day… that matters. And in some cases, that perspective becomes even more layered. Dr. Mark Lewis brings a rare dual perspective to this conversation—he's not only an oncologist, he's also a patient living with neuroendocrine cancer.

Mark Lewis, MD, Director of Gastrointestinal Oncology, Intermountain Healthcare
When you're diagnosed with cancer, it's absolutely terrifying. And I think there's actually some comfort to be gained in seeking expertise, like you go to a medical professional who has specialized in the management of your disease, you want to get the sense that they know what they're doing. Living with uncertainty has taught me humility. It's taught me that the science of oncology has come a long, long way. I have learned to live more with uncertainty and to admit to my patients when there are gray areas. So, for instance, it's very, very common– and I certainly do this still– for oncologists to quote statistics, and the statistic that we quote most often is a median or an average. So, for instance, let's just talk about the big endpoint, quite movingly but predictably, when I meet people in that first consultation, they'll ask me, How long do I have to live? And it's a really

tricky question to answer. I was always taught, you know if you can't give a number, try to get an estimate, because the person still needs to be able to plan their life, which… which, I totally understand. So, for instance, the range might be the best-case scenario, years to decades: less favorably, months to years. And then sometimes, I'll be honest, you meet someone and they are in such dire shape that you might be telling that person and their family, listen, we might have weeks to months or days to weeks. And certainly in those cases, being brutally honest, actually, I think, is appropriate, because they need to make some decisions with some really fierce urgency. And then I also wanted to answer this from the patient side of things, which is, as I've gone through my own NET experience, doctors have quoted to me over the years numbers, and I realized, again, they only get you so far.

Jessica Thomas, LCSW, Director of Patient Education at NETRF
When faced with uncertainty of treatment and outcomes, statistics of outcomes can take on a different meaning.

Mark Lewis, MD, Director of Gastrointestinal Oncology, Intermountain Healthcare
I had the Whipple operation, which some of your listeners will have had back in 2017. An absolutely fantastic surgeon, and he did a great job with the process of informed consent, with telling me about risk and benefit. And he would give me numbers like, Mark, there's a 30% chance that you're going to come out of this surgery and you'll be diabetic. Most worryingly, he told me there was a 3% chance that I would die on the table. And I'll tell you that that number seemed acceptably small until the night before the surgery. All of a sudden, 3% seemed not nearly as close to zero as I might have liked. But my real point to you is I came out the other side of the operation, I did not develop diabetes. So again, statistically speaking, there was a 70% chance that I wouldn't, and I didn't, but I had some rarer complications that, frankly, were way down the list of risks that he had educated me about. And it was as I experienced those rare side effects, I kind of thought to myself, You know what? These percentages—They're actually zero or 100% that they're going to happen to any given person, and it's once that patient is dealing with whatever the adverse outcome is that that becomes their reality. So it's sort of like moving from abstract to lived experience. And so taking that forward, back into my clinic, I still cite risks as percentages. But then what you have to acknowledge is that if there's any chance of it happening to anybody, that means it's happened to someone before, and for them, it's basically a binary of, did they get the problem, or did they not.

Jessica Thomas, LCSW, Director of Patient Education at NETRF
While percentage can sometimes feel abstract, other numbers can be critically important. The NET-PRO Study—short for Neuroendocrine Tumors: Patient Reported

Outcomes—is a large, prospective U.S. study focused on improving quality of life, symptom management, and treatment understanding for people living with neuroendocrine tumors. What the study reveals is something we hear often: uncertainty doesn't just happen at the diagnosis. For many patients, it continues throughout their journey. Even around key details of their disease. More than 35% of patients reported being unsure of their tumor grade, 53% were unsure of their Ki-67 status, and over 16% were unsure of their stage. These aren't just statistics— they point to a real gap in understanding. And in many cases, this is information patients *can* access. So part of reducing that uncertainty is helping people to know what questions to ask… and where to find those answers. Because what this study highlights is that uncertainty isn't just emotional—it's informational, too. For some, information becomes a way to regain their sense of control. But even then, the experience isn't the same for everyone. For Jennifer Rogers Anderson, too much—or too little—information became overwhelming.

