Episode 23
Parenting with NETs:
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 at the NET Research Foundation.

As we continue our mini-series about adjusting to the new normal of your life with NETs, we wanted to take an episode to highlight one of the most emotionally challenging situations that might confront a person who is newly diagnosed -- learning you have cancer while you are raising children.

Parenting is already one of the most challenging and emotionally fraught things anyone can do, and then adding a serious illness on top of it can be downright overwhelming. If this is the situation you find yourself in, we hope this episode will help you to find the strategies and encouragement you need so you can take best care of yourself while also being present and supportive for your children.

For every parent, the wellbeing of their children is always at the top of their priority list, and figuring out how to discuss their diagnosis with their kids is often the first thing on their minds, before even thinking about their own needs.

Here's Lindsey Nowacki, a Clinical Social Worker with AuthoraCare, a palliative care services provider in North Carolina. She supervises the counseling services at Kid's Path, a program that works with children dealing with illness and loss.

> ***Nowacki:*** *"Most parents will think about their children before they even think about themselves. It can be really hard to figure out 'what am I going to say? What are the words that are going to come out of my mouth when I sit my kids down?' and that can be a parent's worst nightmare."*

The challenge here is finding the line between what to say and what to not say. 'If I open up and tell my children what is happening, will that plunge them into fear and anxiety about my situation? And if I choose to not tell them, what will that mean? Will I be able to live a life at home where I keep such a huge secret? And what if I start to feel more sick? Would I be able to keep this from them even if I wanted to?'

> **Nowacki:** *"This is the tricky balance. You know, as a parent, I'm a parent myself. There is a strong need to protect. There is a strong need to keep things safe and secure."*

It's a conversation that many NET patients are able to put off longer than people with many other forms of cancer, because they often don't have external signs of being sick.

Here's Dr. Mark Lewis, an oncologist who specializes in treating gastrointestinal NETs at Intermountain Health Care in Utah. He himself is also a NET patient, and a father.

> **Lewis:** *"So many of the symptoms are internal, they are not visible to the outside world. That is a bad thing when you're trying to get diagnosed. It's arguably a helpful thing if you're trying to... I hate to use the word conceal, but protect your children from your own diagnosis."*

Because of this, many parents with NETs choose to discuss their condition with their children in stages, revealing details in small pieces over time, rather than all at once. This is especially true for patients with children who are very young, who they feel might not have the capacity to understand a situation as complicated as a long-term serious illness.

> **Lewis:** *"So in my case, you know, my wife would often make excuses for me after dinner when I had abdominal pain. She*

would just say, 'Dad has to go lie down.' And the phrase that worked very well in our family for a long time was 'tummy troubles'. So, you know, every child sort of understands on some level when they don't feel well and they feel like they have an upset stomach. That was sort of our code for many years – until I had surgery, until I had something visible and invasive happen.

So our first child, when she was still very young, I was able to completely hide it from her. I think her first awareness that I had any illness at all was when I required the removal of my parathyroid glands. That was the first operation that I needed, and at that point, even, it wasn't a huge deal. I was in the hospital for a night. I was home with drains for a little while. I don't think that was really a huge blip on her radar. I just explained that I had a… I think… I'm embarrassed to say this, I think we may have even used the term 'boo boo' at the time. But you know, we explained that I needed to go to the doctor. I needed to have something fixed. The fact that I recovered so quickly is probably as important or more important than any phrasing that we used with her.

But more invasive surgery was to come, and that was impossible to hide. As a parent, I just was not home. And even when I got home, I was not functional like I wanted to be as a dad.

I do empathize a lot with parents who struggle with NETs as a chronic illness because what I realize is the longer this goes on, sort of the more exposed kids are to a sick parent and it's hard not to wonder, what impact is that having on them."

"My name is Hector Perez. I am from the Salt Lake City area, and I am 37 years old now. I was diagnosed with neuroendocrine tumors back in 2017. So yeah, I'm married, I have a beautiful wife. We have two boys, both under 10 years old.

With my boys, we focus on the good things. The way that we've framed it thus far is, 'Dad has to go to the doctor to… to be healthy.' Just like they get vaccinations, have wellness checks and things like that. 'Dad just has to have some extra stuff'… but up to this point, haven't really delved into much of the difficult, hard discussions that I think at some point many of us in our positions have to have with our kids. Mainly, I think, due to the fact of up to this point… because of how well it's been going for me. So like, medication, treatment and everything, and that's the way that we've, thus far… we've framed our discussions with them.

