

Episode 34:
Young Adults living with NETs
Episode Update

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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 at the Neuroendocrine Tumor Research Foundation.

In today's episode, we're going to talk about the experiences of young people living with NETs. This is an update to an episode that originally came out in 2020.

These patients face a specific set of challenges unique to their age, and they need particular kinds of help navigating the NET journey. This group of patients is often called "AYA," which stands for Adolescents and Young Adults.

For this episode, we're going to concentrate on the "YA" part of AYA - those who are grappling with a cancer diagnosis as college students or young professionals.

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But first: when we say “young adult,” what exactly does that mean? It turns out the meaning is different depending on where you are in the world.

Dr. Aman Chauhan is a medical oncologist, who leads the University of Miami Neuroendocrine Cancer Program.

Chauhan: *It varies by the countries because each country has their own sort of regulatory environment, how they want to allocate resources for pediatrics, young adults and adults. So a lot of it is really dictated by that.*

Lewis: *United States has the broadest definition, which is an age range that spans from 15 to 39, which obviously is extremely broad and covers a lot of biology and even psychosocial circumstance.*

Dr. Mark Lewis is the Director of Gastrointestinal Oncology for Intermountain Healthcare, which serves patients in Utah, Idaho, and Nevada. Dr. Lewis is also a NET patient himself. He was diagnosed with a pancreatic neuroendocrine tumor at the age of 30.

Lewis: *This is a group that's near and dear to me because until quite recently I was considered a young adult, and have now aged just barely out of that category. But when I was first diagnosed with neuroendocrine tumors, I did fit pretty squarely in the middle of what we consider AYA.*

Unfortunately, the number of young people facing this challenge is on the rise.

Among older adults, the incidence of cancer has fallen over the last several decades -

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Chauhan: *But the alarming signs are when you look at the patient population under 30, under 50 for sure, we're seeing an increasing spike in the diagnosis of cancer.*

The vast majority of these cases are among more common cancers than NETs. But while NETs remain rare among young people, the rate of diagnosis is increasing.

Dr. Jaydira Del Rivero is a medical oncologist and a board certified endocrinologist at the National Institute of Health.

Del Rivero: *Overall, we have seen an increase in incidence of neuroendocrine tumors in the last few decades. And we have seen as well in pediatric patients or young adults that there is also an increase in incidence as well. What we know as well is that the type of neuroendocrine tumors that we have seen an increase in incidence are lung, breast, as well as appendix.*

A large part of why these numbers are increasing has to do with better diagnostics. Scanning techniques are becoming more sensitive, and imaging has advanced.

Chauhan: *Also especially in young adults, we are doing more scopes. The frequency of patients getting an endoscopy or a colonoscopy is increasing for X, Y, Z reasons. Somebody might have reflux symptoms. Somebody might have GI bleed. So more of the patients are getting endoscopies and they're getting diagnosed with early-stage NETs.*

But that doesn't seem to completely explain this trend. Dr. Manisha Shah is a medical oncologist at the Ohio State University Comprehensive Cancer Center.

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Shah: *So, that's part of increase, but other part of increase seems a true increase in the frequency of these diseases. I wish I knew the answer why we're seeing the increase so we can work on the prevention strategies, but we don't really know.*

Del Rivero: *We still don't have a specific answer why this may be happening, and that's why we need to do more research to understand that. There is a concept of epigenetics, meaning whether there may be mutations in the environment as well that is helping develop this, but this is a research question.*

In fact, the number of younger people living with NETs is probably higher than we realize. These patients are likely to be misdiagnosed, sometimes for a long time.

Shah: *You know, we wouldn't think 'abdominal pain, oh, is there is something seriously wrong with these patients,' because they are young. The abdominal pain, diarrhea would be labeled as like irritable bowel syndrome or indigestion, some abdominal pain related to maybe the exercise pattern, if they have that. You know, musculoskeletal pain and shortness of breath would be more like anxiety or panic attacks.*

Del Rivero: *They think it could be something else like eating disorder, anxiety, puberty. So I think it's important to recognize that these symptoms can occur and that can be associated with neuroendocrine tumors and not with something different based on their age of presentation.*

Because of how unlikely it is for a young person to be diagnosed with cancer, especially an uncommon cancer like

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NETs, it can come as a shock.