Jennifer Rogers Anderson, Person Living with Neuroendocrine Cancer
I mean, uncertainty can be so many things. You, we all may think we're certain of what we're going to do, but really we don't know. To stress about something that you have no control over, I don't do anymore. I take every day as a gift, and, and whatever happens I am spiritual, so I just asked God to lead me through it, help me through it, not why? What if? It's get me through it. You know+ that's, that's how I, I deal. I can't change the outcome of the scan, so, I… I have learned to not really stress the scans that are coming up, because whatever it reads, we will have to deal with it and go forward.

My problem was working in clinical research. I liked data, and there was no data, especially on the– the type of my specific diagnosis. There was very little data with less than 100 cases. But I knew the prognoses were not well that they had, so I kind of went for the approach: I don't want to know anything.

Jessica Thomas, LCSW, Director of Patient Education at NETRF
For Jennifer, uncertainty wasn't something to solve, it was something to survive. And that meant letting go of the need for answers, even when everything in her background pushed her to search for them.

Jennifer Rogers Anderson, Person Living with Neuroendocrine Cancer
I had my physicians tell me one time they were going to do everything they could to extend my life. And I said, I don't want to hear that ever again. Because to me, I needed for my mental and for the fact I had little boys. I didn't want that thought in my mind at all. I didn't look up a lot about that at all. Like, you know, your survival rate. I didn't look up any of it. I didn't want that lingering in my mind. The only thing I wanted was live for today. But that definitely turned into a lot of my mindset during treatments. So I have two boys, gosh, they were five and seven when I was diagnosed. So that was really

tough. You know, a lot of that went through my head, you know, I need to be there for my kids. But I had a lot of very supportive people. And then there were some that were very emotional and saw it as a doom and gloom. And unfortunately, I had to cut them out temporarily for my own sanity, for my own peace of mind. And I think everybody that encounters anything cancer– any type of diagnosis, or any type of something that alters your life, that you have to get through, no matter what it is. They may want to support you and think they're helpful, but if it's not what you need, or it's stressing you out or making you think bad, you just do what's best for you.

Jessica Thomas, LCSW, Director of Patient Education at NETRF
But even with that kind of intention, the unknown doesn't go away. And for many people living with neuroendocrine cancer, not having clear answers becomes the hardest part to live with.

Jessica Ochoa, Person Living with Neuroendocrine Cancer
The biggest thing with mine is I think what I struggle the most is– is the unknown, as you guys were, were speaking of, right? For my typical cancer, I've tried searching, right? You, you always ask, right? When, when you when the C-word gets thrown, your first question is, how much time do I have left? Right? That's always the first question that comes to mind, and it was my husband's as well. Okay, realistically speaking, how much are we talking, doctor? They can't tell you an answer. The biggest thing is that they will not tell you an answer. Because as much as I would love to think that I'm going to live many years, I don't know. And that's the worst part. I think the biggest thing that I hate living with this condition is that I don't know. We don't know– not even remotely close to how many years I have left. So I am very positive, and I have high hopes that I'm going to live for many, many, many, many years, but in the back of my head, I still have that little, little voice that tells me it could be less so because I have that, I now, I am living purposely.

Jessica Thomas, LCSW, Director of Patient Education at NETRF
What Jessica is describing, that fear of not knowing how much time you have, that's what we call *acute uncertainty*. It often shows up right at the moment of diagnosis. But for many patients, it doesn't go away. It becomes something more chronic, something that lives alongside neuroendocrine cancer. And that uncertainty isn't just about time. It shows up in treatment decisions, in side effects, in cost, in how much of life is disrupted along the way.

The NET-PRO study helps us better understand this—not just as a part of a difficult diagnosis, but as an ongoing experience. Patients may feel uncertain about the specifics of their disease, how symptoms might change over time, how treatment will impact their quality of life, and what the future really looks like.

Although that kind of uncertainty can be deeply distressing, people respond to it in different ways. For some, it's something they carry with them. For others, it becomes something they actively confront.

