Episode 12:
Caregivers and NETs
Transcript

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Welcome to NET Wise. This is a podcast for neuroendocrine cancer patients and caregivers that presents expert information and patient perspectives. My name is Elyse Gellerman, from the Neuroendocrine Tumor Research Foundation.

The shock of a cancer diagnosis causes an upheaval that radiates far past the patient themselves. The lives of those closest to the person diagnosed can be upended just as much, particularly for those who are thrust into the role of caregiving - sometimes forced to completely rearrange their own lives to provide for the needs of someone they love. This sacrifice is not only unpaid, but can also be unrecognized and unheralded outside the family. Well, today we'd like to help change that, by focusing on the unique challenge of being a family caregiver for someone with NETs.

Let’s start by meeting some family caregivers and hearing a bit about their stories. While all of the specific diagnoses their loved ones received were different, all of them were thrust into this new role quickly, with little time to prepare.

Here’s Lisa Yen, who gave up her career as a Nurse Practitioner to become a full-time caregiver to her husband, Tom, who has been living with Pancreatic NETs since 2015. Since 2018, she has also served as Program Director for LACNETS, the Los Angeles Carcinoid Neuroendocrine Tumor Society.

> ***Yen:*** *“I suddenly became a caregiver overnight. I think none of us choose ever to be a caregiver. It's something that happens to us. And that certainly was my case.*
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> *So, the first sign that my husband had anything wrong with him with actually the end of December, which was a pretty bad flu season at that time. It was December of 2014 and he just felt weak and tired for a couple of weeks, which wasn't unusual given a bad flu season. Perhaps he felt a little dizzy, but otherwise didn't have a fever or anything until suddenly on New Year's Eve, he threw up a small amount of blood. So, he was actually admitted directly to the hospital. He had never been hospitalized before. When he went for an endoscopy and they drew his blood, they found that he had dropped his blood volume about half. He had lost quite a bit of blood. So, he had to get a blood*

> *transfusion before they could even take a look. And when they took a look, what they found was quite alarming. So, they left him on the breathing machine. And that was the beginning of the journey.*
>
> *Yeah so, he had… my husband had neuroendocrine tumor that started in the pancreas, in the latter half of the tail of his pancreas. It had taken over the whole spleen and he also was found to have quite large tumors on his liver as well. It wasn't a slow start right. We were dropped into at a sprint pace."*

Chuck Murphy is a retired Federal Investigator in Pennsylvania, whose wife, Patricia, was diagnosed with a Lung NET in 2005. When her cancer was first discovered, it was also because of sudden, acute symptoms that seemed to come out of nowhere.

> ***Murphy:*** *"She never had heart issues. And one weekend she had a massive weight gain, 25, 30 pounds over the course of a three or four day period. She was clearly in heart failure. And when we got her to the hospital from her doctor's office, they put her through all kinds of treatment. And then they followed up with a stress test and they saw this white mass in her bronchus. And eventually it was biopsied and diagnosed as a carcinoid tumor."*

Katie Bourke and her siblings became a care team for their mother, Laurie, when she was diagnosed with a high-grade NET of the colon in early 2019. For her, one of the real shocks came when she realized the true severity of her mother’s condition, and that her mom was going to need a lot of help and very quickly.

> **Bourke:** *"So when my mom originally got sick, I did not think that it was going to end up the way that it ended up. I thought that she was going to have surgery. And then once it was determined that she needed chemotherapy, I just thought, 'Okay, well, this is just, a kind a chemotherapy to clean things up, make sure that we got every last cancer cell' So after the first round of chemotherapy, it was a completely different arena for us to say, 'Okay, wow, no, this is serious.'"*

This was complicated by NETs being a rare disease.

> **Bourke:** *"I had never even heard of neuroendocrine cancer before. And I didn't even know where to begin to start looking that up and researching it because I just thought, 'Okay, I need to research colon cancer.' I just didn't understand."*

When Tim Cape, an audiovisual consultant in Atlanta, was dating Harold Bouis, the man he would later marry, he learned that Harold had had pancreatic cancer many years before, but had been told that it was completely removed and there was little reason to think it would return. So it was a double shock to learn several years later that not only was Harold's cancer back, and now metastatic, but that he had been originally misdiagnosed, and he actually had a Pancreatic NET. Here are both of them, first Tim, then Harold, describing that experience:

Cape: *"We had known. I'd known about the initial diagnosis that Harold had, but when we got to the point of having the recent diagnosis, it was a big shock to us."*

Bouis: *"I just happened to be one point in time, back in November of 2018 that I had blood in my urine. And I went to the urologist to find out what that was caused by. And that was the beginning of him doing an MRI, a CT, and finding out that I was, you know, full of tumors. So, it really just knocks you off of your feet when you've gone for 20 years thinking you're cancer free, because the doctors said they cut everything back to clean margins. And then all of a sudden you find out, well, no, now I've got it back in my pancreas, in my chest, in my adrenal, and in my liver, with over 16 tumors right there."*

Cape: *"It was scary and terrifying, but you know I wasn't feeling like, 'Oh my God, what am I going to do?' I was concerned about Harold and what he was going to do and what this meant for him and for us. I was just right in there with him in the process to try to go through it and having a lot of similar feelings and fear and the diagnosis and the unknown and everything."*

One thing caregivers find is that their own lives can change almost as much as the people they care for. Routines are often upended, change, and priorities completely shift.

> ***Yen:*** *"How didn't my life change? I think it changed in every way possible. You know, I was concerned about the normal person's concerns. I was thinking about my work; getting these things done. And I also was worried about life things. My birthday, a significant age was; it's milestone was coming up. I was worried about aging. I was worried about house stuff, just all these mundane things. Then all of a sudden, to find out that my husband might not make it even through the night, I stood there in the ICU, I was still wearing my work clothes, thinking, 'None of this matters.'"*

And what comes to the forefront is a whole new set of essential challenges and responsibilities which need to be learned and mastered quickly. One of these is that caregivers often find themselves in a position of communicating about their loved one's illness with the world at large. This can often start with complicated discussions about who to tell and when and how.

> ***Cape:*** *"You know, we told a number of people over the past couple of years about what's been going on. And most of them initially react kind of like we did, they're freaked out and they don't know what the prognosis really is. They don't understand how NETs is different.*

> ***Bouis:*** *"We struggled in the beginning with who we should tell. Should we tell anybody? Should I tell anybody at work? Should we tell our friends? Which friends should we tell? You know if the others found out secondhand, then will they get their feelings hurt? We kind of weighed too,*

I think, how we felt those friends would react emotionally, I guess. So some of them, we held off longer than others."

Cape: *"Slowly, we started sharing with people, our friends and family, about what was going on. And once we did that, I had some trepidations about it. But the more that we knew about NETs and what it meant for us, the easier it was to share with other people what was going on."*

Bouis: *"Yeah, definitely."*

Cape: *"And so part of my job as a caregiver, is to and Harold's too, as a patient, is to educate our friends who are also caregivers in their own way. They provide support to us. And so we had to educate our friends to say, 'Look, this is important to both of us, that you guys understand what's going on and help to support Harold as a patient. It supports me as a caregiver and it's kind of our extended family.'"*

And an extended family of support can be a lifeline for both a patient and their immediate caregivers, especially in times of crisis, when dealing with doctors and hospitals becomes a full-time job for both the patient and their closest supporters.

Yen: *"We didn't even have to cook a meal, I think, for probably like six months. We had so much food, so much love and support. We had flowers all through our house. Our place looked like a garden. We had cards sent to us and we put them all up on the wall, so it looked like a prayer*

> *wall. It was just a wall of love. We had all these gifts and cards and we just put them up on one wall and just had all these gifts and so much love showered upon us. And that was a source of encouragement. And then also a lot of practical help so running errands, doing whatever needed to be done."*

But managing the good intentions of family and friends can be its own challenge, as well.

> **Yen:** *"Each moment, you're responding to a text, an email, whatnot, it's time, it's energy. And there's just absolutely no way, as much as I wanted to, to talk and connect with every single person. And quite honestly, I got some criticism for that because people on the outside didn't understand what it was like to be going through what I was going through and how much time and energy it took.*
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> *I had people show up at the hospital the first night that really had the strong belief that all I needed was for them to hold vigil with me. And it took me hours to plead with them to go home so that I could sit at my husband bedside, because as long as they were there, I couldn't be there because ICU had a limit of how many people. And I wasn't going to wait out in the waiting room. But in their mind, maybe that's what they wanted. And so everyone projects their own issues and their own situation and their own experiences. And what I wish that everyone could understand was that their experience was not my experience, and their needs were not mine. And even in this situation, they had a*

> *different need. They showed up because it made them feel better, or they wanted to give because it made them feel better, but it wasn't necessarily what I needed. What I needed was to be next to my husband and hold his hand."*

One technique for managing this well-meaning deluge is to delegate some of this communication. Often caregivers will find themselves organizing an "inner circle" of close family or friends who are then tasked with communicating with the larger "outer circle" about what's happening and how they can help.

