

TRANSCRIPT, NETWise EP 57: When Cancer Enters a Relationship

Ken, Person Living with Neuroendocrine Cancer

We're more deliberate now about things. I think we're still, you know, our relationship hasn't changed that much, except for I think I always say this: we have a common enemy, and it's cancer, and it's probably made us in a certain strange way stronger and more united to fight this thing together, and you know, luckily, Cindy stood by me on this, and we are able to fight this as a team.

Cindy, Wife to Person Living with Neuroendocrine Cancer

Just when you tell people that you have cancer, or they're like, "Oh my gosh, I'm so sorry," and it's like, "No, we're living with cancer. We're not dying of it. We're living with it." Proper treatment and the care we're living with it.

Jessica Thomas, LCSW, Director of Patient Education at NETRF

That was Ken and his wife, Cindy. Ken has been living with neuroendocrine cancer since 2016, and Cindy has been beside him through surgeries, treatments, doctor's appointments—and everything that happens in between. And as you just heard, they see cancer as something they're facing together. Because cancer changes things. It can change our bodies, our routines, our plans for the future—and the roles we play in the lives of the people we love. A spouse can suddenly become a caregiver. Someone accustomed to taking care of everyone else may find themselves needing care. And a relationship that once felt familiar may have to navigate fear and uncertainty, changes in sexual desire and physical intimacy—and even something as basic as how to talk to one another about what's happening. But intimacy isn't just about physical or sexual connection. It can take many forms. It's emotional intimacy, feeling safe enough to be vulnerable and share what you're really thinking or feeling. It's communication, being able to talk openly, listen, and feel heard—it's affection and touch, whether that's holding hands, a hug, or simply sitting close together. Intimacy can also be companionship, trust, laughter, shared experiences, and feeling connected to someone who knows you well? It can be offering comfort, showing care, and making space for one another. And sometimes intimacy is much quieter. It's simply being present, sitting together without needing to fill the silence, knowing that even when life, illness, or treatment changes how intimacy looks. There are still meaningful ways to feel close, connected, valued, and loved. I'm Jessica Thomas, Director of Patient Education at NETRF, and you're listening to *NETWise*, the podcast designed to inform, empower and guide patients and caregivers through the world of neuroendocrine cancer. In this episode, we're talking about relationships in cancer and what it means to stay connected when cancer becomes a part of a relationship. One of the first things cancer can disrupt is something we may not even think about until it happens: our

roles in a relationship and the need for communication—who takes care of whom, who needs support, and what happens when the roles the couple has settled into over years or even decades suddenly don't work the way they did before? Dr. Joelle Kruml is a psychologist who works closely with couples navigating grief, trauma, and major life changes, and she says a cancer diagnosis can fundamentally change the roles we play in a relationship.

Joelle Kruml, PsyD, ABPP, Clinical Psychologist, Southeast Psychotherapy

A diagnosis, a medical diagnosis of any kind, affects the relationship profoundly because people often will shift from their primary role to the new role that they have to develop, and if those skills aren't there, it can become incredibly difficult for relationships to withstand the new norm. So trying to navigate that can be incredibly difficult for couples in those first couple of stages of, “wait, like what just happened? What am I doing? What am I going through right now? How can my partner help me with this? Are they available to? Can they? Do they have the skills to show up for me in that way?” And it can either add to our level of isolation or it can help us feel supported.

Jessica Thomas, LCSW, Director of Patient Education at NETRF

For Ken and Cindy, that feeling of “What just happened?” is something they remember very clearly. Ken's original diagnosis wasn't neuroendocrine cancer. He was initially told he had renal cancer, and he only had about six months to live.

Ken, Person Living with Neuroendocrine Cancer

I've had this diagnosis since 2016, so it's been a long, long road. A lot of surgeries, treatments, and all kinds of things in between. Oddly, I was first diagnosed with renal cancer, and they thought that everything in me was renal cancer, and they gave me six months at that point in 2016. But I found a specialist, a renal cancer specialist, and he said, “No, you have two cancers.” And we're like, “Oh, great!” He says, “No, no. If I'm right, this other cancer may be more treatable than renal cancer. And if I'm right, you've got to find another specialist.” So it turned out he was right. They removed my kidney. It was renal cancer in the kidney, but it was contained. And then everything else that they had seen on the scans were neuroendocrine cancer. At which point, then I found another specialist, and a couple of them actually, and they've managed to keep me alive and doing pretty well ever since.