Gary Murphin, Person Living with Neuroendocrine Cancer
I said, okay, well, I've got, I've got to do some research. You know, that was my first internal response to this. Okay, when my wife got home from her work at that time of year, it was September, and the weather was nice, and so we did kind of something we did back then a lot, was we go walk after dinner. So I didn't tell her when she got home. I waited till we were walking, and I said, By the way, the doctor called and told me that I had this type of cancer. And I told her, because she likes to kind of remember this, and that is, I told her that I'm not the type of person who asked, Why me? I really want to learn the most about my cancer so I can treat it right, and then I want to be able to help others who also have this cancer.

I have to tell you that the greatest changes in my life came before cancer. I spent three years in Vietnam, two as a civilian, and one as an army Intel officer. And I think what I recognize most from those experiences was the fragility of life and the value of time, and both of those lessons applied to my cancer experience as well. But it also made me– the cancer experience made me aware that you know, and particularly in NETs patients, that you have to be a different kind of patient. You have to be more assertive about what you need and be better informed, you know, be a better communicator to your doctors and health professionals about your your situation. And that situation was true back in 2008 when this journey began, and it's still true today, unfortunately.

Jessica Thomas, LCSW, Director of Patient Education at NETRF
When there are gaps in what you understand about your cancer—things like your diagnosis, your treatment options, your prognosis—that uncertainty can create a lot of fear.

But when patients are able to learn more, even just the right pieces of information, it can start to bring some clarity. It can help them feel more grounded, more prepared, and a little less overwhelmed by the unknown. For many people, that instinct to understand, to gather information and take an active role—is incredibly powerful. But in a world where information is everywhere, the challenge becomes knowing what to trust, and how to use it. For Jamie, that need to understand was immediate—and deeply personal.

Jamie Metzl, caregiver
So, it was stage four, late three, early four, metastatic neuroendocrine cancer. And it was really just a devastating diagnosis, and we didn't know anything about it. And first we found out it was cancer, and, and then we were doing trying to figure out what type of cancer it was. And then we came out that there was this thing that none of us had really ever heard much about– neuroendocrine cancer, and it took a while for me to

figure out just to learn more. And so the first, I mean, because, you know, this is my field, and because I write books on the future of healthcare, I thought we really need to get ahead of this.

Jessica Thomas, LCSW, Director of Patient Education at NETRF
But there's another side to that. Is there such a thing as too much information? Because more information doesn't always mean more clarity. Sometimes, it can actually add to the uncertainty. I often think about this like a book. You need to understand the table of contents; you need to know where you are in the story, and have a sense of what may come next. But you don't need to jump ahead to the final chapters—especially when you're not there yet. Because focusing too far down the road can take you out of the moment you're actually in. And finding that balance—knowing enough, but not too much—looks different for everyone.

For Jamie Metzl, an author and healthcare futurist, the instinct was to learn as much as possible. But this time, that search for information wasn't theoretical– it was deeply personal.

Jamie Metzl, caregiver
Once we had the diagnosis that it was neuroendocrine cancer, I thought, well, I'd better learn everything I can about neuroendocrine cancer. And so, you know, I did what anybody would do in those days. That was the prehistoric days when we use this thing called Google. And, I started learning, and I came across the *NETWise* podcast, and that your organization creates, and that we're on, frankly, now. And I'm an ultramarathon runner, and so I would be out for three, four- hour training runs, training for marathons. And I would just, I basically went through the almost the entire series of *NETWise* podcasts, and that really helped me a ton. Because then, when I was interacting with our oncology, with our internist, and then we had an oncologist, I really had a background– not the specialized knowledge that the oncologist had– but I really had a breadth. And so when they mentioned, when he mentioned things like the possibility of PRRT, which we weren't, unfortunately, my dad just wasn't a candidate for based on his his scans, I had enough background to be an informed member of those of those conversations, and that ended up being really, really critical.

Jessica Thomas, LCSW, Director of Patient Education at NETRF
For Jamie, that process of learning became something he carried with him—literally, step by step. And for others, like Jackie Dong, movement itself became a way to process, to cope, and to find some sense of control.