> ***Yen:*** *"It would have been a lot to coordinate all that. So it fell on my, what I call my inner circle, so organizing all the help, all the offers to help, all the help, all the tasks, all the things that needed to get done to free up my time so I could spend as much time as possible with Tom.*
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> *The hard thing is that everyone thinks that they're in the inner circle. They think that they're the best friends. They think that they're the first person that Tom wants to see when he opens his eyes, or they think that they're the ones who I would want next to my bedside. And it is hard to distinguish who I most need. So then I needed my inner circle to form some boundaries and barriers. And then, you know, they basically, they were a wall and they shielded me from some of that. So that was really helpful."*

For Katie, that inner circle was her siblings, who were able to divide the important tasks between them.

> **Bourke:** *"I'm very fortunate. I come from a large family and we all play different roles. My stepdad, he would take her to every single one of her appointments, all of her infusions. My sisters were extremely supportive, you know, especially, being with her. One of my sisters also basically lived with her to make sure to physically care for her.*
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> *So the role that I really took on was kind of understanding the medical side of things, getting second opinions. It was understanding what the different treatment options were. And it was managing a lot of the communication with her medical team because it's so overwhelming. I mean I was even overwhelmed. I did not want my mom to have to go through that."*

And that's another crucial responsibility that often falls upon caregivers – supporting the patient in communication with their care team. Patients and caregivers alike can find themselves spending a lot of time and energy organizing, translating, advocating, and sometimes even badgering to make sure that the right questions get asked and answered and the best decisions get made.

> **Bourke:** *"You need to always advocate and push hard because you are the one helping take care of, you know, of your*

family member that needs help."

Murphy: *"We are vigilant until the point where I think Pat's oncologists might think I'm a little bit of a pain in the ass."*

Of course, being able to be an advocate starts with a lot of learning, particularly for a disease like NETs which is so little known and so often misunderstood.

Cape: *"Having an education about NETs and the treatments and the progress and the studies and the clinical trials is important for us, and I think for a lot of people to be able to make plans. We didn't know really what was happening. We didn't know that much of anything about NETs. And we spent a lot of time trying to get educated about NETs, to find out what it could. And it wasn't as easy as we thought it might be. Not that we thought it would be super easy, but as we started looking around, it was difficult to find good information about what we needed to know. Being knowledgeable about all that gives us a perspective on timeframes and potentials and seeing what's coming down the pike also. So you know in general, we're planning, but we're optimistic."*

Bouis: *"Right. And that keeps the situation from being scary. So many people are scared of cancer, but if you know what's going on and you understand your options, I think that makes it way less scary."*

This is especially important because, unfortunately, the lack of general knowledge about NETs extends into the medical community, as well as the general public.

> **Bouis:** *"So yeah, a lot of it has been having to educate the doctors here on what's going on and how to deal with this and that it's not the typical type of cancer."*
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> **Cape:** *"You know when we went through the last episodes that we just went through with the embolization; when we went into the radiologist, the interventional radiologist, to have that done. There was some confusion about what exactly was being done, what was being requested by the doctor. And so we had to guide them into saying, 'Well, that's not what was requested.' And we knew enough about the different types of treatments to be able to guide the providers to actually give us what we need and what we think that we're supposed to get.*
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> *We've talked to people; we've seen people who've been recently diagnosed and they start out kind of like we did, almost stuck in well whoever they went to before, whoever they ended up coming to first, whatever they say is gospel. So I've got to do what they say, and I don't want to leave because I don't want to hurt their feelings and I don't want to you know that kind of thing. But if you're educated about it to understand that and open enough to understand that the doctor you're with may not be the right doctor for what is happening to you right now, look around, get other opinions, get other information, find people who specialize*

> *in NETs and go to them. Don’t feel like you have to stay with who you’re with just because you started with them.”*

> ***Bouis:*** *“Right.”*

And even when you’ve found your way to NET specialists, it’s really important to get a wide range of opinions, so you can make sure the very best decisions are being made. This is a realm where the advocacy and persistence of an engaged patients and caregivers can make all the difference.