I've had moments of, I think… not full on depression, but feeling just down and out. And so that's usually just 'Hey, *Dad needs to go take a nap'. 'I need to rest'. 'He's a little tired'. So it's more of that, but nothing that's necessarily held me back to where I don't feel like I can fulfill my duties as a, you know, as a father.*

I mean, they've definitely… my older one has asked questions that, you know, it… he's a very smart kid, very inquisitive about everything, because kids are, right? But he hasn't really got us into a position where we don't necessarily feel comfortable sharing what we need to share. We haven't brought up the 'C word' and talked about it that way. At this point there's been enough exposure, whether it's in movies and things like that, where he's heard that, and you know, immediately things come to mind when you hear that word, which are usually bad. So we haven't talked about it that way, and he hasn't asked questions that directly make it difficult for us to explain.

My boys, my wife, that's really what pushes me, day to day, to get up every morning and not to focus or not to have the disease define who Hector is, but to really think about who truly I am - a father, husband – those titles are, I think are what define me personally and how best I show up in that sense and having that focus has helped push me to feel better, even though there's, you know… there's rough patches, but getting treatment, making sure I'm consistent there and making sure I'm communicating everything, how I'm feeling, to my doctor, and having the support and feedback from him to make adjustments and trust that relationship.

> *That's how I think of… just pushing forward, and thinking about my day to day and how I'm trying to show up and be better, actually."*

You may find, though, as your NET journey progresses, that it's hard to conceal something so large and destabilizing, and that the stress of not speaking openly to your children about it outweighs however stressful it might be to let them in.

> **Lewis:** *"I think, actually, sometimes we put too much pressure on ourselves to almost be performative, to put on a brave face. But, you know, home is the place where ultimately your guard comes down, and if you can't be yourself around your family, that's a very lonely experience because you don't really have an outlet. So I think at some point it was important to be honest with my children and there were things that were just impossible to hide, and I think that forces you to have that talk.*
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> *We talked a lot about is it better to tell white lies or is it better to tell the truth? And my wife felt very strongly that the truth is the better option, and I stand by that. Obviously, you'd like to have a fast forward button so you can see how you've affected your children decades from now, but in the moment this is our quote unquote 'new normal'. By not being secretive, again, I can live out my life at home like any other patient would.*

And actually, the current best practices in child psychology tend to recommend having the talk early, rather than waiting.

> ***Nowacki:*** *"All the research and counseling field does recommend sharing. It is recommended to sit down and have a conversation. Kids are very observant, they're very intuitive and very aware. Children, even infants, can pick up on different emotions that their parents are having, so a change in facial expression, a change in gestures, a change in tone - they're gonna notice things are really off. , And so they may be listening, they may be overhearing things. And so as a parent, when we share, we can control exactly what kids hear. That puts the power in the parents' hands to share exactly what they want instead of them having to overhear a phone call.*
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> *When we keep information from them, it can cause more mistrust, and children of any age feel like they're less important, and so they're not important enough to know what's going on. They also could feel more anxious, because what's in their mind is probably very different from reality. It might be worse than what is actually happening."*
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> ***Lewis:*** *"I think it takes disease from an abstraction, something that you are aware of, and puts it right in front of you where you cannot avoid it. And if you think about it, cancer is so prevalent. It is virtually impossible to insulate your kids from cancer, so I think that word… I*

> *know it's a scary word, but it's a word that sooner or later is going to have to be explained."*
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> ***Nowacki:*** *"Everybody will have trauma of some sort in their life. It might be small traumas, it might be big traumas, and so the more we can do to strengthen, to get support, to get knowledge, to process our understanding, that's building up resiliency."*

Of course, this is not an easy conversation to have, but be comforted that you can do it. You're a good parent, and you will figure out how to convey this information in a way that is clear, caring, and appropriate for you and your family.

> ***Nowacki:*** *"One of the biggest things to tell kids right away - kids of all ages, even teenagers, need to hear that this diagnosis, this illness, is not their fault. For adults, we know that a cancer diagnosis is no one's fault, but children do internalize things that might be them to blame, and so that's a big reason why it's recommended to share that information, as soon as possible.*
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> *There might be a lot of unknowns, and it is ok for parents to say 'I don't know, but I'm glad that you asked me that. And when I do know, I can come back and give you that information.' So I guess the best piece of advice I can share is to be yourself. Putting on a front when we're not well, kids see through that."*

And, of course, this is a conversation that needs to be tailored to the age and developmental stage of your particular children. Let's look at some strategies for talking about cancer with children of different age groups – from preschoolers through teenagers. We'll start with the youngest.