Shah: *While none of us want to get sick, when a young person gets sick, it's an extra hard blow because we're supposed to be just living a normal life. We're not ready to have any diseases.*

Here's Kaylen Fletcher. She's a licensed independent clinical social worker who runs a support group for young adults with cancer at Beth Israel Deaconess Medical Center in Boston:

Fletcher: *Fear... denial... how could this be me? I think that's the biggest thing I see is, 'I was just at the gym last week and going on a date. How could this be real?' It's the sense of shock because there's no real reference point. Most people in this age group really don't have a lot of experience with serious illness, so it can really kind of feel alienating to be the one, the person who has this serious illness and needing to explain that to people and just feeling different.*

Shah: *They also tend to suffer longer without a diagnosis. So, they have a lot of things to process emotionally to say, 'Gosh, over the last 2 years, I was told that all I have is irritable bowel syndrome, and now I have stage four cancer.' So, this kind of anger or mistrust to the medical system that we cannot blame them for because that's what they have experienced. And so now, to start this new stage where they have to be able to trust the medical system is another layer that comes into the conversation. Fundamentally, they have to know that this is a new step and we want to set in the right direction.*

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Hannah: *My name is Hannah. I'm 24 years old. I'm from Iowa, northeast Iowa, and I was diagnosed with pancreatic neuroendocrine tumors at the tail end of 2023.*

So, for years, I was unsure what was wrong with me and I went through many doctors trying to figure it out. I was always getting low blood sugars, I was getting dizzy, I was having blurred vision. And then when I was in college, it kind of got worse because I started having tonic clonic seizures. So I went through many doctor's appointments with neurologists trying to figure out what was wrong with my brain.

And then after one of my seizures, I was in the ER and the doctor had come up to me and said, 'You know, you might want to see an endocrinologist because your blood sugar is looking a little weird.'

And I didn't think much of it, but I did make an appointment with an endocrinologist. And I told her my history, and right away she ordered a CT scan. And within a couple hours they called me back and said, you need to get in here. So I skipped my classes for the day, and I went in and talked to my endocrinologist, and she said, 'I've only seen one of these my entire career, but we did see a tumor on the head of your pancreas in the CT scan.'

And she referred me to Mayo Clinic. And within three weeks they got me in for a surgery. And they were going to remove the head of my pancreas with the Whipple procedure. But a couple of days before my surgery, I did a CT scan at Mayo Clinic, and they had found another tumor on the tail of my pancreas that was about three to four times the size of the original tumor that they found in my previous CT.

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So they had to kind of rearrange all the surgery plan and they decided to go ahead and take the distal part of my pancreas completely off, and then they enucleated the tumor that was in the head of my pancreas.

At that point, at the end of my surgery and as I was recovering in Mayo, I still had not been told it was cancer. And it wasn't until I was referred to an oncologist for a follow up appointment about a month, month and a half after my surgery, that I kind of put the pieces together of what was going on.

And I walked into my oncologist's office and I asked right off the bat, 'is this cancer?' And he held my hand and, and broke the news to me and my mom and I were there and it was incredibly hard to hear. But I think it was more relieving than anything because I finally had a reason for those years of really scary symptoms.

I did struggle with anxiety and a little bit of depression after getting diagnosed because there's a lot of unknowns and there's a lot of questions that I had.

You know, my whole life I'd always had these plans. I'd always had these goals, whether it was personally or professionally to reach. So graduate high school, graduate undergrad, get into grad school, graduate that. I always had something that was up next on my plate and I really focused on that.

And so I was diagnosed with my neuroendocrine tumors in the midst of grad school. And I withdrew from my program, which was the hardest decision I've had to make this far in my life. But I wanted to give my body and my- myself the time

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to heal from my surgery. And I wanted to be close to those that loved me.

But it's been a year post surgery for me and I've had time to reflect, I've had time to ask the questions and do the research that I needed to understand my condition.