Jackie Dong, Person Living with Neuroendocrine Cancer
My perspective on life has changed after being diagnosed. I try to just take life as it is, as much as I can– live day by day, cherish the moments, and not try to dwell on the past

and also the future, and it's very cliche, but I've really found that it's helped a lot. And then the other biggest thing that's been a benefit out of all this, I guess you could say, is I started running. I've always hated long-distance running. I was a sprinter in high school, and I was and I've always had my own thoughts about running just being like, hey, the runners are just like the athletic rejects that don't have any dexterity. They can't they don't have any hand-eye coordination, wanting to be a basketball player, so just run it in a straight line. But anyhow, I picked up long-distance running. I gave it a shot. I had heard about all the benefits– meditative, you know, just being able to challenge yourself and show up every day– and, yeah, that sort of culminated ever since I've been diagnosed, and up until the surgery, I've been just running. I ultimately was able to run a marathon two weeks ago right before the surgery, not an official one, but I did get it done in a day, so I'm pretty proud of myself for that.

Jessica Thomas, LCSW, Director of Patient Education at NETRF
Finding ways to take pride in what you can still do—and how you choose to spend your time—can be incredibly grounding in the face of uncertainty. It creates moments of control, and even moments of joy. For many patients, those moments—no matter how small—become essential to getting through each day.

Jennifer Rogers Anderson, Person Living with Neuroendocrine Cancer
I mean, if you want to run a race and compete with people, compete with yourself, compete with your, you know, your goals, not necessarily each other. So I think that's a big thing that helps me survive day to day– is, you know, doing the little things I like to do that make me feel good, and doing the things that I can do, because I've been, I've been given the grace to continue to do them.

You have to do things that make you still feel good, that you can get through it and fill your mind with positivity, happiness as much as you can. And even the days you, you may not feel good, try to find something that you know brings you happiness or peace. I mean, uncertainty can be so many things. You– I mean, I don't know day to day. I try not to focus on things I have no– like I said, I have no control over. I've learned to not dwell or focus on what I can't control. It's just not good for me.

I live for today. I take the trips. I take the vacations. I do the fun things. Tomorrow, I will drive two hours to watch my boys play lacrosse. And I think that's the things– I think we, you know, we all focus and look forward to tomorrow and forward to our future. But I think when you go through certain things in life, you get a different perspective. And my perspective is, do all the things, do all the things. Don't save them, don't, Oh, I'll do that, you know, I can't, or I'll do that in two weeks, because you may not have two weeks. Anything can happen. So you know, I, I survive for today. I strive for tomorrow. But I, I survive for today.

Jessica Thomas, LCSW, Director of Patient Education at NETRF
And for many, those choices—to show up, to be present, to do the things that matter—take on an even deeper meaning. Because it's not just about getting through the day, it's about holding onto the moments that make life feel like life..

Jamie Metzl, Caregiver
If you're fighting for life, you need to know why you're fighting for life. Life has a value because of the value we inscribe in life. And so at the time of my dad's diagnosis, he was crying because his oldest granddaughter was going to have her Bat Mitzvah about a year later, and we were told that he only had 11 months to live, and he was crying. He goes, I don't want to miss– I don't want to miss the Bat Mitzvah.

And so I was very nervous after my dad started on this targeted agent treatment, because he was tolerating it well. And I just remember that day so well, of just this joyous shock of going through these scans, and across the board, the cancer was in remission, and it was pretty amazing, and that was what allowed us to do a lot of wonderful family things

