Episode 21
Adjusting to the New Normal:
Transcript

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

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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, from the NET Research Foundation.

For today's episode, we're going to do something a little different. We've spent a lot of time in this series talking about the science of NETs, but your cancer journey is not just about biology. Living with NETs can be an intensely emotional experience, and learning to deal with that emotional rollercoaster can be just as difficult as treating the disease itself.

The first big drop on that roller coaster is right at the beginning of your NET experience – at the moment of diagnosis. Here’s John Kerns, an interfaith chaplain at Beth Israel Deaconess Hospital in Plymouth, Massachusetts:

> **Kearns:** *‘That kind of ineffable moment of, ‘What did I just hear? What does it mean?’ That confusion, that disbelief, the racing thoughts, you know? Going to places with it from, ‘Will I die? How long do I have? Can it be treated? What about my family? What about my work? How am I going to afford this? I think… just something so hard to process.*
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> *I think even though some people might already have a sense of that's what it is. I think we do a pretty good job of trying to deny symptoms and things that are happening to us. And so I think when the news actually comes, it's like a tidal wave.’*

And here’s Greg Johnson, an interfaith chaplain who serves as Chief Advisor for Family Caregiving at Emblem Health:

> **Johnson:** *‘It can seem like our whole world is falling apart. It's without question, the most difficult moment that most people will ever experience.’*

And that initial moment of fear and uncertainty is followed by an almost endless parade of similar moments, times when it can be hard to know what to do or how to feel. Times when you may be processing so many different thoughts, feelings and emotions.

Here’s Dr. Eric Fromme *(FROH-me)*, a palliative care physician at the Dana Farber Cancer Institute in Boston, and Senior Scientist at Ariadne *(air-ee-AHD-nee)* Labs, a joint venture between Brigham and Women’s Hospital and the Harvard School of Public Health:

> ***Fromme:*** *“There's uncertainty at every turn. The first is there's something wrong. What is it? Finding the diagnosis. Then there's, is this curable? You get the treatment, then you have to wonder, okay, is this going to come back? And then if it's not curable, hopefully it's at least manageable. But then the question is, what will that management be like? What's my life going to be like? There's not just the effect of the cancer, but the effect of the treatments and how you're left afterwards. And it really requires a lot of coming to terms with a new reality, which is hard to accept.”*

People can react to these extremely stressful moments with any number of strong emotions in their own unique way. It is a normal part of this process. Here’s Dr. Sue Morris, a clinical psychologist from Dana Farber Cancer Institute:

> ***Morris:*** *“All kind of feelings are valid, right? It can be sadness and it can be fear. Anger is one we think about because anger often is associated with feeling like something's not fair.”*

A big part of these overwhelming feelings can actually be something many of us don’t immediately associate with a medical diagnosis: grief.

> ***Fromme:*** *“What I see a lot of is conversations about depression that I think actually are really grief. Grief really happens as soon as you realize that something has been lost or will be lost. The experience of a serious illness like cancer is riddled with all kinds of losses, some big, some small, from as abstract as our self image, to as concrete as can you actually get yourself out of bed?”*

> ***Morris:*** *“For when you've been diagnosed with a serious illness you're longing or wishing for your old life to be the way it was or your old self to be the way it was prior to the diagnosis.”*

> ***Fromme:*** *“Grief is not harmful. It's not a bad thing. It's actually a normal reaction to losing something that's important to you that you know helps to define you, that you care about. So I think that a big part of the cancer journey is, how do you relate to grief in a way that allows it to both do its work, and so that something can come after?”*

And that’s what this episode is going to be about: how can someone who is facing the enormous emotional burden of being diagnosed with cancer work through those feelings, handle them in a way that doesn’t allow them to take over your life, and maybe even use them to help build a cancer journey that is more positive, productive, and peaceful.

