Episode 47:
NECs and Caregiving
Transcript

Holly Jensen and her mom, Jean Carney, live about 10 miles away from each other in northwest Iowa. They've always had a pretty close relationship, but it took on a whole new form in late 2023, when Holly, who's in her mid-thirties, was diagnosed with neuroendocrine carcinoma.

> ***Jensen:*** *You know, you hear it different ways, whether it's stage four or phase three, just the highest grade of neuroendocrine carcinoma that you can have.*

Neuroendocrine carcinoma is a highly aggressive form of cancer, which requires intensive treatment. After her diagnosis, Holly immediately started six rounds of chemotherapy. On her second round of chemo, Holly started targeted radiation, which caused painful side effects.

> ***Jensen:*** *I had sores, I could not walk. I was completely drained. Moving just was excruciating.*

Throughout all this, Holly's mom, Jean, was there for whatever her daughter needed. She traveled with Holly to see specialists, helped take care of her young kids, and supported her during treatment.

> ***Carney:*** *It was a struggle as a mom to see her go through this. There were several emergency room visits when things were getting really bad. She was getting the burns so bad, she was in so much pain. So I did a couple ER visits with her that were hard to see.*

Jean supported Holly as a mother and as a friend, but also as something more: Jean took on the role of caregiver.

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You're listening to NETWise. I'm Jessica Thomas, Director of Patient Education at NETRF. In each episode of this podcast, we share expert information and patient perspectives to help neuroendocrine cancer patients and caregivers navigate their journeys.

This is the second episode we are dedicating to neuroendocrine carcinoma, which is an uncommon and aggressive form of neuroendocrine cancer. In the last episode, we talked through diagnosis and treatment. Today, our focus is on caregivers.

Welcome.

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A caregiver is someone who gives their time and energy to support someone with a medical condition. This is often a spouse, parent, or child. It could also be a sibling, a neighbor, or a friend. Anyone can take on the role of caregiver for a patient, and provide whatever support that individual needs.

Jodi Kolada works with caregivers in Greensboro, North Carolina.

> ***Kolada:*** *I think the caregiving definition applies differently to each person. Do they need a hand to hold? Do they need emotional support? Do they need physical support? Do they need spiritual support? Do they need financial support? So it really just depends on what the person's needing at the moment.*

Caregiving for a patient with neuroendocrine carcinoma can be especially intense and challenging. This cancer is uncommon, progresses very rapidly, and is often terminal within a short period of time.

Dr. Robin Lockridge is a neuropsychologist at the National Cancer Institute at the National Institutes of Health. She frequently works with caregivers.

> ***Lockridge:*** *Given that it's a rare disease, you enter with this degree of uncertainty and isolation. And so I think that a lot of caregivers, they initially go into that uncertainty phase, and then there's some transitions to kind of the physical and emotional burden of care.*

Since treatment for neuroendocrine carcinoma begins almost immediately, a caregiver might provide support like driving to appointments and medication management. A caregiver might also take on household labor, and provide emotional support for their loved one.

While a patient is going through their own difficult journey, being a caregiver in this situation can take its own toll. Depression, anxiety, and loneliness are all commonly reported among caregivers.

> ***Lockridge:*** *So many caregivers report higher distress, fatigue, sleep impairments, maybe more unhealthy behaviors because if you're spending a lot of time caregiving, you are not sort of the leisure activities that you liked, when you tended to more socially, you're also not doing that so much because you feel like 'maybe I need to get back home, or maybe I need to get back to the hospital. I need to be available.'*

While all of this may feel necessary and important, it can result in a caregiver struggling to maintain their sense of self.

A caregiver may also have lots of complex feelings about what is happening -- feelings that they keep hidden.