Jessica Thomas, LCSW, Director of Patient Education at NETRF

But before Ken and Cindy knew any of that—before the specialists, the second opinions and a very different prognosis—they had to absorb what they believed was a terminal diagnosis.

Cindy, Wife to Person Living with Neuroendocrine Cancer

When Ken first got that diagnosis, I think we were like—it was like shock, you know. And then Ken, being the—I don't know what the right word is—the take-charge-leader guy. I remember the first thing he did is he called his best friend, who came over to the house. And Ken went into “I've got to take care of my wife” mode. “I have six months. I've got to—we've got to get rid of this. I've got to do this. I've got to get this organized. I've got to make sure she knows how to pay the bills. I've got to make sure she, everything, everything had to be in order” That was overwhelming. I didn't even know what to think. I was like, “Oh my God, what is happening?”

Ken, Person Living with Neuroendocrine Cancer

Obviously, when we first got the news, I mean, I kind of went into lockdown mode for a few hours. Literally, I had to process it. I think we both did. I think we just looked at each other, and I think we cried, and we didn't really even say very much because, like, we were completely in shock. But then after a few hours, even that night, you know, we started talking about it. You know, like this is horrible. What are we going to do? Kind of hugged each other and just kind of held on and kind of got through that first night. And then the next morning, I really didn't sleep. But the next morning, then I decided, you know, like she said, we I've got to get things prepped. I got to you know make sure that everything tees are crossed and eyes are dotted, and I want to make sure then everything was good for Cindy. And then once we did that, I felt like that base was covered. Then I had this conscious sudden switch to where, like, okay, now that's done. I'm going to fight like hell. I'm going to fight. I just made a decision that this is what I'm going to do, and and that's what we did.

Cindy, Wife to Person Living with Neuroendocrine Cancer

Then we went and got a second opinion, third opinion—

Ken, Person Living with Neuroendocrine Cancer

Fourth.

Cindy, Wife to Person Living with Neuroendocrine Cancer

Fourth opinion.

Ken, Person Living with Neuroendocrine Cancer

It was the fourth. The fourth oncologist was the one that changed the treatment plan and changed everything for us. That was it. It was literally the fourth oncologist.

Jessica Thomas, LCSW, Director of Patient Education at NETRF

Ken's first instinct was to protect Cindy. And Cindy's instinct was to protect Ken. That sounds simple—even loving. But there's something complicated happening underneath it. Both people are scared. Both are adjusting to a life they didn't expect. And sometimes both are trying to protect the other person from exactly what they're feeling themselves. Here's Dr. Kruml again.

Joelle Kruml, PsyD, ABPP, Clinical Psychologist, Southeast Psychotherapy

The caregiver is just spinning just as much, but what they often need too is a space where they can share their fears and their worries, and their sense of feeling inadequate. What am I going to do, and how can I be there for them? And what if I don't have the ability to do that? And what do I say? How do I touch them? They have so many questions that they need to be answered, and they too need a supportive space, one-on-one, to have that done because they too feel protective of their partner. The most loving couples often find that they are more concerned about the other than they are themselves, and they just want to do right by the person they love.

Jessica Thomas, LCSW, Director of Patient Education at NETRF

For Ken and Cindy, those roles became very real during one of Ken's major surgeries.

Ken, Person Living with Neuroendocrine Cancer

Early on—I had a really, really major surgery, a big one, and it was far worse than I thought it would be. The kidney removal was really comparatively simple. I mean, at the time, I thought, my gosh, this is a huge, horrible, difficult surgery. I had no idea what was coming. After that, I had bowel resection and liver resection, and they did, you know, cleaned up, cleaned out my abdomen basically. And man, that was really debilitating. It was a lot worse than I imagined it to be. So that's when I really needed Cindy, and she camped out at the hospital and helped me. And when I got home, I mean, it was a good month-plus recovery, so she was right there.