> ***Kearns:*** *“Feelings are information. So instead of judging my feelings or wishing my feeling away or trying to change the feeling, it's, ‘How do I sit with the feeling and understand ‘what are you telling me? What are you helping me understand of the ramifications of what has just happened in my life and how it's affecting and rippling through the rest of my life?’”*

> ***Johnson:*** *“We have to honor all the depth of feeling that goes into it. Being angry at God, being angry at life, being... there's all the variety. And yet once we honor those feelings without going totally off the wall, we can then begin to look at it and begin to deal with it. That becomes the journey that we're invited into.”*

Patient Story #1:

> ***Ashley:*** *“My name's Ashley. I am 38 years old and I'm from British Columbia, Canada. I was diagnosed with small bowel neuroendocrine tumor in October of 2021. My problems kind of started presenting themselves in the pring of 2021. And*
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> *it was primarily extreme fatigue, nausea, vomiting, continuous diarrhea, flushing, weight loss, that kind of*

stuff. And it was really hard because a lot of people didn't really believe me when I was feeling symptomatic. I knew something wasn't right with my body. And I kept on telling my physician. And I was seeing a counselor at the time. And I was telling her that I don't feel well physically. I had been struggling with some mental health concerns prior to this. It took me quite some time to actually have someone start believing that there was something maybe more wrong with me than just my mental illness.

And here I am a nurse, and no one believed me. No one thought that anything was wrong with me. It was getting to the point where I was feeling so hopeless that I didn't think life was going to improve. So I was having lots of intense thoughts of suicidal ideation and that, because I just didn't feel heard. I felt like 'maybe I am just going crazy. Maybe my physical symptoms are only being manifested by the anxiety and my depression.' So this has been one of the hardest things that I've had to deal with in my life.

When I had this severe acute abdominal pain one night, and I went in and tapped my husband at shoulder and said, 'You know what? The kids are sleeping. I don't want you to get up, but I think I need to go to the emergency room and get looked at.' So, my stomach's really hurting. I got in my car and I drove till just about 15 minutes out of the city.

And I had to pull over at the gas station and call an ambulance because I couldn't make it the rest of the way to the hospital.

And then that's where I had the CT scan and these lesions and masses were found. And when I heard that, it felt like the wind was sucked out of my sails.

I think it was a lot harder for me to wrap my brain around because of being a mom. And I think that's what affected me the most. I have two small children. And I cried, but I didn't cry for myself. I cried for my children because I didn't know what my journey would look like. And I was afraid for what my kids may see as this disease could potentially progress or what interventions that I needed.

And then secondly, I had already gone off work prior to all this because of COVID and the loss of childcare and the impacts that it was having on my own mental health. That's been one of the hardest things for me is because I worked so hard for my nursing, and I was good at it. And I was moving into a position where I could be in a nursing leadership role.

So when this all happened, it was really hard to take that step back. And I felt that I kind of lost that piece of me, but that's not my new normal anymore. So I was already in a really low place and I was very fragile and vulnerable and trying to do a lot of personal healing. So when this

> *diagnosis came, I just thought, 'Why me? I'm already down. Why am I being kicked down even further?' I just felt like it was so unfair.*
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> *This is still quite fresh for me. I'm not even really a full year having my actual confirmed diagnosis. So it's been an emotional roller coaster. And I think you have your good days and you have your bad days."*

There are a lot of different ways to respond to grief. Some people really want to talk about what they are experiencing, and others would rather find other ways, perhaps throwing themselves into an activity like art or exercise or gardening. It's important that we practice compassion with ourselves and for the people around us as we each find our own way to channel these big and painful emotions.

> ***Fromme:*** *"I think everybody does it a little differently. Some people are very public and some people want to be very private. And I don't think there's necessarily a right way or a wrong way. Not to be sexist about it, but a lot of men actually will grieve through doing things. Usually what's happening is the person who grieves through talking is trying to get the person who does not grieve through talking to talk about it. And they're worried about them because they're not talking about it. In that case, I think it's helpful for the person who wants to talk about it to know, but just because the other person isn't talking about*

> *it doesn't mean they're not feeling it. Or it doesn't mean they're in denial or that they're somehow not in touch with their feelings or something like that. That's not necessarily the case at all."*

Whatever way you channel your grief, it can be important and helpful to find some way to express your feelings, whether publicly, privately, or with someone you trust.

> ***Morris:*** *"So I would say grief is always better out than in, which sounds simplistic. But it's finding things to express it because otherwise if you keep it running around in your head, it's like boiling water on a stove. If you don't keep taking the lid off and turning the temperature down, it spills over."*

> ***Kearns:*** *"It's going to come out somewhere. And the healthier we are and the more open and honest we are about being able to kind of be comfortable with the uncomfortable, right. But to sit with the pain, all the internalized stuff that really has a way of paralyzing us, it doesn't allow us to even access the resources that are outside of us."*

And there really are a lot of good resources out there – people and techniques that can really help.