> ***Lockridge:*** *They're trying to be strong and not show their loved one, how tired they are, how burdened they may feel, how sad they may feel. They're sort of trying to create this environment for their loved one, while all the while struggling with the what-ifs of the future, the grief, the sadness, the impending loneliness, and kind of that difficulty accepting that.*

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***Susan Meckler Plummer:*** *My name is Susan Meckler Plummer and I was a caregiver for my husband, who was diagnosed with neuroendocrine carcinoma in November of 2012.*

*I met him in a bar, actually, it was at a happy hour thing, and I was with a bunch of other friends from the hospital I was working at at the time. He was also in healthcare - he was a pharmacist - and so that we, you know, we had plenty in common, lots to talk about. That was in, I wanna say May, of '76. And we were engaged six months later.*

*Around the second weekend in November of 2012. We went to bed that night. Everything was perfectly fine. He had not been sick, he had no symptoms. And about two, three in the morning, he woke up literally screaming in pain. And I took him to the local emergency room, they did an ultrasound and they came in and told us that there were over 90 tumors in his liver. And they didn't know what kind of cancer it was, but it wasn't good.*

*Two days later we got an appointment at University of Pennsylvania and our worlds pretty much fell apart. You know, this was the most aggressive cancer there, there is. And if we did not admit him that day and start chemo that night, we're looking at four days. That was the original prognosis.*

*Before he got diagnosed, honestly, our marriage was not in a good place. I was actually ready to leave. And when we went to the hospital that night and I came home, you know, during the night, I literally unpacked all of my stuff that I was gonna leave with, and I just said, 'I've been with this man for 36 years. I love him.'*

*It was like all of a sudden, stuff that was the problem, it, it just evaporated. All of that was gone and all that remained. Was our family and our kids and the future, and what are we gonna do?*

*He knew where we were in that relationship and he probably expected me not to take care of him, but that, that's not who I am. So yeah. But we ended up, over those eight months, becoming just as close as we had been all those years ago.*

*I had to learn how to manage everything at once. All of a sudden I was an advocate, I was his nurse, I was his coordinator, I was his emotional anchor. I was the one that he put in charge of every decision. Because he knew cancer - he worked in oncology for 25 years - he didn't wanna know anything. He wanted zero information.*

*He endured five aggressive rounds of chemo, and then they did liver directed therapy on him, which did not work. At that point did a scan and found, because he had been off of chemo for the eight weeks while they did this other procedure, now it was in his brain. And he passed away on September 7th of 2013.*

*After he passed away, I was grieving, caregiving. And I was shocked at that. I was like, why am I feeling this? But it is almost the entire eight months, 10, whatever the amount of time is, all you're, you're just running on fumes, just trying to get to the next day, to the next day.*

*And you still have all your other stuff you're responsible for, you know, in your life. But this becomes everything. The exhaustion, the fear, the sleepless nights. The impossible choices you have to make for treatment options. It's a form of bravery that I don't think people really understand, because that's what it is as a caregiver to somebody with an aggressive, terminal, very quick terminal disease. The work is sacred. It really is.*

*He said one thing to me that I will never forget. It was towards the end. He looked at me and he said, 'I'm not sure how you're going to continue on.' He said, 'as bad as it is for me, it's gonna be a thousand times harder for you.' That acknowledgement, that validation of what I was going through, because nobody ever asked me how I was, that was a gift he gave me that I think enabled me to do what I do today.*

*I administrate eight groups all related to treatments for neuroendocrine tumors and neuroendocrine carcinoma. Every new patient I speak with or zoom with, they want to know my story.*

*And I will often say to fellow caregivers that I get it. I see them. I know. Those two words: I know.*

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Caregiving for someone with neuroendocrine carcinoma is one of the most difficult and generous things a person can do for someone else. But as important as it is for a caregiver to take care of their loved one, it is also essential that they care for themselves.

The number one thing caregivers can do for themselves is maintain their social circles as much as possible. This can be challenging -- it's easy for caregivers to become isolated amid all the stress and uncertainty.

> ***Lockridge:*** *We know - we all know - how valuable social support is, but it's almost the first thing that goes for caregivers, because of time, energy, and sometimes motivation.*
>
> *It's difficult to plan anything, because you don't really know what the future holds, or you don't know what's going to go on that day and where you need to be.*

It may involve some amount of effort to maintain connections, but it can make a big difference.

> ***Lockridge:*** *Even if it's a phone call, if it's 30 minutes. It's important to, to really make sure you have that social support there.*

To the extent possible, getting mental health support from a therapist or counselor can also be hugely beneficial.