And now I've taken a step back and realized that it's okay to focus on the now. I still have those professional and personal goals and I'm still doing things to reach them. But what I'm doing is just more out of happiness.

My last checkup was in November and they did a CT scan and some blood work and as of right now, there is no growth. So I'm feeling good.

There are several aspects of young adult NETs that can make them difficult to treat. First, some NETs that are rare in adults are more common in young people, like NETs of the adrenal gland. That can make it harder to find a specialist for proper treatment.

Second, overall treatment strategies used for NETs in adults are not well-studied in younger patients.

Chauhan: *The basic tenets of how we manage a neuroendocrine tumor patient is very similar regardless of age because the biology of disease is very similar. But it's always good to develop drugs which are specifically for pediatric patients. A child or a young adult is not just a smaller adult.*

Del Rivero: *The way we treat the pediatric population is based on the adult studies. They have some adjustments in the dose based on their height and their weight, and then whether that's effective as we have seen on the adults is*

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something that is a question that to me isn't answered.

Some studies are being done to try to answer these questions. One study currently underway is called NETTER-P. It's looking at the use of PRRT in treating some kinds of NETs in young people.

Chauhan: *It's already FDA approved for the use in metastatic gastroenteropancreatic neuroendocrine tumors in adult patient population. But this would- this is the first study to be done in the young adult patient populations. Hopefully we'll see some data soon and that would give access to adolescent and young adult patients with good quality medicines.*

Even with the treatments that are currently available, many young patients can live with the disease for a long time.

Lewis: *I have actually had to conceive my own illness as chronic, something I will never be cured of, but one that still allows me to work, and be productive, and do something I find very fruitful. I'm very, very blessed in that.*

But managing NETs as a long-term condition also presents challenges. This includes thinking about downstream side effects that wouldn't be an issue for an older patient.

For instance, some treatments could have serious side effects 20 or 30 years down the line. That's not much of a problem for a patient in their 80s, but it could be a serious concern for a patient who is 18.

Lewis: *You have to exist in the moment and cure the person of the disease if you can, but you also have to think about: How are you affecting this person in the long run? And it's hard not to sound ageist, but that really is part*

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of the calculus when you're taking care of young people. The average age of a patient in my practice is 68. And so, there's less years of life to protect is one way of looking at it when you're treating an older person as opposed to life years gained treating a younger person.

This might make a clinician think twice about giving a treatment to a young person that they would have no hesitation recommending to an older patient.

Chauhan: *So it boils down to risk-benefit of some of these treatments, right? And I think individual decision needs to be made regarding the urgency and the need of certain treatments. So if a patient is not a surgical candidate, then effective treatments that are radiopharmaceutical can certainly play a role.*

And in addition to the long-term and cumulative effects of different treatment options, the cumulative effect of radiation exposure from imaging also has to be considered.

Lewis: *So, when you get a CT scan, it's a glorified stack of x-rays. That's literally what it is, is x-ray upon x-ray then reconstructed in the computer. So, CT is computed tomography. So, it's putting it all together, really allowing us to reconstruct you in 3D, if we want. But a standard CT scan, say of the abdomen and pelvis, is 200 x-rays. And for a long time in oncology, the dominant paradigm had us scanning people every 3 months. So, if you do that over 5 years, that's 4,000 x-rays, which in someone who has already had cancer is potentially enough to stimulate another one. So, one of the things I'm very cognizant of in myself and in patients I'm following over time is radiation burden.*

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One of the ways that this radiation burden may be reduced is with new blood tests that are being developed. These can be used to monitor the disease, and could potentially lessen the amount of imaging a patient needs.

***Chauhan:** So that part of the field is getting exciting. And there's some really promising blood based biomarkers that we are being studying and hopefully if it turns out to be accurate, then that might offload some of the CT scan requirements.*

One unfortunate truth about cancer treatment is that some medications and procedures can have serious consequences for a patient's ability to have children.