Not only did he go to the Bat Mitzvah and dance at the Bat Mitzvah with with our mom, but his beloved Kansas City Chiefs went on an incredible run. So after his cancer diagnosis, the Chiefs beat the Eagles in an incredible come from behind victory where Patrick Mahomes had a bum leg, and it was a miracle victory. And then the second year, when my dad was doing so well as a result of this treatment, we decided we were going to surprise him, my brother, Jordan and I, and so we flew him to Las Vegas, where we met him, and we took him to the Super Bowl. And my brother Jordan does some work with ESPN. He's a physician, but does work with ESPN. And when ESPN heard that a Holocaust survivor, cancer survivor, Kansas City Chiefs super fan was coming to the game, they pulled out all the stops. They gave him a suite on the top floor of the Mandalay Bay Hotel in Las Vegas, just across from the stadium. And when he came into his room, the entire bed was covered with Kansas City Chiefs swag, including a helmet signed by Patrick Mahomes. And we went there, we went to this game, and it was kind of depressing for most of the game, because the Chiefs were getting killed, and they were playing terribly, and in the fourth quarter, because of my dad's wishes– and maybe because of of Patrick Mahomes– the Chiefs came from behind and won in overtime. And just it was the three of us there, and actually it's the cover photograph in the AARP piece was just seconds after the Chiefs won, and it was this double miracle, like we had pushed back the cancer, not forever, we always knew that, but enough to seize these moments of life.

Jessica Thomas, LCSW, Director of Patient Education at NETRF
Moments like these can feel like a breath of relief… a chance to hold onto something good. But for many patients and families, that sense of certainty is often temporary.

Because with each new scan… comes a new wave of waiting, wondering, and what many have come to call “scan-xiety.”

Gary Murphin, Person Living with Neuroendocrine Cancer
The “scan-xiety” experience, this is very real. I mean, it really is. And in the early days when I was trying to deal with this cancer and the scans, frequent scans, I might add, I spent, you know, a number of sleepless nights. My lesson learned was I needed to be my best advocate, and that meant I needed to be as well informed as I could be in order to make decisions with a doctor about my, about my case.

Jessica Thomas, LCSW, Director of Patient Education at NETRF
Advocating for yourself is such an important part of navigating a disease like neuroendocrine cancer. But for many patients, that doesn’t happen in isolation. It often grows out of something else, the people around you, the support, the relationships, and the sense that you’re not facing it alone.

Jackie Dong, Person Living with Neuroendocrine Cancer
It takes a village, and I have an enormous village, and I am so, so grateful I have a loving mother, a loving father, a loving brother, older brother, and…emotionally, it's been a lot, and I thought about it like the other day, like it would really suck if I didn't have that support. And I also have a lot of loving and very thoughtful friends that have also really been supportive of me. That's one of the things that's– that, that was one of the immediate things that went through my mind.
My company has been super supportive, also the people I yeah, I'm so so lucky that everything else is going well for me. I'm a software engineer, and I work remotely. My team, teammates, manager, are all super supportive and just want me to do as much as I can, but just worry about my health as a priority. I have been working pretty much full time just because, you know, I don't want to just sit idly, like this is an impact to me too much physically, and so I don't want to just sit idly and sort of bubble up with my thoughts. But having cancer is a very tough thing. And, it’s okay to internalize that and all of the emotions that come with it. It can be so isolating, and it can change fundamentally the way you view yourself, but that's okay, and internalizing that– I'm not even done, like, internalizing this post-surgery, like a week ago, I was like, wow. Like, I can't believe I have to deal with this. I've cried a lot. I've, yeah, I've cried, I've grieved a lot, but I've also laughed, smiled. You know, it's the whole broad spectrum of emotions, so it's okay to be sad, it's okay to feel lonely. You're a human being. You have cancer…. and that's sort of what I've been telling myself. I'm like, eight months into this, so, yeah, I'm still learning myself.

Jessica Thomas, LCSW, Director of Patient Education at NETRF

And for many people, that process of learning—about the diagnosis, about themselves, and about how to move forward—doesn’t stop. It continues over time. And how people seek out that information… is changing.

Mark Lewis, MD, Director of Gastrointestinal Oncology, Intermountain Healthcare
So you and I are having this conversation in 2026 and I used to think it was common and understandable that when a person was facing a diagnosis of a serious illness that they would go on the internet and they would use Google, like there was all this reference to Dr. Google.
But I want to update that part of our conversation and say what I see happening now with a huge number of my patients, is they ask AI. And what is so interesting to me about that is that AI– and I know there's all kinds of different models, but as a general rule, AI does not want to give you incomplete answers. AI confabulates. So AI will often fill in those gaps with misinformation, like it will often tell you what you want to hear.