> ***Nowacki:*** *"We all know that toddlers are all about themselves. Preschoolers are all about themselves. That's developmentally appropriate. That is super normal, for them to think about themselves first. And so we might have a conversation about cancer and, you know, they might go and play. That is to be expected. They act unfazed, but we don't want to assume that they're not being impacted emotionally. It would be very natural – toddler, preschool, even elementary age – for parents to see them making sense through their play. It could be art that they're drawing, a doctor's office, going into the doctor's office… they may identify their feelings, they might not, and so it's normal for children to do that on their own.*
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> *Younger kids may say things like: 'mommy is sick.' And so it could be as simple as that. They may blurt out, 'my mom has cancer' to strangers, and so that is completely normal. And you know, them saying it out loud as practicing what their understanding is. And so for toddlers, preschool aged children, we expect conversations to be brief, but maybe more frequent. Their concept of illness is it's temporary: we get the flu, we get a cold, and it goes away. And as an*

adult we can explain that this type of illness isn't something that you can catch.

Children who are very young also need to know how this impacts their day-to-day routine: who's going to take good care of them? That's what they're going to want to know. And so I think the most important thing would be to share that mom has an illness, that she's going to be going to more doctor's appointments, she's going to have a treatment at the doctor's office one day a week, whatever it is, so that they know what to expect. And so if there's a change in their day to day routine, if now all of a sudden an aunt is coming over after daycare, someone else is preparing dinner… they just need to know exactly what's happening.

In the initial conversation, we need to keep it brief, keep it short, but truthful. We also can ask them 'If you have any more questions or need to talk about it, I'll be checking in again.' and so that way the invitation is open.

Most kids of any age like to be helpers. And even little things – they shouldn't get caregiving roles, but little things that they can do to help – bring water, bring snacks, draw pictures, bring in some flowers from outside, or whatever it is that they can do, they feel important, they're helping. So this could actually provide some resiliency for kids, because they're participants in the family system. They have things in their control, and so it *actually feels good to them when they have the opportunity to do that."*

(Patie

My name's Ashley. I am 38 years old and I'm from British Columbia, Canada. I was diagnosed with a small bowel neuroendocrine tumor in October of 2021. You know, I thought maybe I'd probably get cancer when I'm in my seventies or eighties, but I never expected that at 37. My children are seven and six, they're 13 months apart.

My whole focus is on my kids. Of course, I want myself to be well and to live long and to not be in any discomfort, but I don't want my kids to feel that they're alone or lost or they can't talk about it. I want them to be able to have the tools to be able to also manage this as best as they can, with the help of myself, my husband, and those that are close to them. In our family, we are very open and honest with our kids, according to their age and the appropriateness of it. And because we live in a small community and a lot of people knew about my diagnosis, I didn't want them hearing the term cancer from someone else, like from their peers or their teacher or something like that. And plus, you're surrounded by cancer everywhere. You see it in magazines, you see it on TV, you see it on the news, you hear kids say 'My grandma died of cancer'. Like, everybody's been touched by cancer in some way, shape, or form, right?

> *So, we had a discussion with each of my children, separately, and we were as honest as we could. We told them that mom has cancer, and we talked to them about it prior to my surgery because I would be… I went in and had this done in October and they had seen me being unwell and that kind of stuff. And we just said that we don't have to be scared of this, that mom is doing the best that she can to keep well, and that she has good doctors looking after her. It's okay to feel sad. It's okay to have questions, and we want you guys to ask us anything if you have a question or if there's anything that's bothering you.*
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> *One child of mine, the older one, wants to know all about cells and all about areas, like what's affected and what's a tumor and that kind of stuff. So with him we were a little bit more… We explained things a little bit more on a physical level. My youngest son, he didn't need as much of a detailed explanation, and he processes things in a little bit different way. So even now, he'll just randomly come up to me after he's running around and then he'll stop and stare at me and he'll be like, 'Mommy, do you still have cancer?' And I'm like, 'Yeah, honey, I do.' He's 'Okay'. And then I just say, 'Don't worry, mommy's doing the best that she can to keep herself healthy.' And he's 'that's good', and he goes off and plays, right?*

As children get older, it grows more likely that they will have preconceptions about what cancer is, and it's likely that they will want more details about what exactly is going on with your health.