The second most important thing for caregivers to remember is: don't neglect your physical health.

> ***Lockridge:*** *Go to your doctor's appointments, take care of yourself. It sounds so silly to remind people to do that, but the number of caregivers who say, 'I'll take care of that later,' is really astonishing. And it's admirable because they want to be fully available to their loved one, but it really is at the risk of their own health.*

The third thing that's important for caregivers to remember is that it's ok to ask for help.

This might be help driving to an appointment, or making a grocery run, or mowing the lawn. While asking for help is sometimes difficult, having that help can provide a lot of relief.

> ***Kolada:*** *When you are caregiving for someone, it is hard to ask for help because you feel as though you might be burdening other people, and it might also make you feel as though you can't do it all by yourself. And that is really true though. Nobody can do this by themselves.*

Finally, caregivers should remember that what they are doing is enough, and their needs are important, too.

> ***Lockridge:*** *Caregivers are, they're often so amazing, you know, in what they're giving to other people. And I see very little grace being given to themselves. Very little compassion being given to themselves. Because they already judge their concerns to be less important. And that's not true. They're playing this amazing role, but they still need. And they still need care as well.*

More often than not, caregiving starts from a sense of love and a desire to help another person. But dealing with a disease like neuroendocrine carcinoma – and everything that comes with it – puts a strain on the relationship between the caregiver and patient.

Relationship dynamics can be tricky no matter what – with cancer thrown in the mix, they can become even more complicated. And sometimes, complex relationship dynamics don't lend themselves to a loving and supportive situation over a prolonged period of time.

The two most common caregiving relationships are a married couple and a parent and child. Each of these comes with its own set of challenges.

With adult children who are caring for their parents, one common issue that arises is a sense of familial obligation.

> ***Kolada:*** *This is someone who took care of us, who provided for us, and now we feel as though the role has reversed a little bit. And we need to provide that support for a parent. And we are doing this out of an obligatory feeling.*

This sense of obligation can sometimes lead to resentment.

The same thing can happen with married couples, where the caregiving role can also be taken on as a default.

> ***Lockridge:*** *It almost feels like the obvious choice, right? They are often the ones that you spend the most time with. They know you the best, they live with you, you guys already share finances and responsibilities, so this just becomes subsumed under that.*

> ***Kolada:*** *And then after a while there are some uncomfortable feelings. We might feel some resentment. We might feel like we're doing this out of obligation. This is what a married couple does.*

Meanwhile, other essential aspects of the marriage may be neglected.

> ***Lockridge:*** *You forget about the aspects of intimacy. You were sort of accomplishing the task of I'm going to help you clean up. I'm going to give you medicine and I'll get you some food, and then I'll walk away.*

> *And maybe you forget to give that extra snuggle or you forget to talk about how each other's day was going. That is a really easy slope to go down where it becomes very transactional. I'm doing a job, I'm trying to just sort of keep my head above water.*

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***Shannon:*** *My name is Shannon Page Corte. I currently live in the North Atlanta area. I just moved here from South Florida. My diagnosis is neuroendocrine carcinoma.*

*I got diagnosed in March of 2022. KI 67 of 90% primary tumor pelvis of uterine, original, they're not sure. And then with metastasis to my chest wall. I'm a pretty healthy person, and it was just crazy that I would get diagnosed with something like cancer. It was kind of shocking.*

*I think my husband was pretty shocked by it too, along with my kids, and at first was really immersed in being supportive. Almost a little too much, which I'm sure that other people experience that, where it- it's a bit much. But he, I was glad he was supportive. And we, he went to all my appointments, took me to chemo - I started carboplatin and etoposide in March, 2022. I did that for six full cycles at max dosing till July, I finished that last cycle.*

*The tumor in my chest was gone already. The pelvic tumor was much, much smaller, probably a third of the size.*

*Towards the end of chemo, I saw a little bit of a trailing off, where it just wasn't quite the same. And I think, you know, based on the statistics that you read online, I wasn't gonna be around for long. I think he started sort of making plans for that. As a way maybe to cope with it. And I think he just thought he was just gonna move on. He didn't tell me, oh but he moved on!*