***Shah:** When one enters into the advanced stage therapeutics, certainly we have several targeted therapies as well as cytotoxic chemotherapies that are definitely high risk for causing infertility.*

***Lewis:** So, some of the drugs that we use in NETs- not many of them, but it's some - are alkylating agents, and it can damage a woman's ovaries and make it almost impossible or much more difficult at least for her to have children. So, that actually is a conversation that we often have in AYA oncology, whether we're dealing with NETs or not.*

In young adults, this can force really consequential decisions that they might not be ready to make.

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Fletcher: *Yeah, the fertility piece is really hard because it's another thing that feels like it's being taken completely out of your control. And oftentimes for folks, especially in their 20s, most of my patients aren't really thinking of having kids in the next year or so, but having fertility impacted by treatment forces them to kind of think about that and whether they want kids before they're ready and before they wanted to.*

Del Rivero: *Am I going to get married? Can I father a child or can I have - If it's a woman, can I carry a pregnancy to term? What are the options? And that's a very common question that I have with a younger patient.*

Fortunately, as hard as these decisions are, there are some strategies available for preserving fertility.

Shah: *There are several things one can do in advance. So, the more in advance a patient is informed, they have time to think about it and either if they want to have a pregnancy that they would plan a pregnancy if they're able to because they're not on any medications or that they want to have a referral to the specialist for ova preservation or sperm preservation and banking and things of that nature. So, these days, we have a lot of technology that make so much possible.*

Unfortunately, these strategies can often be very expensive, so that needs to be planned as well.

Lewis: *Insurers... And I have to bring this up because there's the practice of medicine, but then there's the business of healthcare, we have to consider both of them.*

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Insurers do not - and you can argue this is shameful - do not universally cover oncofertility, meaning efforts to preserve someone's childbearing potential even when it's endangered by lifesaving cancer treatment.

All in all, these questions about family planning and fertility can sneak up on a young person who is already overwhelmed by dealing with cancer, and can strike them in ways that they weren't expecting.

Fletcher: *It brings up a lot of emotion. And I think it surprises a lot of people the emotion that it brings up because it can feel like a real loss, kind of this loss of spontaneity around thinking about these things, and it turns into much more of like a medical plan and decision. And it's really hard. It's really hard.*

Questions of family planning can be complicated by the fact that neuroendocrine cancers in younger people are sometimes caused by genetic conditions. And in many cases, these can be passed down from parent to child.

Lewis: *Neuroendocrine tumors that tend to happen in really young people like adolescents are probably driven by germline mutations, so meaning that they inherited that risk from their parents or it actually happened de novo.*

So, there are some mutations that your parents don't have at all, and they just happen in you. So, tuberous sclerosis, for instance, is a condition where that actually happens more often than not that the patient is affected, is the first one in their family to be affected.

Dr. Lewis has a genetic mutation called multiple endocrine

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neoplasia type 1 or MEN1, which affects a person's thyroid. This often causes symptoms related to the way the body processes calcium - some of which can be quite painful and debilitating. In a significant percentage of patients, MEN1 can also cause the development of pancreatic NETs.

***Lewis:** So PNETs in MEN1 are not universally prevalent. And the other word that we use in genetic syndromes is penetrance, meaning that if you have the mutation, how likely are you to have a given condition like, say, PNETs in MEN1? So, hyperparathyroidism is 100% penetrant in MEN1, meaning if you have MEN1 and you live long enough, you will get hyperparathyroidism. The penetrance of PNETs is not nearly that high and the estimates vary, but it's probably at least half.*

However, PNETs are the #1 cause of premature death among people with MEN1.

***Lewis:** It used to be that MEN1 patients died of stomach ulcers. They don't anymore, thankfully, because our medicines have gotten so much better. Now, the main threat to life is PNETs, and specifically PNETs that either are hormonally overactive and or PNETs that spreads to the liver.*

For Dr. Lewis, as for many younger NET patients, diagnosis of both his NET and the underlying genetic condition that caused it came as a surprise.