> **Nowacki:** *"Some preteens are old enough to talk about what they know about cancer. They may have a totally different idea about what it is. There are many, many different types of cancers, and so what they may know may be completely different from this situation. And so it's good for parents to, you know, ask questions like, 'tell me what you know about this. What have you noticed?' That way you're getting the information from them and the parent's not having to start at this unknown place."*

Children's emotional lives deepen and grow more complicated as they grow, and so it's important to make sure they also have access to resources like counseling – places where they can have outlets for dealing with sadness and anger and stress.

> **Nowacki:** *"It's difficult to be in middle school. It is a difficult transitional period. Preteens can often feel isolated or misunderstood, more and more children are reporting having depression, having anxiety. And so if there's something like that already happening, we might see symptoms increase with news like this. That's not to deter a parent from sharing, because if parents can model their own feelings, talk about them, we're also teaching children at the very same time: 'Everyone's got feelings. We don't have to hide them. We don't have to bury them. We don't have to avoid them. We can support one another with what*

> *we're going through.' That might be difficult in the beginning. That's okay.*It's okay to share with them: 'This has been a hard day for me. I'm also having a hard time.' It validates kids'experiences too, because when teens, preteens, don't see healthy grief, then what's going on inside feels even more isolating. It feels overwhelming, and they might feel like they're not normal. So if they see it, then it helps them to digest all of these new feelings."

As kids get older, their own social circles also become more and more important to their wellbeing. If they run off to be with their friends during a stressful time, it doesn't necessarily mean they're in denial or abandoning the situation, it might just be the healthiest way for them to process their feelings.

> ***Nowacki:*** *"If kids can get opportunities to hang out with friends, teenagers really need that. They need connection with friends to share. Maybe they don't talk about it at all. Maybe they need time to be a normal teenager, and when they come home, they face what's happening."*

And maybe the most important thing to remember is that your children are now on their own NET journey, in parallel to yours, and that their feelings and needs will develop and change over time, throughout their childhood and beyond.

> ***Nowacki:*** *"So as children get older, they enter adolescence, they enter young adulthood, naturally grief is on a*

continuum. We don't complete grief, right? It is a lifelong journey."

I'm Mary Zeller. I live in Indianapolis, Indiana. I'm 65 years old. I was diagnosed with a neuroendocrine tumor in 2007. My daughter was a senior in high school. I was diagnosed in October of her senior year, and I just wanted her to have to enjoy that year and to go through everything and not worry about her mother being sick. And my son then would've been a unior in college. And I guess that's another part of having an illness, and a serious illness is, worrying about and thinking about, and to some extent feeling guilty about, how this impacts others, not just me, but those I love. And,that was really a particularly difficult time for me.

In terms of how they reacted, they were quiet and I think they were worried, but they didn't have a really strong worried reaction. Which later, my husband at the time and I talked about it and I think it… we think it was because of how I presented it, which was like, 'It's going to be okay, and I'm very worried about the surgery, but we've looked into everything and talked to people and feel really comfortable with my medical care, and, they think they can get it all'. And, you know, I kind of probably presented a rosier picture at that point than maybe reality called for.

But in actuality, I did go through the surgery in the first week of January in 2008, and recovered enough to accompany my daughter on her senior spring trip to Mexico. Then I had no evidence of disease for five years. So it was basically, for me, those first five years were recovering from the surgery… and it was more how they reacted to the recurrence, and then the knowledge that after the recurrence, that I would always have this. And I think that for them was probably a more significant hit. They were a little older and so could realize the significance of it. And I think were a little more worried. It's not always present and spoken about, but it's in the back of your mind.

I was spending some time with my daughter and her son who live about five hours from here this past weekend, and we were talking about times when we could possibly get together. And she said the hard part out loud because she was a little frustrated with our mutual schedules and said, 'Mom, you have cancer. I want to spend as much time with you as I can'. And we were just at the park playing with her little boy. So that's a good example of how the situation I'm in permeates our lives and in ways that are hard, but they're also real and we deal with them realistically and we… we move on. We continued our park playdate and I said, 'I know, sweetheart. I think about that a lot too. And we will make this happen and we'll be okay'. And then we,'oh look, there's the butterfly', that's how you live with it."