Jessica Thomas, LCSW, Director of Patient Education at NETRF
Access to that information can be empowering… but only when that information is accurate. In a world full of Google searches, AI summaries, and endless opinions online, one of the biggest challenges is knowing what to trust. Because information can either reduce uncertainty, or deepen it. And learning how to separate helpful guidance from overwhelming noise becomes a part of the journey in itself.

Jackie Dong, Person Living with Neuroendocrine Cancer
It's so easy to, you know, go on Google. And even when you go on Google Now, you're not really looking at the results. The first thing is an AI-summarized, you know, finding an answer, of, like, whatever you're searching and you can sort of fall into a rabbit hole and immediately trust that.
But yeah, again, reiterating and echoing the theme of, like, self-advocating. I, I just think that, like me personally, I really wanted to know sort of the availability of treatments out there for me, as well as, I guess, the future and ever so, ever-evolving landscape of like, NET therapy. And that's how I found NETRF, actually, because, you know, I, I've done a lot of digging, believe me… NETRF has a lot of digestible and easy-to-understand information, and I love the monthly, like updates, as well as yearly with, you know, that big one with, like, all the sort of promising and upcoming treatment and therapy. That's stuff that I really like to look into.

Jessica Thomas, LCSW, Director of Patient Education at NETRF
Jackie’s referring to NETRF’s *Know your NETs Annual Patient and Caregiver Virtual Conference*. It’s one of the many ways patients can stay informed and connected to the latest research and emerging treatments. And for many, that kind of knowledge

becomes more than information. It’s hope and becomes a foundation for how they move forward.

Gary Murphin, Person Living with Neuroendocrine Cancer
Patients have to understand–they have to become their own, they are their own best advocate, and they have to understand the nature of their their cancer.
I've never labeled what I do to cope with my NETs, but in reality, I am trying to survive and I'm trying to thrive.

Jessica Thomas, LCSW, Director of Patient Education at NETRF
Gary touches on something important—this idea of not just surviving… but thriving. And in the context of uncertainty, thrivership doesn’t mean having all the answers. It means learning how to live well… even without them.

Mark Lewis, MD, Director of Gastrointestinal Oncology, Intermountain Healthcare
So we have many, many metrics that matter to us because we, the oncologists and the scientists, because we can measure them. But my favorite quote about this came from one of my mentors, and he told me, Mark, not everything that can be measured matters, and not everything that matters can be measured. So when you talk about thrivership, what that means to me is we can't always restore someone to the vitality and fitness they had before diagnosis.
I haven't been the same person physically since I had surgery in 2017, and I knew that going in, I knew this was both a life-saving and a life-changing operation. I had sort of no misconception that I was going to be completely the same before and after.
Having said that, you know, now I've enjoyed, literally enjoyed, years of life in a different body. And to me, that's part of thrivership. It's, you know, some people like the phrase “new normal.” Some people don't. It's adapting to your new circumstances to the best of your and your doctor's ability.
Thrivership is often the result of a negotiation between the patient and the doctor. And the term I love for this– and I didn't come up with it– is shared decision making. It's not just being alive, which is obviously one goal. It's being alive with quality of life. And again, I cannot stress enough, our studies of this to date are very, very scant. I do think and hope it's where medicine and oncology in particular is going.

Jessica Thomas, LCSW, Director of Patient Education at NETRF:
And that distinction— between what can be measured, and what actually matters — becomes especially clear in the day-to-day experience of living with neuroendocrine cancer.

Mark Lewis, MD, Director of Gastrointestinal Oncology, Intermountain Healthcare
There are times I've gotten to see my surgeons and they're like, Mark, your scans look fantastic– and yet I felt awful. I might have felt awful that day. I might have felt awful for weeks or months. One really interesting aspect of that is wearables. So when patients wear either a smartwatch, or some patients will wear a smartring, that's actually a way that we can kind of convince these scientifically minded people who like quantifying things. That's, that's a way we can convince them that you can do this both ways, but, but the final verdict really comes from the patient's subjective experience and to thrive, I think means, can you do most or all the things that you want to do.