***Lewis:** When I was 30, I was just starting my cancer*

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training. I had horrible abdominal pain. And showing you the folly of self-diagnosis, I actually thought it was appendicitis. But when I went in to get checked out, it was actually my calcium level was very high and what that does is it's almost like the brakes on your gut. So, I had a condition called bilious where my bowel just wasn't moving at all, and that can be quite painful, and that's actually what was setting me off.

So, I'd already gotten through medical school and residency, so I was committed to my profession. I'd already invested a lot of sweat equity and student debt at that point. So, I was pretty convinced that this is what I wanted to do. And I was married. And so, I almost sort of felt like I had sold my wife a bill of goods. Like when she married me, she didn't know sort of what she was getting into. And you can argue the other way too, is that when you already know as a young person that you're dealing particularly with a hereditary syndrome, it does affect your relationships and sometimes your sort of willingness to have a family.

By the time I found my syndrome, I had already had my daughter, and I kind of always wondered in hindsight would our decisions around having a family have changed if we had known before we started having kids that I had this condition because there's a 50/50 chance that I would pass this on to each child. As it happens, that daughter is unaffected, but I also have a son who is affected.

He's 9. His name is Alan, after my father, and he is a ball of energy. And he has zero, at this point, outward signs of MEN1. And my wife is a pediatrician. And we had a long talk actually, especially once he tested positive, about how to tell him. And it's interesting, I've actually... People

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love to tell you how to parent. I think everybody has to kind of figure out how to do it on their own, but some people have told us, or told me at least, that we've robbed him of his autonomy because we should have waited till he was 18 and then allowed him to find out this on his own terms. Personally, I would not have wanted to celebrate my 18th birthday with news that I have a genetic condition. And I think the counter argument there is to the extent that we can, we try to normalize this for him in the sense that he understands now when he goes to the doctor, it's slightly more involved than, say, when his sister goes to the doctor.

So, my son really has viewed our condition honestly as something that we share. We have a special handshake that we do, and he calls it our shared tummy troubles, which I find very endearing.

And the other thing is I'm an only child, so if I hadn't had an affected child, this syndrome in my bloodline actually probably would have ended with me. So there is a little bit of guilt, to be honest with you, associated with the notion of transmitting the syndrome on.

I took sort of a huge step towards prolonging my life by temporarily endangering it. So, by doing the Whipple surgery in 2017, it's the largest operation I've had by a long shot, it was really an investment in my current state of health. So, it was a big, big surgery. I had complications from it, required feeding tubes and a variety of other things for months on end. But ultimately, it's been worth it because now I'm here. I feel fine. I do take pancreatic enzyme supplements because I have lost about half of my pancreas and that affects digestion. Other than

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that, I feel great. I feel able to do the job that I love. I'm very active with my family, and I'm very fortunate. But I also live in a state of, without sounding paranoid, surveillance.

With so much to learn and so much to think about, getting a NET diagnosis in your 20s or 30s can be extraordinarily challenging.

Fletcher: *There's usually just a lot going on even without a cancer diagnosis. Most people are really discovering their identity independent of their parents and families. They're beginning to make their own money and make financial decisions. They're deciding who they want to spend their time with. And many, many folks are beginning to think about serious romantic partnerships and family planning. So, therefore, if you put a cancer diagnosis into all of this, it's really emotionally confusing and complicated.*

These complications exist on several levels for young adult NET patients – starting with basic questions of logistics and finances. Very few people in their early 20s come to a cancer diagnosis with many financial resources or experience with the healthcare system.

Chauhan: *It's also very helpful to engage a social worker earlier in the younger patient in order to understand the insurance issues and provide all the help that we can to younger patients because they are in this very vulnerable state that they might have a good coverage or they might be losing a coverage, they might be under their parental*

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coverage. So it's really important to provide them as much resources as possible.