Maybe the source of all the challenges of these conversations is that they force us to talk about something that people would rather not think about, let alone discuss - mortality. Death is a really hard subject to bring up with your children, and there's really no way to speak openly about a serious diagnosis like cancer without your eventual death being the elephant in the room. The truth, though, is that mortality is something every child has to come to terms with, whether you had this diagnosis or not.

> ***Lewis:*** *"I think one of the interesting things about childhood is the dawning realization that your parents are mortal. It's a rite of passage, right? At some point you realize what's happening and that you're even… you are going to die one day. It's just a matter of when. And I really don't think we completely understand in terms of child development, is there a right age for everybody? And I think everybody is situationally different.*
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> *All of us, sooner or later, certainly around puberty, most people deal with these issues and it's just a matter of when. And as a parent… of course you have, sort of, these rehearsals in your head of how it's going to go. And this is the script, but we all know that in real life it's often forced upon you. It is far more spontaneous and extemporaneous than you might like and you don't have complete control over how it's going to go."*

Nowacki: *"And so based on the developmental understanding, we want to explain what death means. And so, this might sound really bizarre to adults, because this is not how we normally talk about death, but for younger kids, they do need to know that when someone dies, their body doesn't work anymore. So they don't need to sleep, they don't need to eat, they're not breathing, they don't need to be active and go to school or go to work.*

If a family does want to explain whatever afterlife or cultural beliefs that they have, just check in with them about their understanding. The concept of heaven or afterlife can be really confusing to younger kids. Younger kids might think that heaven is a place that I can go visit and come back. They may think that their loved one who died is coming back, and so as painful as it is to remind them that they're not coming back after they died, we can't go to heaven and visit and come back. There are books, children's books, there's resources out there that are very inclusive. And so also seeking out some tools that help kids. That way if there's a part of the story that they don't understand, the adults can help provide better understanding."

Unfortunately, thoughts about mortality and the nature of cancer may become even more present for your children, because some NETs – not all, or even a majority, but some – have a known link to a specific genetic mutation, meaning that it's possible to pass an increased likelihood of developing NETs on to your children. Genetic screening can reveal if your particular NETs have a known genetic driver, and if your children have inherited it. If they have, you'll have to consider carefully when and how to share that information with them.

> ***Lewis:*** *"This is a problem that goes far beyond NETs. If I had to guesstimate, probably something like a fifth of all cancer patients have to at least think about whether or not they have a hereditary condition to pass on. And then these days, there's genetic counseling that, frankly, has never been better in allowing people to make these decisions in an informed fashion. There's still a big equity problem, where some of this reproductive technology is prohibitively expensive to most Americans, but the fact that it even exists tells you that we are making progress with the scientific part of it, if not the logistical part of it, and letting people minimize the impact these mutations can have on their families."*

Dr. Lewis' NETs are related to a genetic condition called "MEN-1", which he had a 50/50 chance of passing on to his children. He learned he had this condition between the times when his first child was born and his second was conceived. Deciding to have another child with that risk in place was not a decision he and his wife took lightly.

> ***Lewis:****"When my wife and I had our first child, I had no idea that I had neuroendocrine tumors. I certainly did not*

know I had a genetic cause for neuroendocrine tumors. My daughter was a coin flip and that coin landed, I hate to say heads up as I'll explain it in a minute, but it certainly landed in a manner where she did not inherit my condition. Having our second child was in some ways a lot more… fraught, if that's the right word, than having our first child. Because of this weight now that, okay, there's a 50/50 chance, he's going to have my genetic condition.

And I'll say two things: one is, one of the things about my genetic condition – or our genetic condition – is almost everybody lives long enough to pass it on. That's how it perpetuates, which also tells you something about its survivability. You know, I feel very fortunate to say this, it's not the kind of syndrome that cuts people down in infancy or childhood. It usually lets you survive long enough that you can have kids if your own. So I'm certainly not the first person with Multiple Endocrine Neoplasia, Type One to grapple with this problem.