> ***Bourke:*** *“It was so important for me to get second opinions. And at first I thought, ‘Oh my gosh, am I going to upset her doctor? Does it seem like I'm going behind their back?’ And then I realized that that was not the case at all. And I think I spoke to four different hospital systems and different oncology teams, just to make sure that we were on the right track. And that helps me a lot because each doctor explained things a little bit different. And so I was able to take pieces away from each doctor and it also generated additional questions for me to go back to my mom's care team. So it was really helpful. And even though sometimes it didn't result in anything different than what we were doing, it at least gave me and then ultimately my mom, the confidence of going into that next phase of treatment saying, ‘Okay, this is what we should be doing. We shouldn't really have to doubt that. We've talked to a lot of other specialists.’ And that confidence was really important just in the mental aspect of going into treatment.”*

It’s worth saying here it’s important to remember your loved one’s medical team is on their side, and working hard to provide the best care they can. Being a team builder and helping make sure everyone is moving in the same direction is often another crucial service that a caregiver can provide.

> **Yen:** *“I think it's important to make friends with people. It's easy to get frustrated and then to direct your frustration out on those closer to you and in your immediate proximity. So in the hospital setting, that's often going to be the medical staff, nurses, doctors. And that's really common. And I understand because I was on the other end, the receiving end often times. I understand because people are the most stressed in the hospital, but they are not your enemies. They are on your side. And it's also wasted energy. Why direct all that frustration and anger towards people and expend all this extra energy and angst when we have a limited bandwidth of energy that you might as well save and savor and spend with your loved one and enjoying that time with your loved one?”*

And this job of medical translation and communication runs both ways – a caregiver who can at one moment be an invaluable support to the patient in being successfully heard by their medical team, may in the next moment find themselves wanting to make sure the medical team is heard and understood by the patient. In the stress and anxiety of dealing with their illness it can be difficult for a patient to really take in all the information that is being given to them, and a caregiver can be an invaluable aide – listening, taking notes, doing research and looking for connections.

> ***Bourke:*** *"One of the hardest things for my mom was especially when I would go and seek second opinions. I think she would start to get her hopes up that maybe one of the physicians would have this magic treatment that we haven't even known about before. And if they said, 'Oh, no, you're on the right path,' on one hand, we were relieved. But on the other hand, she would get sad and she would get frustrated because she thought, 'well, no, I want something that could potentially be my cure.' And so that was realization settling a little bit more in, that there is no cure, and what we're really dealing with is lengthening her life and the quality of life as much as possible. And what was also difficult is some of the other private conversations that we'd have with physicians as to what does that expectancy look like for her life?"*

There's can be a significant amount of paperwork and logistics that come with any serious illness – things like managing insurance and finances and estate planning. This too, very often falls on the shoulders of a caregiver.

> ***Cape:*** *"So, we've gone through the whole process in the past few years of getting updated wills and power of attorneys and advanced directives, and all the things that you would normally need for estate planning and that sort of thing.*

So, I guess the bottom line is we're planning for the future, but it's not, at least for us, not that much different from planning for retirement and old age. We just don't know when the incapacities might be becoming more prominent."

Bouis: *"You know, I've put CDs and bank accounts and things in Tim's name as well, because I want him to have all of that. Because if he needs that to live off of and want to stay here in the house, you know, then that's what I want him to have. I don't want him to be that financially in a shortfall because something happens to me. He's been my caregiver. I'm here now because he's been by my side every step of the way. I owe him that to make sure that he's financially secure if something happens to me.*

The most difficult time in a NET journey is when treatment options run out and end-of-life issues need to be addressed. This brings new waves of emotions, of course, as well as new realities and legalities, and often a new physical intimacy that comes with caring for someone who is losing control of their body. For many, all of this arrives many years after diagnosis. For Katie and her family, it was quicker.