Lewis: *One of the huge things to talk about is insurance. Things really change at age 26. And so, again, this is going to be the case for as long as we have the Affordable Care Act. So, under the ACA, you can get coverage under your parents, sort of living under that umbrella, up until 26. And then we've noticed a drastic shift in financial toxicity as people then get into their very late 20s, and it's because largely they're having to acquire their own healthcare coverage.*

And I often feel like it's double jeopardy because a lot of healthcare coverage in this country, as you know, is tied to your job. And if you're too sick to be employed, then it's very, very difficult to secure affordable health insurance. It's almost like these young people sort of get hit both ways. We're seeing that to be an enormous struggle. Some of the treatments we're talking about are hugely expensive. I mean, I often tell patients that if you're just paying market price, PRRT probably costs something on the order of \$160,000 over the 4 treatments.

That's money that very few young adults are going to have unless they have a trust fund, and so you can see how readily treatment for NETs can bankrupt you. And again, it can hit you both ways. It can make you less employable, and it can make your coverage more expensive.

Young adults who are too sick to continue working will often need to explore programs such as social security disability benefits.

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Fletcher: *And that's really challenging for anyone. However, most folks in their 20s have never even thought of applying for disability or taking time away from school or work, and it's really hard to put a pause on those things.*

And perhaps the hardest thing of all is that young people are responsible for managing their own care - often for the first time. Is it up to patients to make decisions about how, and when, and where to be treated. And they also need to attend to their medical records, and make sure that all the members of their care team have the information they need.

Shah: *What I always tell patients is that the patients are my collaborators and I really am very grateful for this collaboration. Many of the ideas, many of the energy that I get to do what I do comes from these one-on-one conversations between patients and myself, and so I'm very grateful for that.*

On top of all these logistical challenges, there are huge social challenges. Interpersonal relationships of all kinds can be strained by a cancer diagnosis, and learning to navigate these changes can take time.

For young adults, this often starts with their relationships with their parents.

Fletcher: *The dynamics that parents and children have like adult children can be really complicated as we know. It's also very common during this time that parents often kind of regress. They see their child, even though it's their adult child, really sick, and they kind of go back to how they acted when their kid was 3 or 4. And I see that a lot where they just kind of want to be all-hands-on-deck,*

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really involved, there all the time.

Del Rivero: *It's kind of like treating the whole family, right, as a nucleus of what's going on. Because as we know, it's affected the whole family. It's not just the patient that is diagnosed with the neuroendocrine tumors, but it's also the family members, caregivers, but especially parents, which has a greater sense of responsibility whenever they have somebody at home that is- requires the care.*

But the truth is that even as a young adult, you are an adult, and YOU are the ultimate decision-maker about your care. This can be overwhelming, but it can also be empowering. Who you allow in your circle is something you can take control of at a time when it may feel like everything is out of your control.

This also applies to how you spend time with friends.

Fletcher: *I think that that is one of the biggest fears of especially younger folks with cancer is, you know, 'I don't want to be that person. I don't want to be the person like, 'Oh, the friend who has cancer' all the time.' And I think for some folks, taking control of that and setting boundaries with friends, you know, 'For 20 minutes of our time today, we can talk about my cancer, we can talk about what's going on with me, but then I want to switch gears because I want to hear about what's going on with you. I want to talk about The Bachelorette from last week. I want to talk about the other things that make me, me,' and realizing that cancer is a piece of your identity and it's always going to be, but it's not all of it by any means. So, making sure to kind of set the tone with friends - with friends and family - can be really helpful, and that takes*

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work. That definitely takes work, and it takes practice.

But this is important work. Building and maintaining positive relationships with friends and family can make a huge difference.

Fletcher: *I have definitely experienced patients who are just like, 'I'm done. I'm just going to kind of hole up and not talk to anyone.' And that's really hard, and it's something that I work a lot with people who just kind of turn inward. And over time, people tend to realize that social support is one of the best tools for getting through a cancer diagnosis and getting through cancer treatments.*

With that said, patients tend to figure out on their own who the people are who are going to be most supportive to them, who they're going to want to come to appointments with them, who they're going to want to talk to about their hard days. And there are going to be certain people, especially within a peer group, within a friend group, who might not be able to tolerate that and who might not be the best to go to for all those things. And it might surprise you. Oftentimes, I have patients who are like, 'The people I was expecting to kind of be there and be my go-tos were not, but the people that I did not anticipate to be there all the time were. They were the people who I wanted to come to hard appointments with me and I wanted to talk to about the really tough stuff.'