Also, once I had my basic endocrine problems addressed, I felt great. In fact, I felt better than I had in years. So I was like, 'Well, you know, my quality of life right now is superb. And that means that my son, especially if he has forewarning, hopefully ought to have as good, if not better quality of life, because he'll see all this coming. Provided he's not psychologically scarred by that foreknowledge, then his life should be better than mine.' And that gave me a lot of hope that even if we flipped the *coin and he inherited the mutation, which he did, that all hope was not lost.*

What is encouraging, and also maddening, about my condition is that no two people, even with the same mutation, have the same course. So I couldn't look at my own life and say, 'This is the exact blueprint that my son is going to follow at this age'. The only hallmark that is a hundred percent likely in everybody is you will have a high calcium level. Okay. That's it. That's the only thing that all of us are going to get. That is very manageable in the grand scheme of things. Yes, you might get kidney stones, which are horrible. Yes, you might get osteoporosis, as I did at age 30, but when I looked at that against my son's entire upcoming life, I thought, 'that's something we can handle', especially if we see it coming. So I actually felt weirdly optimistic about that. I felt that was freeing him from some sort of self-fulfilling prophecy. And that made me feel more empowered to have him naturally than if I was selecting an unaffected embryo.

Have I parented him differently than my unaffected daughter? Gosh, I hope not. For us, each phase of his childhood has looked slightly different in how we communicate. That's part of parenting. We tried to adapt the messaging to the level he is at. And again, I'm not saying this is the template everybody should follow. But for us, making him understand early on that when he goes to the doctor, it's going to be slightly more involved than *when his sister goes to the doctor. We thought it was better that he knew that I think maybe early he felt like that was a special treatment being afforded him. For us, the earlier we could introduce the concept, the better. And you know, at 11 years old, he doesn't act paralyzed by fear of the future. He does not fear going to the doctor.*

Some people have told us, 'Hey, listen, you should have waited until he was 18 to tell our son'. And I don't know, that seemed like a weird birthday present to me. Yes, it respects his entry into adulthood… with this sort of sudden awareness that we had kept something from him. And again, I know, everyone listening to this is going to have a different view on that, but for us it just felt like a weird ambush, and we thought it would be a lot easier if he saw it coming.

So don't get me wrong, this calculus is dramatically different by person. It's dramatically different by disease. If you've got a disease that's a lot more harmful and causes a lot more problems earlier in your life, you're going to feel a lot differently about that heading into parenthood than I did."

We should talk now about an entirely different situation at the intersection of NETs and parenting. Adolescent NETs are rare, but are being diagnosed more and more often. So what if you are healthy, but find yourself parenting a teenager with NETs? It's a situation that presents challenges that most parents can only imagine.

"My name is Lynn Pierce, and I live in a small town called Richmond, which is just north of Detroit. My daughter, Lillian, was diagnosed when she was 17 with NET cancer.

It was the summer before senior year when everyone else was touring colleges. We went to our primary care physician because Lily had a wart on her foot. And the doctor said, what else is going on? Because she'd known Lily for most of her life, and Lily was really embarrassed to say anything, but then she mentioned that she had been having diarrhea. So she said, let's look at that. So they started to look at diet, they cut out dairy, they cut out gluten, each for six weeks and tried to figure out if that was causing anything, and it wasn't. So she did an ultrasound on her abdomen and saw something. So then she referred us to a gastroenterologist and he assured us it was nothing, and that Lily was just having these symptoms because she was a teenage girl and she had finals and she had broken up with a boyfriend and said it was no big deal. But I started crying, and this doctor could not handle me crying, and he said, 'Just because you're hysterical, we'll do a biopsy to put your mind at ease'. Just to prove that it was nothing to worry about. He saw that there was a mass, but he said it was just like a fatty tumor.

And then about two weeks later, I was driving home from work and I got a phone call and I didn't recognize the number, but I picked it up and he didn't say who he was. He just said, 'I'm so sorry. I got her into the University of Michigan with another gastroenterologist'. He didn't say the word 'cancer' and I was too stunned to ask questions. We went to the gastroenterologist there and he talked about going to an oncologist. He talked about everything that you can say without saying the word 'cancer', so that when we left the office and we were standing at the checkout, making the appointment to go see the oncologist, my daughter actually said, 'Mom, do I have cancer?'

And that, that was really, really hard because I had to tell her… like, she had heard the term surrounding it, but she didn't really necessarily know what they were. You know, you don't know what 'growth' and 'metastasize'…. and you don't know necessarily when you're 17, what those things are. And so yeah, I had to tell her stand standing in front of the checkout lady that she had cancer. It was really, really hard.