> ***Fromme:*** *"And so I tend to take a very pragmatic approach to it, which is that grief is normal. Grief is not something*

> *that we have medication to treat. But we do have resources to help people manage grief."*

A good place to start is by finding a professional – a therapist, counselor, social worker, or chaplain who is trained in helping people in situations like yours.

> ***Morris:*** *"Finding a clinician, if the person is receiving treatment in a comprehensive center or somewhere or it's a team, seeing first of all, if they have somebody you can talk to. Maybe there's a social worker or a chaplain. And even if you don't feel that you need them now, it can be really good just to have an introductory session because not everyone is aware of the resources that are available. And then if you do need more help later, you've already had that kind of connection.*
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> *People aren't used to having these really strong emotions, that can be really scary. So it's a real guidance model to some extent. It's kind of support and guidance. So as a psychologist, I would be wanting to allow people to have the space to express how they're thinking and feeling, and then working out what constructive ways they can do to tackle it."*

It may seem like finding help with your feelings is less important than the surgery you're scheduling or medical regimen you're about to go on, but really it's just a totally different kind of help, and it’s ultimately just as important for your overall wellbeing.

> **Kearns:** *“I walk in the room and this patient is alone with this diagnosis, but now there's someone else. And that someone else is really listening and really cares about how can I companion you? How can I accompany you through this so that you can talk about the terror? You can face the anger, the frustration of why did I get this. Those questions, right? Did I deserve this? Is God punishing me? What did I do wrong? Is it my fault? All those questions that alone are really terrifying. But then with someone, are not as terrifying and that other someone might be able to connect you with other resources if you can make it less terrifying.*
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> *I can't fix it. I know I can't fix it. And I think that's one of the big assets that a chaplain has going in is, I can't fix these things for someone, but I can be with someone. I can listen to them and I can support them through the process of facing it. How to withstand the uncomfortable, how to be able to be present to what is fearful, terrifying, painful, and not run away from it.”*
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> **Johnson:** *“We are about care, not cure. And that is an important distinction. Care is accepting something just as it is and being present for that. May not be what we like, but it's the reality of it. And we don't get anywhere if we live in a world of fantasy. I mean, I love theater and I*

> *love fantasy. It's lovely to escape, but the reality is this. And so it's care that we're looking at. We need to meet each other where we are."*

One of the goals of this work is to amass a set of tools that you can draw on through the course of your journey that will help you find balance when you're feeling overwhelmed.

> ***Morris:*** *"Tools that help increase someone's sense of control, tools that increase someone's well being, and then tools that decrease isolation."*

Speaking regularly with a therapist or a chaplain is one of these tools, another is joining a support group.

> ***Morris:*** *"I'm a big believer in support groups, right? Because that is a tool in the toolbox that tackles isolation. Even if you've got a wonderful family and friends around you, unless any of them have the same kind of cancer diagnosis, they really don't know what you're going through. So we know people do better in support groups with people who are going through something similar, because it helps tackle the isolation. But also it's a safe space where you can talk about these kind of fears or worries."*

There are also a lot of things you can do on your own to help express and understand what you're feeling and provide relief if you're feeling too much.

> **Morris:** *"Write down what you're thinking, right? Because often when we have worries, it kind of can feel like it's tormenting us if they keep going around and around.*
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> *It could be, I call a technique, 'worry time'. You want to schedule yourself worry time every day or every couple of days, depending on how difficult things are, kind of as time on your calendar, not too close to bedtime, where you say I'm going to spend 20 or 30 minutes. Look at the clocks. Set your clock. And I'm just going to write down what I'm worried about today, or what's on my mind. And then that can form not only getting it out, but also helping you prioritize or look at things. I do need to do this, or this is a question for my oncologist. It just helps contain it. And it's not saying don't worry, because if the phrase, 'Don't worry,' worked, I wouldn't have a job. It's really about saying 'This is important, but I'm going to contain it.' And then when my time's up, I'm going to close my book and go off and do something positive or constructive for myself."*

Building a whole collection of these tools will give you new things to draw on as you progress in your cancer journey, and maybe find yourself needing something different from when you began.

> **Morris:** *"What somebody needs soon after they're diagnosed may not necessarily be the same set of tools that they're*

> *going to need a couple of years down the track. So we want to have different tools in the toolbox that people can go back and use the ones that help them."*

We mentioned that one of the main stressors is feeling that you've lost control of your life, and it's true that there are a lot of things about your disease that you just can not control. It's important, then, to look for things that you CAN control. One of these is deciding who is and who is not on your team. No one has the right to be involved in your care unless you want them to be.