Carrying the weight of all these new challenges, both medical and social, can be really difficult for young people with NETs. There are many ways they might react to their situation - from trying to ignore it, to giving up hope.

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Shah: *With young adults, you know, there could be scenarios where they have this sort of a positive attitude, everything is going to be okay, so the sense of taking things lightly. And so, I try to emphasize the seriousness of this disease and the long-term consequences of this disease.*

Lewis: *I often tell patients at the beginning I intend to have a relationship with them therapeutically that will last decades, and I don't want them to fall into the self-fulfilling prophecy of nihilism, where they forego care that can be life preserving because they just assume it's all for naught.*

Shah: *So, I think that is kind of the first thing, to just get on the same wavelength about what these diseases and what its implications can be in their lives and their family and friends' lives. The goal here is to really open up the space where they can be living their life as fully as possible so that we are not imposing limitations. We don't want them to clear up rest of their life to just be a full-time patient and talk about like, "Okay, I have this, I have that, now I can't get married or I can't have travel." Not let cancer cripple you because that would serve no purpose, whether one has 2 weeks to live or 2 years or 20 years to live or longer. And that's what we are here to help them live their life to their fullest potential.*

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Bethany: *My name is Bethany Ross. I am 36, and I live in Southern New Hampshire.*

My diagnosis is stage four, grade one neuroendocrine cancer with a pancreas primary that spread to my liver, lymph nodes, and now I'm dealing with it in my duodenum. And I also had a diagnosis of a separate primary in my appendix.

I was 30 when I got diagnosed. So I'm coming up, it'll be 6 years in August that I've been living with, stage 4 neuroendocrine cancer.

At the time I started to get sick, I was running half marathons, so I was probably the healthiest I had been in my life, and I started vomiting every day. So my PCP that I saw at the time did some tests - like just generic blood work kind of tests - and she asked me if I was bulimic because I was vomiting every day. And I was like, 'I'm not, this is not what I want to be doing!' Then she told me, 'Well, it's anxiety or depression.' And I did not believe that was the case. I've dealt with anxiety and depression my whole life and this was different.

So then I begged to go see a GI specialist, who gave me a bunch of different tests, but never actually did a CT scan. So, they chalked it up to IBS, so Irritable Bowel Syndrome. And then, I was just very frustrated because I didn't feel like that was the right answer. I felt like there was something really wrong and no one was listening.

So, I ended up going to Boston. I went to a hospital in Boston to see what they said. And they did a CT scan, and they saw something on my appendix, but it was small, they said, 'Don't worry about it, it's a benign finding, you

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should have your appendix removed at some point, but we don't think it's anything. Schedule it when you have time.'

So I waited a couple months because I had a bunch of stuff planned in my life and was like, okay, I'll deal with it in August of 2018 is when I ended up dealing with it. And I had surgery to remove my appendix. And ten days later I get a call.

And it was the surgeon and he said, 'So, we got the biopsy back. It is neuroendocrine- the neuroendocrine tumor' is what he called it.

Because of my age, what I kept being told is like, we want to reset the clock on your cancer. So we want to remove as much of it as we can. So in January of 2019, I had a liver resection and lymph nodes removed, but they never found the primary tumor in my pancreas.

So I was just in very active monitoring, where they were giving me PET scans or CTs or MRIs, depending upon the situation, so, every three to six months.

In May of 2023, my symptoms came back. Like, I knew. I was like, uh..my cancer's back. And I had a PET scan scheduled, they moved it up a little bit and I had an MRI and they found another very small tumor in my duodenum.

So they put me on Octreotide. And I did that for four months. But the side effects from the octreotide were really rough. So I ended up doing some research and approached my oncologist and asked if I could switch to lanreotide.

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I am on the lanreotide injections every 28 days. My next scan is in June. And they don't really know... I mean, I've looked up, I've been like, are there 10 year survival rates? Because I want to know numbers. I'm a numbers person.