So they removed about a third of her liver. They removed several lymph nodes. They removed her gallbladder because they were going to give her this treatment called Lanreotide. But they never found the primary tumor. So because they never found the primary tumor, they told us to expect WHEN it comes back, not IF it comes back.

I think we were all just stunned. Out of the whole family, she was the most healthy. She played sports – travel softball. She played basketball. She did pilates. She ran. She wasn't a teenager who smoked or drank. You know, I like wine. I like food. I am not as active as she is, none of the rest of the family is. So it was a shock that out of all of us, she would come down with something. And I told her like, 'This was really hard'. I had to tell her, like, 'I don't know what's going to happen'. And it's hard as a mom to admit that we don't have the answers, that we can't make things right. So I just said we would figure it out together.

As much as I wanted to completely break down… and I did, sometimes… I had to be the person who took care of everything we could control, you know? So I didn't let her know about… not that I hid anything, but I didn't talk about finances, the fact that one test the doctor ordered, he ordered a PET scan and it was initially approved by the insurance and then it was not approved, so we got a bill for $20,000. So I didn't tell her that, because I didn't want her to… I didn't want to add to the worries. I didn't tell her that my job was giving me a hard time about taking time off to take her. So I tried not to… I never lied, I never tried to sugarcoat anything… but I just tried to protect her from the stuff that I could, you know?

I've tried really hard to have those embarrassing conversations without being embarrassed or at least hiding *my embarrassment. Things are really embarrassing for a teenager, to talk about diarrhea and have your mom ask you every day, 'How was your poop today?' like you do when they're babies. That was hard and embarrassing to talk about, but if you don't let that stop you, then they know that they can tell you about anything. And so we have talked about that. We've talked about getting close to someone and having them see your scars. You know, that's obviously one thing, how to tell people, if you're entering your relationship that you don't necessarily know what's gonna happen down the road.*

One of the things with NET cancer, at least in Lily's case, you don't have chemo, so you don't lose your hair, and that's how people identify a cancer patient. So Lily didn't have chemo and when she went back she had like a eight inch scar in her abdomen, but no one's looking at her abdomen in the school day. So a lot of people thought she was exaggerating for attention, which was really hard. The people that she knew, people she thought were friends were saying, 'Oh, you just want attention? And she's 'no, I have to leave' and one of her good friends warned her that there are rumors going on about you. We weren't expecting those responses. So there were a lot of things that we weren't expecting.

Lily went to a very competitive school and she had completed her first three years. She was going into senior year and she really wanted to stay at that school and

> *finish and do her exams, because she had worked so hard, and her biggest fear was not being able to do that. She worried about whether or not she could go away to college, or if she'd have to stay home. She worried about whether she would be able to have kids one day. And, insurance long term – will she have to get a job right out of school so that she can get insurance? Will she have to take a job that she doesn't like just because it has insurance?*
>
> *Probably just in the past year and a half, maybe since she was 20, she took over. It's nice to see her facing it a little bit more, but it's also hard because you… she's still my baby and you still want to protect them and take care of things so that they don't have to stress out about things. She'd probably be mad at me for saying this, but like for the first maybe six months after she was diagnosed, when she had surgery and stuff, she slept with us. It was just so hard to deal with. Like, she couldn't sleep unless we were right there. And now to see her… she has a house with eight other girls and she's doing really well at school. She has accepted a position in a Master's program in Ann Arbor next year. And it's nice to see her kind of coming into her own and not having that as the forethought all the time.*

No matter your situation, it's important for everyone – you, your kids, your partner – to have an outlet for their feelings during this journey, someone to talk to and express themselves, because the stresses on a family that can come from a cancer diagnosis are real and serious, and if they're swept under the rug they can lead to even bigger stress down the line.