> ***Johnson:*** *"You do have the opportunity of deciding with whom you're going to be. I am surrounding myself with people who are positive, affirming, understanding. And that begins by your team. I mean, if there were a doctor you weren't dealing with, you can change that. If there's a therapist you don't like, change it. You are not here to please the doctor or the nurse or the clergy person. You're there to get well."*

This extends to everyone in your life. With very few exceptions, you get to choose who to share information about your illness with and when. Making careful decisions about who really needs to know what can help make sure that you're not spending all of your time thinking and talking about cancer, and that the people who are advising you are the ones who are going to be the most helpful.

Fromme: *"One experience that people have when they get a serious diagnosis is they find out some of the people that are their friends are good in this situation and some really struggle. And so I think identifying the people that actually can relate to you in that situation is important. And probably the most important thing is finding people who can encourage you and who can validate your experience."*

Morris: *"I would certainly be encouraging people to, it sounds horrible to say, but to kind of categorize the people in their life, right? Because some people need to know more information than others. There may be people who don't really need to know everything at all. Right? And clearly for something like work, if someone needs time off, then there's got to be some information that is required. But I encourage people to kind of... It's a little bit like an elevator speech. Think about what am I going to say to whom? And I may have three versions of that. I may have friends who are my acquaintances, but they don't need to know every detail. I may have my family who does need to know.*

And too many cooks spoil the broth, right? That's the old saying, right? So there's also a danger with sharing everything with everybody, that you get too many different opinions. And especially in cancer, it's very specialized and very unique. And often people will say, 'Well, yes. Well, I had a friend who had that same thing, and this is

> *what they did,' which is not really anything to do with what you've got."*

These kinds of decisions can get especially tricky when it comes to family members. Having family around who want to help you can be a real blessing… but as we all know, family relationships can be complex and fraught with their own stresses.

Sometimes even loving and supportive members of your family can be TOO encouraging, pushing past what is helpful into a space where you might feel guilty for not working hard enough to get well.

> ***Fromme:*** *"One of the things that distresses me the most about the work that I do is how many people that I see who are really dealing quite heroically with their… and often with great grace with their illness, feel like they're not doing it right, especially if they're not getting the outcome that they want, they feel like they're doing something wrong, or they're not doing well enough. But what I see from family members is often some desperation that if they can only get them to eat enough or exercise enough or do enough that maybe things will turn around. And so I think it can also serve as a barrier between the person who's ill and the people taking care of them because the people taking care of them are like, 'You got to do this. You can do this.' They're in this sort of role of encourager.*

> *The reality is being seriously ill means you are sick and you don't have the energy and the capacity to do all of the things that if you were in perfect health, you would do. And of course, nobody does everything. That would be crazy. You'd literally spend every moment of your life somehow doing something related to your illness and you still wouldn't have enough time to do everything."*

The trick here – and it's tricky – is learning to only accept help that is actually helping you. You can decide what you need and what support looks like to you.

> ***Kearns:*** *"One of my little sayings to myself is not all help is help. And so someone might feel as though I'm doing this because I'm showing you how much I care about you and love you. And I'm taking care of you. But to me, it's the last thing in the world I want. You can request from people, whether it be your husband or your friend, what you need and why you need it. Because all of these people only want to support you. But they don't necessarily know how to.*
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> *And so it's up to you to figure out, so what do I want from them? Or what do I need or what would give me comfort? What would feel supportive? What would feel loving? And then request that from them. And more than likely they'll want to do that because they still love you. They still want to be around you. They still want to be part of your life. They want to support you, but most people just don't know how to."*

It is important to have support people with you on your NET journey, but it is also important to set boundaries not just with your friends and care team, but also with your family.

> ***Kearns:*** *"There's a mistake I think in our culture where we think just because someone is related, they have an automatic ticket in, or a privilege or a right to see someone, regardless of whether that person wants to or not. And I think that's really false. And I think that message even needs to get out to our patients: you can decide who visits you and what's right for you."*

> ***Johnson:*** *"And it's for you to decide, 'Well, that person doesn't get it at all'. And there can come a point if somebody is being insistent upon being there and we don't want them to simply say, 'I appreciate what you are trying to do, but you are not helping me. I thank you, but I'm going to ask you to leave.' Bless them and send them on their way and find the next person. That's life. Not everybody gets where we're coming from. And we are in charge of our lives."*

That can be really hard to do, but this may be a place where someone you DO feel supported by.