Cindy, Wife to Person Living with Neuroendocrine Cancer

I've talked to so many friends, and they're like, "I would have never stayed at the hospital for 10 nights." And I'm like, wow, that shocked me. Because it's like, he really needed me there, and they brought in a chair, and I sat in that chair for like 10 nights while he was in the hospital. But you do what you have to do. And plus, when you're there with your person, you can keep an eye. You have to be their advocate while you're in the hospital. I'm watching the machines, his blood pressure, his oxygen. I'm watching everything to make sure it's where it's supposed to be. You know, you have to be there.

Jessica Thomas, LCSW, Director of Patient Education at NETRF

But being there for someone doesn't mean a caregiver stops having needs of their own.

Cindy, Wife to Person Living with Neuroendocrine Cancer

For me, getting outdoors and walking, having time with my dog, exercising—that, that is my decompression. And when Ken had his first surgery, the major surgery—not the kidney one, but the second surgery—that one was very hard because that was like the first real major surgery that either one of us had ever been through together, and you know, you don't know what to expect. And then, you know, I have guilt sometimes because I wanted to leave the hospital because I just needed to get out of there. But at the same time, I didn't want to leave him. But then I just had to realize, you know what? You've got to get out. You've got to do what you need to do. Take a deep breath. Get away for an hour. It's okay.

Jessica Thomas, LCSW, Director of Patient Education at NETRF

That tension—wanting to be there every moment while also needing to take care of yourself—is something I think many caregivers will recognize. Because taking care of yourself isn't abandoning the person you love. It may be what allows you to keep showing up for them.

Joelle Kruml, PsyD, ABPP, Clinical Psychologist, Southeast Psychotherapy

For caregiver support, we really have to visualize putting our oxygen mask on ourselves first before we support anyone else in our lives. Because if there isn't anything left to pour in, then we're not going to show up well for somebody who we know needs us and that we want to show up for in the right way at the right time.

Jessica Thomas, LCSW, Director of Patient Education at NETRF

And taking care of each other isn't only about doctor's appointments, medications or getting through treatment. Cancer can also change the way couples connect. It can affect energy and sexual desire. It can change someone's body—and how they feel about that body. Pain, fatigue and side effects can make physical contact difficult. And sometimes what someone needs most isn't connection through sex at all. Dr. Kruml says it can help to start by expanding what we mean when we use the word intimacy.

Joelle Kruml, PsyD, ABPP, Clinical Psychologist, Southeast Psychotherapy

Intimacy covers a wide range. It's a spectrum. For many people, intimacy—you cannot get to physical intimacy without emotional intimacy. For other people, they don't need emotional intimacy to have physical intimacy. And I say this a lot, but everyone is different, and everyone has their own

definition of these things. But when we are going through a crisis, whether it's a medical crisis or an emotional crisis, people often need more emotional intimacy than they do physical, depending on how they're feeling inside. So we have to redefine and expand a definition of intimacy when we don't feel good, physically don't feel good, or we are emotionally wrecked. Now, following traumatic events, there are people who—they want to connect with the people that they love in more physically intimate ways. But intimacy itself is about communication. And communication—whether we're talking about lovey-dovey feelings, you know, or we are talking about communication about what feels good and what doesn't feel good physically—it really comes down to communication. I think that's the umbrella of intimacy in general.

Jessica Thomas, LCSW, Director of Patient Education at NETRF

And I want to pause here for anyone listening who isn't in a long-term relationship. Some people are single. Some are dating, or thinking about dating again, and a cancer diagnosis can add another layer of vulnerability: When do I tell someone? How much do I share? Will they see me differently? There isn't one right way or one right time to have that conversation. And as a therapist myself, I've learned people come back to something that's worth remembering: cancer is a bad thing, but that doesn't mean there's something bad about you because you have it. Cancer may be part of your story, but it isn't a measure of your worth or what you have to offer another person. And it doesn't make you any less deserving of connection, intimacy or love. And that communication can include something very simple: letting the person going through treatment help define what closeness looks like today.

Joelle Kruml, PsyD, ABPP, Clinical Psychologist, Southeast Psychotherapy

I always encourage couples to have the individual who is the one struggling take the lead. If they need to be in their head a little bit more, and what they're looking for is more closeness in non-traditionally physical ways like cuddling and just being close or talking, reconnecting in that atmosphere, then that is what we should do. We need to let them take the lead because a diagnosis takes away all of their power, takes away all their control, and having some say helps them kind of balance out a world that can just feel like it's out of control.