> **Lewis:** *"Cancer is incredibly disruptive. One of the things that I see happen a lot is… I call it almost finding the fault lines in relationships, putting them under immense pressure and seeing where the cracks are. And because there's a ton of stress, right? It's almost like a stress test for certain families. It can be a stress test for marriages, it can be a stress test for parent child relationships."*
>
> **Nowacki:** *"And also as a family, we can build resiliency when we're talking about feelings. Now, a lot of people – kids, adults, teens – might tell me, 'Oh, I don't do feelings. Not me. We're not that type of family. We don't talk about our feelings.'*
>
> *We can think of this model, it's called the 'Volcano Model'. We can imagine a volcano in our head. And so the ground represents changes. Changes might be: my holiday is looking really different. I'm not going to be home for my holiday. Who picks me up from school is different. My mom often goes to treatment – who I spend Saturday evenings with is different. So all kinds of changes since we learned of our loved one's illness. So then the next step of coming from the ground is a mountain. The mountain includes all the different feelings that relate to this big change in*

our family. That could be anything from anxiety, to anger, to sadness, to depression, to feeling loved and cared for, having fun, feeling excited. It could be feeling guilty or shameful. Any feeling at all, it all goes in that mountain. So what comes through… the mountain, it's actually a volcano. When these emotions get stirred up, when we don't take good care of them, we don't express them, they explode. And so, like, explosions might be: I'm yelling at my brother, I'm slamming doors. For younger kids that might be talking back, it could be not listening to my teacher when I normally would. They are normal things that get in the way when our feelings explode. So, in order to prevent those explosions, what we need is little pockets of air in the mountain.

So, we call that venting. If we can get these little pockets of air vent the volcano, we actually prevent these explosions. So that would be our coping skills.

These things build resiliency: listening to music, hanging out with friends, playing, crying. Crying is a coping skill because it's letting out our sadness, it's letting out an emotion. Let's add some more. Let's add more ways to vent this volcano so it doesn't explode. And when we do, that's okay. It's okay to have these explosions, because we can apologize if we need to. We can acknowledge to ourselves, 'Whoa, that was a big one. I'm riding out these emotions just like a big wave.'"

Ashley: *"I'm pretty much the primary caregiver. Like my situation, I live in a rural community and I'm not near a very big center. It's about an hour away. So, I live out on some acreage and my husband works away for two weeks at a time.*

At the time when I was working, I was juggling a full time nursing position – two days, two nights – and then coming home caring for my kids. And then, like, when my husband was away, it was all on me. You know, the kids getting them to school, pretty much raising them, and then everything that has to do with living on a hobby farm, so all the work that entails. So that was quite difficult. There were times where we got a lot of snow up there and so I remember when the kids were, they were still babies, and I'd come home from a day shift and I wouldn't get home until about nine o'clock at night, and I had left about six in the morning. And then I would come in and say goodbye to my caregiver and then I would go look at, you know, my kids and then I would jump on our tractor and pretty much plow snow until one in the morning, and then go to bed and then get up at six to go to work the that morning. And I need my house clean. I need my laundry done. I need to cook good meals. I need to be a good neighbor, all that kind of stuff. And I definitely had this unrealistic expectation of myself. There's that underlying expectation when you're a mother and you're a wife and I have to make sure my kids are

> *occupied and they're happy and they're happy all the time, and they got this perfect life. So it was a lot.*
>
> *So I just think about all the things that I've had to work through and to try and manage in my life. I'm like, I've been stuck in this fight or flight position for a long time."*

Please remember that you can't do right for your kids if you're not also doing right for yourself - give yourself the time and space and care you need to deal with your own illness, or you won't have anything left to share with them.

> **Nowacki:** *"We can't ignore our own feelings. And that's why, if we need a moment in the car… there can be a lot of therapeutic moments in the car. And if the parent really needs a five minute time in the bathroom to recompose, ground, center, do whatever you need to do. My best suggestion is to get support. Building parenting resiliency means not doing it by yourself. So asking for help, receiving support. When community members, friends, family members, anyone offers help, take them up on it."*

And even if you're looking back and thinking that you handled something the wrong way - were secretive when you should have been open, hurried when you should have been patient, or short when you should have been gentle... it's OK. This is a process, and it's very hard to mess things up permanently with a single mistake.

> **Nowacki:** *"Now if we have parents who are listening and they haven't shared truthfully what's been happening, it's not to shame or guilt anyone because this is really tough stuff. And so, you know, if it's been some time, that's okay. There is something really powerful called a repair. If something random comes out, in our own behavior or what we say, we can stop, take a moment, take a deep breath, and share – 'That is not how I wanted to say this' or 'this is not, you know, what I wanted this conversation to be like', 'I'm not feeling well today, you might have noticed that. Let me take a deep breath and share what I really meant to say'. 'That was an oops'.*
>
> *We're providing that consistency and safety and caring. So, showing that we care, we're listening, we're willing to have these open conversations."*

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

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