> ***Kearns:*** *"You need a gatekeeper. You need someone who is your trusted other, companion, partner.. and if you don't have one, then it can be the chaplain in the hospital or*

the social worker or the nursing team say 'These people are not allowed in to visit this patient because they're toxic, and it's not helpful to the healing process of this person to have them, right.' So if it's too hard for the person to do it, use others who are close to do it for them.

You may choose at some point to see that person, but you may also determine under what conditions and when you're feeling up to it and what conversation you might want to have. I mean, I think reconciliation's a huge thing and a great thing and an important thing. And if someone can get to that with someone, all the better, but it's on the patient's terms, not on the other person's terms."

And in the midst of all these difficult decisions, it can also be helpful to make sure you're being grateful for the people who are supporting you in the way that you need.

Johnson: *"You have a wonderful team of people around you. You've got doctors, you've got nurses, you've got specialists, perhaps a therapist, perhaps a clergy person. You've got this whole team. The first thing I would urge you to do is spend a little time first of all, being grateful for them, because you are going to feel better when you are feeling grateful, even amid this difficult time. We all feel better when we're feeling grateful. Also in times of meditation, if that's part of your world, in times of quiet prayer or thought, bless each one of them, because with that, you are partnering. You're not becoming* *the disease. You're journeying together. And each of these persons comes with many blessings and much knowledge and they really only want to help."*

Patient Story #2:

"My name is Mary Langel. I live in rural Ohio. I'm 59 years old as of this past Sunday. And two years ago, I was diagnosed with metastatic pheochromocytoma.

I was working in a factory. I worked in an outdoor power equipment factory, just general laborer, for a total of 33 years. So it had been about 30, 31 years at that point. So when I went into a family practitioner, I believe it was 2017 and said, 'Something's not right.' I have an overall feeling of unwellness. I had fatigue and sweating and I coincidentally had been exposed to someone that had mononucleosis. So she did blood work and she said, 'I think you have mono.' So I was off for a few weeks. Just didn't feel well. But I was taking over the counter vitamins and she just told me, 'Drink lots of fluid. Get lots of rest.'

11 months later, I went back and I said, 'I feel like I have mono again.' So she did blood work and she said, 'This is highly unusual." So I made the appointment with the Cleveland Clinic. So I went in to see that new doctor. And he said, 'I think it is either lupus or rheumatoid arthritis.' And I said, 'All right.' He said, 'But I want *to do an abdominal CT and look at your lymph nodes.' And I said, 'Okay.' So then he called me back and I was feeling great by then. I was sure he was going to say 'It's all in your head'. He says, 'Incidentally, we found a nine centimeter tumor on your right adrenal gland. It's called a pheochromocytoma and they're very very rare.' And I said, 'well then let's pop it out.' And he said, 'We can't quite just pop it out. This is beyond us.'*

Everything moved very fast. I am a firm…my faith is very very strong and I was never afraid. And I knew that God was directing my path, and he was putting everyone in the proper place at the proper time. And on August 27th of 2019, I had a robotic adrenalectomy. I was back to work by November.

So I was about one month away from my one year checkup. Well, I got the blood work back and my tumor markers, my metanephrines, ketacomines were high. And I just knew. So I got a phone call back from him. He said, 'You need to go back to the clinic. There's a spot on your liver.' So I went back up to Cleveland. I seen the surgeon. He did a PET scan, and I found out that it had metastasized to bone, liver and lung. They were all very small, but needless to say, they were there. And I felt terrible.

And I went to work one day and I said, 'Why am I even here?' I looked around with all of those people that I had worked with and the job that I had done for 33 years. And I *said, 'There is more to life than this. I have decisions to make.' So I told my boss that day, I said, 'I think tomorrow's going to be my last day.' And he said, 'Until when?' And I said, 'Forever.' And I explained what happened. And I said, 'I've got decisions to make.' I just stopped and had to think about what was important to me. I don't even know that cancer was part of the equation at that moment. It was just a matter of this isn't what I want from my life.*

And I just knew that no matter what happened, I was going to be provided for. God was going to take care of me. And all of my dedication to my job was going to take care of me. It was just going to happen the way it was supposed to happen. It was a profound moment. It really and truly was. I just stood there frozen in time at that moment and looked around at all of those people that I worked with and what I did every day. And I just said, 'Why am I here? This isn't it.' And I woke up the next morning and I said, 'Yesterday was my last day.'