Jessica Thomas, LCSW, Director of Patient Education at NETRF

Dr. Kruml sometimes makes that even more real by asking couples to think about different ways they can connect depending on how the person is feeling that day.

Joelle Kruml, PsyD, ABPP, Clinical Psychologist, Southeast Psychotherapy

There's a check-in when they have a moment, you know, like, "Oh, today may be a good day for us to go for a walk," or, "I'm not feeling very good today. Maybe today's a great day for us to sit at home and watch a movie together and snuggle on the couch."

Jessica Thomas, LCSW, Director of Patient Education at NETRF

That's an important shift. Instead of asking whether intimacy is the same as it was before cancer, the question becomes: What does connection look like for us today? And sometimes the answer may be a walk or a conversation or simply being close. But sometimes the answer is physical intimacy or sex. Sex can be an important part of physical intimacy, and cancer can raise some very practical questions about it. Is sex safe during treatment? What if you're immunosuppressed? Are there times when intercourse should be avoided? Should couples use barrier protection? You might expect questions like those to have clear medical answers. But in some cases, they don't. Dr. Sigrun Einarsdottir is a hematologist who works with patients with blood cancers and bone marrow transplantation. Her interest in this subject began when she was part of a multidisciplinary group developing clinical guidelines—and started looking closely at what the medical literature actually says about sexual activity during periods of immunosuppression and neutropenia. Neutropenia simply means having low levels of neutrophils—the white blood cells that help your body fight infection. What she found was a surprising amount of inconsistency.

Sigrun Einarsdottir, MD, PhD, Hematologist, Sahlgrenska University Hospital

The question about barrier protection was what sort of sparked the interest around this. So I started looking into all of these papers, and some papers said that you can't have sex at all. Some papers said that you can have intercourse, but with barrier protection, and it wasn't specified—do you need to continue this forever when you're immunosuppressed? And some papers said that you didn't need to have it if it was with the same partner. So it sort of struck me that there's—you know, it's often like that when there is no data available—that this is just based on opinions. So I felt when I was in this group, we really need to highlight this specifically, that there is very little evidence on what to recommend. But, I mean, sexual activity is—it's a part of life for a majority of the population. So I think bringing it up and just, you know, being open with the lack of evidence and sort of to somehow reach some consensus on what we tell our patient to our best available knowledge—we sort of owe our patient that, I feel.

Jessica Thomas, LCSW, Director of Patient Education at NETRF

And that's important: there isn't one set of rules that applies to every person with cancer. Someone who is severely immunosuppressed may face very different risks from someone whose immune system is only mildly affected. The treatment matters. Symptoms matter. The individual

patient matters. So the answer isn't simply yes or no. But first, someone has to be willing to have the conversation. And Dr. Einarsdottir says that can be surprisingly difficult—for patients and clinicians.

Sigrun Einarsdottir, MD, PhD, Hematologist, Sahlgrenska University Hospital

I think also, like, there's both that this is an area that's sort of a little bit embarrassing to talk about. It makes both the doctor and the patient avoid the subject. You don't say anything because you're maybe afraid that you're gonna step on someone's toe, you know, if you bring it up, and the patient maybe feels the same way. So it's a little bit— But I remember there was a colleague that had found this paper a few weeks ago, and he sent me an email, and he told me he had met some patient in the emergency department. And when he was on his way out of the room, the patient asked, like, “So, doctor, you've been so detailed on the fact that I can't see sick people and I can't, you know, be in crowds, but, you know, can I kiss my wife? Can I be intimate with her?” And he told me, like, “I became very sort of unsure of what to say, and that's how I found your paper.”

Jessica Thomas, LCSW, Director of Patient Education at NETRF

It's a good example of how even a very basic question about intimacy can leave both the patient and the doctor unsure of what to say. And Dr. Einarsdottir says sometimes, simply opening the door to that conversation can make a difference.

Sigrun Einarsdottir, MD, PhD, Hematologist, Sahlgrenska University Hospital

We are very used to these different precautions that we tell patients that are sort of comfortable for us to say—avoid sick people. But I think somehow getting some of this in, maybe just opening the door to say that, you know, “If you have questions about intimacy or sex, you can also talk to me. I can provide you some advice.” There's also this—is that this is an embarrassing topic where also many doctors feel very insecure because they don't have data to lean on, and then it becomes even more awkward.