Bourke: *"It was not quite two years. She was diagnosed in February of 2019, and she just passed away on November 16th. So, dealing with someone's just estate and figuring out what all the end-of-life plans are, it's a very uncomfortable conversation to have, even when you know that your illness is terminal. You just don't want to have to*

> *talk about what the end is going to be like, but you have to have those conversations. And so fortunately, we had… my mom had known that this was most likely going to be terminal. So earlier on, she was settling her will and her estate, and then with hospice, they did go over with my mom and my sisters what her wishes were. So, while those conversations were difficult, very difficult, we did have a lot of those conversations while she was there.*
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> *The end of care was, it was so hard. It was incredibly hard, and my mom knew that it was going to be difficult. And she was scared for it, especially because the cancer had taken over her liver and liver failure is just such a scary thing to experience. And so we did work with hospice, and she was able to stay at her house, and we were able to have some hospice care. And my sisters and I and my stepdad, we really just kind of took over and cared for her. And it was just incredibly, incredibly difficult to be able to see her rapidly decline, but on the other hand, we were a little bit fortunate that she rapidly declined so fast because we just didn't want to see her suffer anymore."*

Two things helped her work through that process. One was faith, her spiritual approach toward the situation.

> ***Bourke:*** *"I had to hold on to that. I had to have some spirituality, because I can't believe that my mom is just gone. I have to believe that my mom is still with us in some form in heaven, however it is. She has to still be*

> *with us and still be able to look down on us. And that definitely is helpful, and it is comforting to know that... Can she still be with us? We may not be able to see her on this physical world, but inside of us, she is still with us."*

And the other was continuing to be an advocate for NET patients, even after her mother's passing.

> ***Bourke:*** *"I just felt like it's been a journey for almost two years. I can't just stop. I'm like, 'How do you stop researching? How do you stop advocating? How do you stop caring for that person?' That was really hard for me to figure out. How do I just stop here? Because she's gone and I can mourn, but I can't just stop. And so that's why it was so important for me to figure out how can I continue this journey that I've been on with her, even while she's not here."*

All-in-all, NETs are a journey, for caregivers as much as for patients, and along the way there will be highs and lows, better times and worse ones. Learning to navigate those peaks and valleys takes time and practice.

> ***Yen:*** *"So I've been on this for six years now, and for the first two years, I think I prayed every single day that, I prayed every single day for Tom's pain, for his physical pain and suffering. Because he said to me that if only his*

> *pain was better, he would be happier, that he would feel like life is worth living if his pain was better. So, of course, I associated pain with the reason for his suffering. And I just thought that, 'Okay, if these things could be fixed...' So first, it's like, 'Okay, stop the bleeding. Okay, then stop the disease progression. Okay, then it's pain. Then perhaps you'll feel better, and then I can feel better. I'll be freer.' What I came to understand was that it's so much more than fixing the amount of tumor he had, or controlling the disease progression.*
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> *So, it's easy as the spouse advocate to assume that, 'Okay, well, the times when you're going to feel better are when your disease is better,' but it's not necessarily the case. Someone could have a huge disease burden and be optimistic and hopeful, or they could have very little disease or have no disease progression, and suffer from severe depression. It's more like a dance, and that dance keeps changing, and we don't know how that person will feel.*
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> *Also, the times that it might be better for me, it might not be better for that other person. So we have the shared journey for sure, but how we're doing individually can really... It can be really different. It's unique."*

What that dance requires of the caregiver is love also dedication, and often putting their own plans and priorities on hold in order to care for someone else. And it can be easy, sometimes, for people who have given that much of themselves to feel… consumed… that they've lost a bit of their own identity in the service of the person they care for.

> **Yen:** *"Well, I think it's really challenging, because we spend so much time concerning ourselves with the cares, concerns, the disease, the treatments, everything involved with the person we're advocating or caring for, that the boundaries get blurry."*

> **Bouis:** *"So I realize, you know, he does need his own space to recover mentally from what's going on. And so we kind of try to check in with each other every so often, and just make sure, you know, that is what I'm seeing on the outside is that as okay on the inside as it appears to be on the outside."*

> **Bourke:** *"You have to check in with yourself a lot and figuring out are you okay, and be honest with yourself and say, 'How am I doing? What do I need,' and to not be afraid to ask for help. Whether it's something small, just helping around the house or helping with something that you need to get done, or if you need help mentally, seeking professional help. It's just so important to check in with yourself, because if you're not helping yourself, there's no way that you can help the person who you're caring for."*

At LACNETS, Lisa runs a support group specifically for caregivers, as a place where they can work through some of these challenges.

