You can find information about subscribing to this series at netrf.org/podcast, where you’ll also find helpful infographics, and videos that expand on this material.

If you’re new to NETWise, we strongly recommend you go back and listen to the first episode in this series. It will give you a solid grounding in the basics of neuroendocrine tumors and how they’re treated. And you can find a whole library of episodes on different topics at netrf.org/podcast, and wherever you get your podcasts.

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. My name is Jessica Thomas, Director of Patient Education at the Neuroendocrine Tumor Research Foundation.

In each episode of this podcast, we share expert information and patient perspectives to help patients and caregivers on their NET journeys.

Today, we’re going to be talking about the end of that journey.

This is something that can be uncomfortable to talk about. But there is a lot of information that is important to know. From the medical and legal, to the emotional and spiritual -- it's a complex time.

So in this episode of NETWise, we’re going to talk about end-of-life care.

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Questions about end-of-life care tend to arise early on. Many people, when they're diagnosed with a disease like cancer, have worries about what that means for their life expectancy.

Jaydira Del Rivero is a medical oncologist and a board certified endocrinologist at the National Institute of Health. She’s been treating NET patients for more than a decade.

**Del Rivero:** There is so much fear around having just this diagnosis and having a cancer diagnosis, which is– can be quite scary. It’s like the world stops for them and it’s very difficult.

Some kinds of NETs are aggressive, and may come with a serious prognosis. Many other kinds of NETs are slow-growing and can be managed for years, allowing patients to live long and fulfilling lives.

Julie Hallet is a surgical oncologist at Sunnybrook Health Sciences Centre at the University of Toronto, who specializes in NETs.

**Hallet:** While we may not be able to cure, meaning getting rid of all the cancers and giving them a life without cancer, we may be able to control this. And I think the analogy a lot of us use is that of a chronic disease, so I'll tend to say this is, you know, like people who have diabetes or high blood pressure, they will never get rid of it, but it can be controlled with treatments over time. So, even in patients who have pretty widespread and advanced disease, that we consider a stage four, so metastatic, we don't necessarily face a short life expectancy.

Even though people can live a long time with NET cancer, it still reduces a patient's lifespan. And there's always the possibility that something unexpected could happen in the course of the disease or its treatment.

So even though it may be difficult to think about, one of the best things a patient can do is begin to think about end-of-life planning early on. This is called "advance care planning."

Jena Fosdick is the regional director of clinical operations for St. Croix Hospice in Omaha, Nebraska. She's had experience providing hospice care to NET patients.

**Fosdick:** Even if you were a healthy individual, you never know when your expiration date is going to happen. So advance care planning is a super important piece to start that conversation, and to start thinking about those things that you don't want to have to leave your family with.

Advance care planning involves communicating your treatment preferences for end-of-life care, in case you are not able to do so later on. It ensures that those caring for you can follow your wishes.

These plans may begin as conversations, but they must be formalized through signed documents, called “advanced directives.” Each state has its own set of documents, which you can find online.

There are two key components to advanced directives. The first designates medical power of attorney to a person of your choosing. This allows them to make medical decisions on your behalf, in the event that you are not able to speak for yourself.

The second is a living will, which outlines your preferences for treatment. This includes things like what kind of procedures you do and don’t want, or whether you would like to donate your organs. You may also establish “do not resuscitate” and “do not intubate” orders.

Patients should talk about all these preferences with their doctor, and with their loved ones.

**Fosdick:** If we can have those conversations and become comfortable having those conversations with each other, it just sets up a better end of life experience. And takes a lot of the guesswork out of it.

There are also lots of resources online that can help you think through all of this.

**Fosdick:** The hospice that I work for, St. Croix Hospice, we have a workbook that you can fill out and it walks you through everything that you need to start to think about, when it comes to the end of life, but even though you're not near that yet.

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**Mailman:** My name's Josh Mailman. I am a patient advocate. I serve a lot of hats in both the neuroendocrine tumor community and also the community for cancer care at large. And really, at the end of the day, I'm a patient and I run a local support group.