Jessica Thomas, LCSW, Director of Patient Education at NETRF

And having that conversation matters because intimacy doesn't mean the same thing to everyone—especially during cancer treatment. Some people may have little or no interest in sex or physical intimacy. Others may still want that part of their relationship and have very real questions about what's safe. Both are normal.

Sigrun Einarsdottir, MD, PhD, Hematologist, Sahlgrenska University Hospital

This is a whole spectrum of being close to each other. And I think it's also super important that we tell our patient, because it's very common when you are in a cancer treatment that you don't feel—or, you know, you don't have any sexual desire. You're focused on surviving. You are not thinking about it. But you might need, you know, to be close to your partner for comfort, because also your life is often threatened. So this closeness and intimacy in that sense is very important to many people. But many of my patients, they are not—they tell me, you know, "I'm not thinking about sex. We don't have to discuss that." But then there are also patients where you wouldn't expect them to be having sex and intercourse that are saying, "Is it safe? No one has told me. Is it safe when I come home from being hospitalized for this leukemia treatment?" So obviously, for some people, it's also very important to not just have the hugs and that, to also have the intercourse and that part. And that has to be okay to talk about as well.

Jessica Thomas, LCSW, Director of Patient Education at NETRF

For people living with neuroendocrine cancer, the specifics will depend on the treatment you're receiving, your immune system, symptoms and your individual medical situation. So questions about sexual activity during treatment should be discussed with your own care team. But when we asked Dr. Einarsdottir what general guidance she would give someone with neuroendocrine cancer, her message was reassuring.

Sigrun Einarsdottir, MD, PhD, Hematologist, Sahlgrenska University Hospital

For patients with neuroendocrine cancer, I mean, many of them go through chemotherapy and are immunosuppressed for periods of time, and some have targeted therapy. And I think it's completely fine to, if you feel like it and are in the mood, to be intimate and to have sexual intercourse with your long-term partner, just using basic precautions. Just not having intercourse when you have mucositis or ulcers, and not to have, you know, multiple partners without protection, and just using very basic, gentle hygiene. No need for, you know, excessive soaps or anything like that. So it's completely fine to continue to enjoy life and explore with your partner what you feel like and what you're comfortable with. And also, it's super normal not to feel like being intimate at all and just focus on surviving. And that's completely okay as well and very normal. And that usually, you know, it usually returns after a while for most patients.

Jessica Thomas, LCSW, Director of Patient Education at NETRF

There isn't one definition of what intimacy should look like during cancer. For one couple, closeness might include sex. For another, it might mean holding hands, sleeping beside each other, taking a walk, talking—or simply sitting together. And what feels right may change from one

day to the next. The important thing is making it something you can talk about. Because sometimes the greatest barrier to intimacy isn't physical at all. Sometimes it's the things we're afraid to say. Talking about intimacy is really part of a much bigger conversation. Because communication itself can change after a cancer diagnosis. We've already heard how Ken's first reaction was to take care of Cindy—to make sure she'd be okay. Ten years later, that instinct to protect her is still there. And Ken admits that sometimes it gets in the way.

Ken, Person Living with Neuroendocrine Cancer

You know, I tend to want to protect her. And so, like, when things are a little rough or we get some bad news, you know, I tend to hesitate to communicate that because I don't want her to worry. I want to protect her. At the same time, I also acknowledge that I have to communicate these things, and, you know, she deserves to know more than anybody. So I have to communicate that. But I find myself hesitating because I want to protect her and I don't want her to worry. And, you know, it's a struggle for me. I'm not going to lie. It's hard for me to express it when it's bad. When it's good news, man, I'm just on the mountaintop screaming it to her, you know, probably too much. But when it's bad news, I hold it in because I'm trying to protect her, and it's not really the right thing to do.

Cindy, Wife to Person Living with Neuroendocrine Cancer

No, because then sometimes it's—you know, he's holding it back, and then it's—

Ken, Person Living with Neuroendocrine Cancer

She knows.

Cindy, Wife to Person Living with Neuroendocrine Cancer

Yeah. And then it's like, you know, he has a belly ache, and it's like, "Oh my God, what's the belly? Why? What's going on?" He'll tell me at midnight, and I'm like, "You've got to go to the ER now. You had this seven hours ago!" "I didn't want to worry you." You didn't want to worry me.