There's no 10 year survival rates I can find for neuroendocrine cancer with a pancreatic primary that's considered stage 4. I couldn't find any published. So, um, I have no idea what the future holds. I mean, right now, my goal is to make it to 40.

When I got a cancer diagnosis, I was 30 and was faced with a very real reality that I probably wouldn't make it to 35. And that makes you question your entire life.

And I decided my life is going to probably be short, shorter than I would have ever thought, so I'm gonna make it have meaning. If there's something I want to do, I do it.

It has caused me to jump out of airplanes, go rock climbing, Learn to snowboard at 8,000 feet elevation, get tattoos, go speak to rooms full of doctors, and share my story because I want to leave the world better than I found it.

As we come towards the end of this podcast, we'd like to offer three pieces of advice for younger people who are wrestling with a NET diagnosis.

First, it may feel like your life is now entirely out of your control, but you might be surprised by how much control and confidence you still have.

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Fletcher: *When a cancer diagnosis comes up, it really feels as though all control has been lost, particularly when you're in the beginning of a career, you're in the beginning of a relationship and then all of a sudden this big, huge thing comes up and it's like, 'I have no control over anything here.' So, I think really piecing apart the things, even if they're small, that you can control in a situation... You know, I often have patients make a list of the things in their day they can control and the things in their day they can't control. So, getting a certain medication at a certain time maybe you can control. You probably can't. The fact that you have cancer, you can't control. The things you can control are the routine you set for yourself, so the time you wake up in the morning, the individuals that you contact during the day. Really kind of sussing out the specifics of what you do and do not have control over can feel really, really liberating. And also, it's a good reminder that there are things that you have control over.*

The second is that you are not alone. However rare your particular condition, there are others who know what you are going through. And because of the internet, there has never been a better time to find them.

Lewis: *So, I've had several patients recently and heartbreakingly tell me, 'I'm the only person of my age going through this.' And that's another place where actually we can lean into advocacy organizations and support groups that allow people with really rare illnesses to come together and find that, actually, they do have kindred spirits. They might not live in their town. So, when I was diagnosed with my condition, it was a 1 in*

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30,000 incidence in United States, so I didn't know anybody who had MEN1. So, actually, I found them online. That's how I found my community, and that's where I've stayed in oncology social media for over a decade now. So, I think the other thing to realize in AYAs is they do get the sense that, 'Oh, my gosh, why is this happening to me, and why me, and why only me?' And the latter part I really try to mitigate by telling them, 'Listen, you're not alone.' And I think that's hugely empowering.

Fletcher: *Some cancer centers, not all, have young adult support groups. I cannot recommend support groups enough, even for folks that don't think it's for them. I think try it. If you hate it, you never have to go back. Also, most support groups right now are virtual, so you don't even have to leave your space. The Samfund is an excellent resource. They have tons of information regarding grants and other financial tools that can be helpful for folks who are going through cancer treatment. The last one I will mention is Stupid Cancer, which is an organization solely based around young adults with cancer. And they have a conference every year, and this one was actually virtual and recorded, so there are sessions on everything from fertility to body image, to navigating disability, things like that.*

The third is do not give up hope. There have never been more successful treatments for NETs than there are right now.

Shah: *I think a lot of hope that I see and I have experienced within our field just of neuroendocrine tumors over last couple of decades that keeps growing is that what has happened in the field about variety of progress in the testing, the diagnostics as well as the treatment aspects*

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of these cancers. So, I would be the last person to tell somebody to say, 'Gosh, okay. Well, these are the only choices you have.' I tell them that these are the choices that you have now, but I am hopeful that there are more choices coming in coming times.

Del Rivero: *There is something I always tell my patients: you need to live your own life, let me do the worry for you. It's important for them to continue going to school and continue doing what they want to do... I mean, a lot of these patients, they're very young and, you know, they still have so many dreams to follow, right? But we're working the best and doing the best to- for them to fulfill those plans and dreams the best they can.*

Thanks for listening to NETWise. I'm Jessica Thomas, Director of Patient Education for the NET Research Foundation.

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Special thanks to everyone we interviewed for this episode. We are grateful for your expertise.

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