And I took an emergency vacation day and I went out on sick leave. I did what I had to do. My best friend took me on an amazing vacation. We went to the ocean and we sat and talked about life and what was in store for us. And at that moment, I said, 'It doesn't matter how much time I have. I know where my eternity is. I just have to make sure my family knows where to find me.' And I had two goals. One was to get my pension out of my employer's hands into my *husband's hands. And the other was to outlive my mother. And I said, 'The rest is all academic.'*

I did my first Azedra treatment in January of 2022. And I did my second treatment in April of 2022. On April 19th, three hours after I had received my treatment, I found out that my mother had passed away that morning. And it was expected. She was ill before I left. I was able to spend two weeks with her before my treatment. And I knew the time was going to be near, but I just felt at that moment that

she passed a portal open between heaven and earth. And I had received my healing. And with the Azedra treatment, you are in quarantine for an entire week. Nurses couldn't even give me a hug. I couldn't be with my family. But I was okay because the second part of my goal had been met. I had outlived my mom.

I have now decided that I'm going to take a break from cancer and live my life. Enjoy my grandkids, enjoy my family, enjoy my kids and my husband and my horses and my farm and whatever happens, happens. But I'm tired of doctors and I'm tired of pokes and prods and scans. All of the days and hours and weeks and calendars and phone calls and traveling. I'm sorry. I'm getting a little emotional, but it has consumed so much of my life in the past three years. I need a break. I need a break. We'll revisit it again maybe in September, December, something like that.

And six months from now, they say, 'You know what? There's nothing else we can do. Okay. I had six great months.'"

Fromme: *"Bringing your whole self to yourself is a healing experience. In a lot of ways, the ways that we get wounded by illness, we feel cut off from parts of ourselves."*

Johnson: *"We all wear masks. Often they're the only things that have saved us from emotional breakdowns. Well, when those masks are pulled away and we have to meet who we are, that becomes a very powerful time. It gives us pause as we say, to reflect on our whole lives. 'Was I my job?' And now I maybe can't be doing that job. 'Does that mean I've disappeared?' No. With help, you might meet the person that you were. That may ultimately be one of the gifts of the diagnosis.*

Now I know very few people think that we use the word gift with diagnosis, but I have seen some incredible lives totally turned around and changed from being very self-centered, 'I've got to win' and 'I've got to be blah blah…'. The 'I' perpendicular pronoun was the center. Well, that's kind of crumbled. And that's going to happen to each and every one of us. I mean, this old Cadillac starts to fall apart and we begin to look at life extremely differently."

One of the things a serious diagnosis does is make us become very aware of some of the universal truths that none of us like to spend much time thinking about. There are things in our lives that we can not control. Life isn’t fair. Bad things happen to good people. The awareness of mortality. Everything that lives will someday die.

> **Johnson:** *“America does not do well on talking about death. It's one of those subjects we don't want to talk about. When the diagnosis comes, we need to open our hearts and our minds to realizing finitude… and we're all born to die. You are. I am. But the gift is that today we're here.”*

And this may be hard to even consider when the shock of a cancer diagnosis is new, but there may be an opportunity here to take a parallel journey to the medical one you are embarking on, a cancer journey that is about facing those truths and learning from them.

> **Johnson:** *“And guide that journey based upon their own spirituality. We're not talking about religion. We're talking about spirituality, the essence of a person. How do they make their decisions? What are the things that inform them? What are the things that they've grown up with in a culture? What are the pieces? Now it may include a religious component and that's fine. But if it doesn't, that doesn't matter either”*

Kearns: *"Even though someone might not have a religious or spiritual tradition that they could name, that has any kind of structure that they could draw from, there is something for everyone that gives them meaning and purpose. Meaning to like who we are as a person, to ourselves, to who we are in relationship with others, to who we are as a citizen in the world, to as a created being, and then to whatever else we think there is out there. So what is that? What gives you hope? What gives you comfort? What gives you motivation to live? What's important to you?"*

Fromme: *"It's funny. The advice that seems to make the most sense in the situation of living with a scary or difficult serious illness is actually the serenity prayer, which is*

usually associated with Alcoholics Anonymous, which is may I have the serenity to accept the things I cannot change, the courage to change the things I can, and the wisdom to know the difference. That's the answer. And it's not an easy answer. And unfortunately, the way you get the wisdom to know the difference is you try to change things and then you learn over time what are the things you can and can't control?"