Ken, Person Living with Neuroendocrine Cancer

That has happened. That exact thing has happened.

Cindy, Wife to Person Living with Neuroendocrine Cancer

It's okay. You can worry me.

Jessica Thomas, LCSW, Director of Patient Education at NETRF

"It's okay. You can worry me." There's a lot in that statement. Wanting to protect someone you love is instinctive. But sometimes protecting them can turn into keeping them outside of something they're already experiencing with you. And no matter how well two people know each other, neither one can always know what the other person is thinking—or what they need. Dr. Kruml says one of the most useful things couples can do is also one of the simplest: Ask.

Joelle Kruml, PsyD, ABPP, Clinical Psychologist, Southeast Psychotherapy

One small thing is to ask someone, "What do you need today? How do you feel today? What can I do for you today?" And that can go both ways. If the caregiver is looking like they may need something today, then maybe the patient is the one asking that. But checking in with each other is, I think, the simplest and most effective thing to do. And when someone asks you that question, really answer the question. You know, don't give the "I'm fine. I don't need anything." We can't read each other's minds. But really show up and be humble and be vulnerable and try to go to that place of, "This is what I need today."

Jessica Thomas, LCSW, Director of Patient Education at NETRF

But your partner doesn't have to be the only person you talk to. Cancer can put enormous pressure on a relationship if two people begin to feel as though they have to meet every emotional need for each other. Sometimes it helps to talk with someone who already understands what you're going through. For Ken and Cindy, support groups gave each of them that opportunity.

Ken, Person Living with Neuroendocrine Cancer

I think one of the things that really helped us a lot, a lot early on, both of us, is we went to some support groups and we met other patients with exactly the same situation. Not only, you know, they have cancer, but I mean even specifically this cancer. And then we could talk to the people, and, you know, Cindy could talk to the caregiver, I could talk to the patient. And it's kind of interesting because you get this different dynamic, you know, of different people and different partnerships, and how do they handle it? And it's really helpful because, in the end, we're all in the same boat. It's... everybody experiences their own things, but also a lot of the same things. And that was really helpful for us in the beginning.

Cindy, Wife to Person Living with Neuroendocrine Cancer

Yeah, I think the support group is really good, or just—not even if it's a support group—if you can just talk about it. I always, I always call this an emotional puke sometimes because you're just

getting it out. You've got to talk about it. You can't leave it all built up inside of you. So if other people that are facing the same situation can, then, you know, talk about it, get to the support group, just talk to friends about it, talk to family about it. It's just—you feel so much better being able to get it off your chest. And even if you don't—you're not even looking for someone to fix it. You just need to get it off your chest, and that's it, that's it. You don't need anybody to repair it or fix it or give you any advice, really. You just need to talk about it. And then when you're done, you feel much better.

Jessica Thomas, LCSW, Director of Patient Education at NETRF

That support can also come from a mental health professional. And Dr. Kruml makes an important point: asking for that kind of help doesn't mean a relationship is failing. In fact, she believes emotional and relationship support should be treated much more like any other part of cancer care.

Joelle Kruml, PsyD, ABPP, Clinical Psychologist, Southeast Psychotherapy

I think the moment someone is diagnosed, that should be offered to them immediately. And not in this—oh, it's fear-based, "You need to go now. You guys are going to need this." But in this, "Hey, we all need a place to just be raw and emotional and vulnerable without judgment." And I think if it was a part of the normal care plan, it would be another thing to be referred—like you're referred here, like you're referred for this X-ray or this CT. You're referred here for support, so that they know that it's part of their care.

Jessica Thomas, LCSW, Director of Patient Education at NETRF

Support can look different for different people. It might be a therapist. A support group. A close friend. A family member. Or simply someone who understands enough to listen without trying to fix anything. The point isn't to build a perfect support system. It's recognizing that neither the patient nor the caregiver has to carry all of this alone. And neither partner has to get everything right. Needs change. Roles change. Some days are harder than others. And through all of that, Ken and Cindy have tried to hold onto something else: Cancer is part of their life. But it isn't their whole life. For Ken and Cindy, not letting cancer become their whole life has also meant not trying to think of themselves as patient and caregiver every moment of every day. There are times when those roles matter very much. And then there are times when they're simply Ken and Cindy.