Jessica Thomas, LCSW, Director of Patient Education at NETRF
And what Dr. Lewis is describing is something many patients experience. You can have good news on paper, and still not feel okay. Because the data doesn’t always match the lived experience. And while information can be incredibly valuable, it doesn’t always take the uncertainty away. So for many patients, the question becomes—what do you do with that uncertainty? How do you live with it day to day?

Part of that begins with shifting the goal. Instead of trying to eliminate uncertainty, we start learning how to live alongside it. That may look like creating small moments of stability, simple routines… movement… breathing… things that can help regulate your body and bring you back to the present. It *also* means learning to separate what’s actually happening from what you may be feeling. Because uncertainty lives in the future… But reality is what’s happening right now. And when we can gently bring ourselves back to that, it can ease some of the anxiety. Over time, it becomes about building a sense of steadiness. Not controlling everything, but knowing you can handle what comes. And finding small anchors in your day– a routine, a conversation, a walk—things that remind you that your life is still happening here. Because uncertainty doesn’t go away, but your relationship to it can change.

Jamie Metzl, Caregiver
My ultimate message after a cancer diagnosis, by all means, do what you need to do. Do it as well as you can, but don't make that the only story. Make the real story celebrating the life that you've had and the life that you still can have.

Jessica Thomas, LCSW, Director of Patient Education at NETRF
These are just a few ways to begin navigating uncertainty—but you don’t have to do it alone. There are resources, conversations, and communities available to support you along the way, including more at NETRF.org, our *Thrivership* series on YouTube, and the opportunity to reach out directly. Because while uncertainty may be part of the experience, so is connection, support, and the ability to move forward.

Jackie Dong, Person Living with Neuroendocrine Cancer
For those newly diagnosed, there's hope. You know, the landscape of NETs is evolving rapidly. A lot of the systemic and novel treatments weren't even available a few years ago, and so there's a lot of good progress there. So stay hopeful, you know, try to keep your head up. I'm trying to keep my head up. It’s funny, because I've always been a pessimistic person. I was a little jaded. I'm still definitely jaded, and, you know, have some negative outlooks on life, but I think positivity is something that you, if you manifest and think you know positive thoughts, it does influence your behaviors and patterns. So be positive and stay strong.

Mark Lewis, MD, Director of Gastrointestinal Oncology, Intermountain Healthcare
Our days are valuable because they're finite. I mentioned my father, his oncologist was very straightforward with him that he was terminal. He finished a book that he had been writing for years. A quote from that book, and I just love it, it's probably my favorite quote from any book, so he says, "The crisis of cancer is the opportunity now, however brief or lengthy, to discard the trivial and the shallow and to fill every moment in relationship with meaning, intensity, and value."

Jessica Thomas, LCSW, Director of Patient Education at NETRF
That quote is powerful… and worth hearing again: “the crisis of cancer is the opportunity now, however brief or lengthy, to discard the trivial and the shallow and to fill every moment in relationship with meaning, intensity and value.”

Even in the face of uncertainty, people find ways to move forward— to stay connected, to stay informed, and to live with intention. And while the future may not always be clear… the way we show up for each day still is.

Thank you for listening to *NETWise*. I'm Jessica Thomas, Director of Patient Education at NETRF, and you're listening to *NETWise*, the podcast designed to inform, empower, and guide patients and caregivers through the world of neuroendocrine cancer. This episode was brought to you in part by the generous support of Lantheus, Novartis Boehringer Ingelheim, Exelixis, and ITM.

Special thanks to everyone we interviewed for this episode. For more information, visit our website at NETRF.org. You can find a whole library of *NETWise* episodes on different topics at NETRF.org/podcast, where you'll also find infographics and videos that expand on this material. And if you would like to join NETRF in our mission to fund research for neuroendocrine cancer or help support educational programs like this *NETWise* podcast, please go to NETRF.org/donate. If you have a story to tell about your own neuroendocrine cancer journey, please email us and let us know: podcast@NETRF.org. *NETWise* is a production of NETRF. We are committed to improving the lives of patients, families, and caregivers affected by neuroendocrine