Johnson: *"Ultimately, I've got to accept it and then taking action within the structure. Think of all the brilliant people whom you've known, whom you've heard speak, and sing and play, who had all sorts of limitations. They accepted the limitation, but they weren't defined by it.*

> *Yesterday I ran into a man from our building, an older man who has had a very serious eye problem. And he now knows that that is absolutely not going to get better. And I said to him, 'How are you doing?' He said, 'I've accepted the fact that the eye is what it is, but I'm not letting it take over the time I have to see with the other eye.'*
>
> *We need to get from the moment of grief, which is real. And we need to acknowledge it and honor it as we do with all of our feelings, but slowly move to surrender. And that doesn't mean I lost. It means letting go gently, letting go*
>
> *of the anger, letting go of the fear and opening our hands because we are still here. We aren't at the point of death. There are always people who immediately begin planning the funeral. Well, I have news for you. There's a lot between the diagnosis and the funeral. And sometimes it's the most positive and powerful point of someone's life. All of us need to remember. We don't know how this story's supposed to go. We're living it."*

Ultimately, no one can understand what you're going through except someone else who has lived their own NET journey. So for today's episode, let's let the last pieces of advice come from the NET patients who generously shared their stories with us.

> ***Mary:*** *"First breathe. Just breathe. Then build your support team. Find out who needs to be in your circle. My circle got smaller. The thousand people that I worked with for 33*

years, maybe I have contact with three of them. Advocate for yourself. If you have an overall feeling of unwellness and you know something's wrong with your body, don't take no for an answer. Have faith in whatever it is that you put faith in. If it's God, if it's the universe, if it's Mother Nature, draw your strength and your faith from that and find your own power within yourself. But don't take no for an answer because the only one that can say no is you."

Ashley: *"I just do a lot of reflection and give myself thankfulness for the things that I have accomplished in my life. And even though I feel like my body is failing me, I*

try and think about the things where I have accomplished in my life, that have given me joy. But I had to really rely on putting the initiative towards finding coping skills for this. So I really surrounded myself with nature. I got really into gardening and spending time outside, going for some walks on my property, trying to find people that I felt safe and comfortable in talking with, without any kind of underlying expectation, just able to vent and release.

And then if you don't feel like you're getting what you need, trying your best to seek out the help that you need. But for me, I know it is hard because I'm not one to take help from other people. So that's a challenging thing for me. And it's still a challenge that I face today.

For me, a big thing was just giving myself permission to be where I'm at, be comfortable in this physical state, the mental state that I am in that day. And just think about it that day and not think about what was going to happen tomorrow, what's going to happen next week, and then don't dwell on what was happening in the past. So if you didn't feel like you could clean your house that day, giving yourself that permission to feel that way. If you wanted to feel sad, feel sad. And it's okay.

I grew up crying was kind of a sign of weakness and to stop crying you're just getting yourself worked up. Well, cry. If you need to cry, cry. If you need to scream, scream, if you need to go for a run, if you can run, then go. If you want to lay in bed and rest, do it.

You never know what you're going to wake up to and how you're going to wake up feeling. You never know what your next scan is going to be like. You never know what your next lab or work is going to be like. So people have often told me, "Well, you can't live in that fear," but it's really hard not to just excuse that out of your mind. It's going to be there and people can't really tell you how to think or how to feel. So it's an ongoing struggle to find that happiness or find that calm amidst the storm when facing something like this."

Thanks for listening to NETWise. I’m Jessica Thomas, Director of Patient Education for the NET Research Foundation. Our Production Partner for this series is CitizenRacecar. This episode was written and produced by David Hoffman; Post-Production by Alex Brouwer; Production Manager, Gabriela Montequin *(mon-ta-KEEN)*. It was made possible by the generous support of Ipsen; Advanced Accelerator Applications, a Novartis Company; TerSera Therapeutics; and Progenics Pharmaceuticals, a Lantheus Company. Special thanks to everyone we interviewed for this episode. We are grateful for your expertise. This is a production of the Neuroendocrine Tumor Research Foundation. We’re committed to improving the lives of patients, families, and caregivers affected by neuroendocrine cancer by funding research to discover cures and more effective treatments and providing information and educational resources. Please visit us at NETRF.org