*And this is really hard. So you kind of ignore it a little bit. You kind of just turn your cheek because. I'm just trying* *to be alive right now. I'm just trying to work and eat healthy and exercise and be a good mom to my kids, and all these things. And I don't know what he's doing over here, but I, I don't have the energy to even worry about it. But finally, I think just God has a way of making the timing where you can handle it. He waited till I could handle it and then I found out and was like, yeah, no.*

*So I just said, 'I'm, I'm, I'm not doing this.' When you don't know how much time you have left, and it might not be much time, I would rather just be on my own or be with someone that has a little bit of respect for other people.*

*So I filed for divorce. And then work brought me to Atlanta. So it's really good that I get to get out of that whole area.*

*So then I started Keytruda, and that's where we are today in 2025. I'm still on Keytruda. I've done, gosh, probably 15 cycles and I'm no evidence of disease right now.*

*I think the most important thing is first of all, for the person that has cancer, to really think about: what do you want? Who do you want to be your caregiver, and what do you want that to look like? Because I was so devastated by the diagnosis, I, I wish someone had said, 'you gotta think about this. He's your husband. He'll be there. That doesn't mean he has to be your caregiver.'*

*And I'm not saying he never did anything good. He did some really good things and was very supportive at times. But I think when things really started to turn, walking away was not very hard.*

*And my kids support me. My parents are still alive. They support me. I've got sisters and brothers that support me. So I have people. And it feels, it feels good. I feel sort of free. Just…free.*

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In all caregiving relationships, communication can help everyone navigate the challenges of neuroendocrine carcinoma more effectively. More often than not, there are multiple people in a family who can take on caregiving responsibilities. One person may be designated as the primary caregiver, with other family members or friends helping to support the patient. Making these plans requires an honest and open discussion.

This isn't always easy, and there are resources available to help with these conversations.

> ***Lockridge:*** *In most cancer centers there are palliative care teams, and those are teams that are really designed to address kind of a family-centered approach to sort of life-limiting or a terminal illness.*

These teams include social workers and psychologists.

> ***Lockridge:*** *They're skilled at this, and these sort of interpersonal relationship dynamics that come up with a terminal diagnosis. And so my initial recommendation would be to go ahead and tap in to those teams, because they will help you have those conversations.*
>
> *They're hard conversations to have. And it is sometimes really helpful to have a third person in the room that asks the difficult questions, but also makes sure that everybody is sort of hearing one another in terms of wishes and desires.*

For everything that can be difficult, frustrating, or sad about being a caregiver for someone with neuroendocrine carcinoma, it isn't just a negative experience. As their relationships evolve, many caregivers and patients discover new kinds of joy, connection, and love.

> ***Lockridge:*** *There are caregivers who do mention, you know, I have grown so much in this role, I'm stronger because of this. My spouse and I have become closer. So it's a*

> *very different experience and I don't want to, you know, sort of paint it all with one brush stroke of it’s all terrible and, you know, the outcomes will be bad.*

For Holly Jensen and her mom, Jean Carney, going through the experience of being a patient and caregiver strengthened their bond as a daughter and mother. In the two years since Holly's diagnosis with neuroendocrine carcinoma, they have been through a lot together.

> ***Jensen:*** *I mean, with everybody, but especially like your parent, you know, and myself as a parent, like, I couldn’t imagine what she's going through. But I wouldn't want anybody else by my side. You know, I love my husband, I love for my husband to be with me every step of the way, but it's different when it's your mom, you know?*

> ***Carney:*** *Yeah, I've always felt that we had a very strong mother-daughter relationship. And she knows I'm always there no matter what. She's always known that anyway. But you know, it really, it really drives that home.*

After Holly finished her six rounds of chemotherapy, she had a scan in July 2024 that came back clear. Since then, she's gotten a scan every three months to monitor her disease, which has so far remained at bay.

Jean is still Holly's caregiver, supporting her daughter through this new stage in her journey.

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Special thanks to everyone we interviewed for this episode. If you have a story to tell about your own neuroendocrine cancer journey, please email us and let us know - podcast@netrf.org

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