Yen: *"Caregiver support group is interesting, because I think most caregivers, even if they attend a patient and caregiver support group, which most of them are open to both patients and caregivers, we're all used to introducing ourselves based on our relationship to NETs. So, 'I'm Lisa, I'm the spouse of someone living with pancreatic NET.' And then when we have questions or conversations, it's all related to my spouse's NET journey, so his symptoms, his treatments, questions about that. So when have I talked about myself? Not at all, except for my name, right? So that's actually what I found with the caregiver support group. That was the trend and the tendency that we all identified by our person that we were supporting, and all of the questions and conversations were surrounding that.*

So it took a lot of effort on our part as the facilitators to reframe the conversations to say, 'This is not the place where we're going to be talking about our person. We have other forums for that, and we're going to shift now, and this is our space. This is the only space you may have to just talk about you.' And it took quite some time for everyone to first of all to go, 'Huh, okay,' and then to figure out who that person was and to say, 'Okay, so I'm Lisa, and I may be living with a PNET…' and then express the concerns that were unique to myself.

I think it's helpful to find whatever space it is where you feel understood and where you feel that you can find release, a safe space, wherever that might be. And it may be with other NET caregivers, and it may not be with other

> *NET caregivers. It may be a place where you feel like you can be normal and you can be yourself, whether it's work, friends, family, and wherever that is that's safe so that you can express what you need to express and have that bank right… replenish, have your cup refilled."*

We'd like to leave you with three final thoughts that we hope will help you climb the mountain you face as a NET caregiver. First, this really is the best time there ever has been for NET patients – new knowledge, new imaging, and new treatments are letting people lead happy productive lives with a NET diagnosis for longer than they ever have.

> ***Cape:*** *"I've seen people who have been newly diagnosed in some of the groups that we've been to, and there's a lot of deer-in-the-headlights kind of look that you can see, and you can feel the fear that they have and the uncertainty. The thing that I would say first and foremost is education, for the patient to understand what's happening and what the prognosis might be, and the caregiver to be able to provide support as needed, but also to help participate in the decisions to be made as you go through the process."*

> ***Bouis:*** *"And I just feel like through all of the research studies we see, the things that we hear, the new medications that have come out, the new medications that are in process, all the research studies that are being done, I just feel like other people that started this whole*

> *process years ago didn't have anywhere near the knowledge that we have nowadays, or the treatment methods. So I just feel like I'm in a much better position now with everything that's in the pipeline and coming down the pipeline, as far as new research and methods of treatment."*

Second – don't panic. Make plans, but don't feel you have to cross bridges you haven't yet come to. While some NETs progress quickly and become a medical emergency the moment they are discovered, many do not. Take an honest assessment of what the situation is right now, and what you and your loved one need to get through it.

> ***Cape:*** *"We don't focus on, 'Well, we need to plan for something in 2 years or 3 years or 5 years or 10 years of when he may become more incapacitated', because we don't know. And there's no sense in trying to get too concerned about what's going to happen in a few years, unless there's some reason to. We've talked to people who have survived for decades with different kinds of NETs.*
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> *In the initial diagnosis and period that we went through trying to kind of processing that, there was a lot of just unsettled times where we were so fearful and stressed out about, "What does this mean? What's the future going to bring? What's the prognosis?" So, we had to kind of live within that for a while. But once we got more knowledgeable about what his case is like and what, as I said, how NETs are different from other cancers and how his case is different from other cases, we got back into a pretty*

> *normal routine. And now we don't think about it as much as we did initially, for sure, and we're able to feel like life is normal a lot of the time."*

> **Bouis:** *"Right."*

And finally, know this: you are appreciated. We see the work you do, and how valuable it is, and we appreciate it and celebrate it.

> **Bouis:** *"Yeah. I mean, it means everything. You know I couldn't have gotten through this without Tim and his support, and knowing that he's there and that he's knowledgeable. He knows what's going on. He's clearly very interested in learning and knowing what's going on. I mean, it's very much of a major roller coaster ride that you're on all the time with major highs and major lows, and just to know that somebody's there and they understand what's going on and they're there for support, I mean, it just, it means everything."*

Thanks for listening to NET Wise. I'm Elyse Gellerman, and I'm the CEO of the NET Research Foundation. This episode was produced by David Hoffman of CitizenRacecar, assisted by Garrett Tiedemann. It was made possible by the generous support of Ipsen, the Vincent E. Taylor Patient Education Fund, Advanced Accelerator Applications, a Novartis Company, and Lexicon Pharmaceuticals. Special thanks to everyone we interviewed for

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