Cindy, Wife to Person Living with Neuroendocrine Cancer

We never make it the center of attention, ever. I mean, I think we only—then there's the doctor's appointments. You know, now he's going on the clinical trial now, so we're there like every three

weeks or whatever it is. But I don't think we make it the center of attention ever. I think we just kind of go on with our normal all the time, and then when it needs to be brought up... Right?

Ken, Person Living with Neuroendocrine Cancer

Yeah, I agree. We don't... we just kind of live our lives, and a lot of people, when they find out, they're shocked. I mean, people are like, "I had no idea. Like, oh my gosh." I don't want you to think of me any differently because I'm just a person, and I'm living my life. But at the same token, we're also not secretive about it. We both are very open about my cancer and about, you know, the treatments and what we're doing. We don't try to hide that or shield that from anybody or anything like that. We're very, very open about it, but we don't broadcast it or say anything, either. We just kind of go about our life.

Cindy, Wife to Person Living with Neuroendocrine Cancer

We don't dwell on it. When we're here at the house and he's doing great like he is now, I don't really think about the caregiving thing. I think more of it as when he's been in the hospital, or when we go to the doctor's appointments, or when I need to call insurance for something, or make a phone call for medical or something—that's kind of the caregiver mode. But I really don't... it's not something I think about myself as that every day.

Jessica Thomas, LCSW, Director of Patient Education at NETRF

It does. Because before Cindy was Ken's caregiver, she was his wife. And she still is. And when we asked her what love looks like after everything she and Ken have been through, she didn't talk about grand gestures. She talked about the little things.

Cindy, Wife to Person Living with Neuroendocrine Cancer

Love to me—it's not glamorous. But for me, love is just the little things. Love is wiping his forehead when he is in the hospital and he doesn't feel good. Love is giving him a little foot massage when he doesn't feel good. Love is a pat on the back. Love is just saying, "I love you." That's love, right? Love is a lot of different things.

Jessica Thomas, LCSW, Director of Patient Education at NETRF

And after everything cancer has added to their lives, Ken says some of the moments he values most are the ones where almost nothing is happening at all.

Ken, Person Living with Neuroendocrine Cancer

Our most cherished time is when we're doing nothing. And we're just sitting on the couch, got some silly TV show on or something. Doesn't even matter what it is. You know, our dog's with us, so we love our dog. And we just kind of hang out with no particular agenda. You know, and we just talk and just enjoy being together. And you don't even say anything necessarily. You know, you're just there. You're just present. That—that's it.

Jessica Thomas, LCSW, Director of Patient Education at NETRF

You're just present. Maybe that's one of the simplest definitions of intimacy we've heard.

Ken, Person Living with Neuroendocrine Cancer

And to add to that, from my perspective—and I've learned this very clearly—is love looks like being there when you don't have to be, and when things are tough, and you're not getting any reward. There's—there's no... I mean, Cindy doesn't get any reward for helping me in the hospital. She doesn't get anything for that except she helped me. And I would do the same, and I have done the same. You know, like, love is when you do things for someone that there is no reward or there is no—

Cindy, Wife to Person Living with Neuroendocrine Cancer

You don't expect it in return.

Ken, Person Living with Neuroendocrine Cancer

You don't expect anything. You're doing it because you care about that person. That's the only reason. There is no other reason. That's the reason.

Jessica Thomas, LCSW, Director of Patient Education at NETRF

Cancer can change a relationship in ways no one is prepared for. It can change our bodies and our roles. It can affect sex and intimacy. And it can make communication harder at exactly the moment when communication matters most. But as we've heard, intimacy can take many forms. Sometimes it's physical. Sometimes it's asking, What do you need today? Sometimes it's giving someone space—or sitting beside them when there's nothing to say. And perhaps that's what Ken and Cindy remind us. Cancer may become part of a relationship. But it doesn't have to define the relationship. Sometimes love looks like: simply being there. Thank you for listening to *NETWise*. I'm Jessica Thomas, Director of Patient Education at NETRF, and you're listening to *NETWise*, the podcast designed to inform, empower, and guide patients and caregivers through the world of neuroendocrine cancer. This episode was brought to you in part by the generous support of

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