You know, I was diagnosed in 2007. I went for my annual 46-year-old checkup and my doc felt something unusual under my rib cage. And…nothing serious because everything else was fine. And said, you know, ‘come back for an ultrasound whenever you actually have time to be around.’

And I didn't have time to be around for about six weeks. And I went to urgent care because I had some other medical issue going on. And while they were waiting for some tests to come back. They said, ‘Oh, we see you have an ultrasound that needs to get done. Why don't we send you down there while we're waiting for the test?’

And it’s an unusual experience, and maybe that was my first brush with the idea of death. Because after they walked me back from the ultrasound to urgent care, the attending physician who brought me there would no longer look me straight in the eye. Uh, and she had been told by the ultrasound tech what looked to be a rather large malignant tumor in my pancreas.

And I don't think they thought I had a long time to live.

So you start facing your own mortality pretty quickly. You know, at the time I had a 10-month-old and I did not know how I was going to plan to see his first birthday.

You know, this is back in 2007, and so there aren't many options back then to treat this disease. And at the time, none of the options fit where I was. I wasn't a surgical candidate, there wasn't any of these new drugs that have come along in the last decade. And so, I was faced pretty early on with the fact that I may not be here for long.

You know, I'm a *Hitchhiker's Guide to the Galaxy* kind of guy. And the cover of the book, if you remember, and the cover of the Hitchhiker's Guide has just two words on it: don't panic. And it's something that we tell everyone, don't panic, because when you panic, you make… not irrational decisions, but decisions without all the information that you can.

You know, we have this term in oncology called watchful waiting, I hate the term, but it's where you don't– you just watch. And I've, you know, famously turned that term from watchful waiting, into watchful learning. Cause I think you can use that time to educate, to figure out what your next steps are.

And so that's what Josh did -- he learned everything he could, attended conferences, and made connections. He sought out different treatments and specialists, and has lived with NETs for more than 15 years.

He's also been instrumental in pushing the needle in many areas of NET care, and is an internationally recognized advocate for neuroendocrine tumor patients.

**Mailman:** What I tell patients who ask me, you know, How do you plan your life? What do you, what do you do? How do you, how do you do this in a world where there's uncertainty? And, you know, how long are you going to live? It's like, I don't know. I'm here way, way past the right hand side of the curve.

You know, there's only one episode where there was only one guest in the entire history of the Letterman Show.

So there's a dear friend of David Letterman, is Warren Zevon, the person who actually wrote Poor, Poor, Pitiful Me for Linda Ronstadt, wrote Excitable Boy, Werewolves of London, great musician, late 70s, fantastic, really great guy.

He got diagnosed with small cell lung cancer, and he, there's a lot of– you know. And so Letterman invited him on, and with Warren Zevon being the only guest for the entire show, to play music, to talk about life, and to talk about death. And it is a powerful episode.

You know, Letterman looked at him across the table and says, ‘you're, you're facing your own death. You know, is there anything you want to tell us mere mortals who don't, haven't done this or haven't faced death and, and words of wisdom that we can live by?’

So Warren looked back at David Letterman and kind of with this pause in his eyes and said, ‘enjoy every sandwich.’ And that was his advice. Because that is the point of figuring out: enjoy your life, favor everything that comes to it, figure out what it is you want to do and enjoy it. If you're going to have a life and you're going to continue, then figure out: what's the– enjoy the sandwich?

The simple act of enjoying the sandwich of sitting down and enjoying what's going on is enjoying life. And to work on all these medicines and all these treatments and want to extend your life, but not to enjoy that life you're extending? Find what matters most.

NET patients can live for a long time with their diagnosis, and we are making strides in developing new treatments. But at a certain point, the conversations patients have with their doctors tend to shift.

**Hallet:** I think it's different for every patient in terms of, you know, the timeline, or at what point they want that shift to happen, so the relationship we have with them is very important in that way. If we talk about end-of-life care, often it’s when you realize that the disease is still progressing and we don't have more options to stop that, whether it's the growth of the tumor, whether it's the, you know, the hormones that are produced by the tumor are becoming overwhelming and, it's overtaking patients lives. That's when we can start having those discussions.

Or sometimes it's patients themselves who will come to us and say, you know, well, there are these other therapies, but I'm, I'm tired. This is not something I want to go through anymore. It's not something that's aligned with my preferences at this point. And then we can start having those conversations.

At this point, a patient may begin to transition to hospice care. By definition, hospice is available to any patient living with a life-limiting disease who has an estimated 6 months or less to live.

In the United States, hospice is covered by Medicare. This includes support from hospice staff, as well as medical equipment and prescription drugs.

Because of its associations with end-of-life, there can be a certain amount of stigma around hospice.

**Fosdick:** So when we think hospice, people have this misconception that, ‘Oh, this is the last days to hours of my life and, and, and we're, we're done here.’ So they think that once your treatment options are over, then care stops. And that's just not true.

Studies have shown that starting hospice early can result in better symptom control and a more positive experience for patients and caregivers. Studies have also shown that in many cases, patients live longer on hospice than they would have if they continued treatment.

But it’s important to remember that this is a choice a patient gets to make when the time feels right for them.

**Fosdick:** Long-term NET patients, um, it's– it's hard to start that conversation because, you know, they've been fighting for so long.

So I would compare those types of patients to like a heart failure patient or a COPD patient, someone that's been living with some disease for a long time, and they've been beating it.

When it comes to like rare, more aggressive type of NETs, we're often meeting them too late in the process. So we can provide them so much help and support, but we're too late to the game, so we're now having these conversations when they only have a week left, and so we have a whole team there to support them, but we're all rushing to meet them. And so often what we hear is, ‘I wish it would have been sooner that we would have come to you.’

Transitioning to hospice care means that a patient has chosen to stop using active therapies that treat their disease, and instead focus on care that improves their quality of life. In other words, hospice care is limited to only palliative treatments.

We want to take a moment to talk about palliative care, which is important for NET patients. It’s often associated with end-of-life care, but NET patients will know that palliative care can be given at any time during the course of disease.

Its focus is on symptom management, and it can be complementary to other therapies a patient may be receiving. You can learn more about palliative care in episode 15 of NETWise.

**Hallet:** In patients with neuroendocrine tumors, especially because of the endocrine repercussions, so the repercussions of the hormones that are circulating, and the repercussions sometimes of the local tumors, for example, in small intestine, local tumors like fettering of the bowel and creating cramping, etc. Everything that we do is aimed at alleviating those symptoms, number one, and number two, preventing future symptoms. So to some extent, everything that we do is, in part, palliative care.

When a patient is getting closer to the end of their life, the focus of care is almost entirely on symptom control. And palliative care comes to the forefront.

**Hallet:** At the end of life, we don't care so much about whether we're going to get tumor control or preventing things from getting worse in the future. We care about making some, somebody feel better in the moment. All these things have to be very, very tailored to patients and what they wish for.

This brings us back to hospice care. When a patient transitions to hospice, their team is focused *solely* on palliative care that will help them feel better.

But there are some challenges unique to NETs that are important to acknowledge.

Like we said earlier, hospice is limited to palliative treatments. With NETs, palliative care tends to include pain management, as well as managing symptoms related to hormone excess.

This is different from other kinds of cancer, where there is generally a distinction between medications that treat tumors, and medications that alleviate symptoms.

With NETs, many of the medications that are commonly used for treatment also have palliative effects. For example, somatostatin analogs are used to treat tumors – but they are also the best way to manage symptoms like diarrhea and flushing.

There are also some surgical procedures that may be done as part of palliative care.

All of this should still be on the table when a patient enters hospice. But sometimes, hospice workers may not know the best way to treat NETs, or the high cost of drugs may be a financial challenge.

**Del Rivero:** That's when sometimes we have heard that it's some difficulties getting these medications. Because based on the regulations of, during hospice care is that it's indicated that no active therapy can be given, and most of the therapy is to control pain, when it's needed.

But I think that since the neuroendocrine tumor patients is very unique, not only because of the tumor growth related– but also because of the symptoms related to the hormone excess, that's when it's important to increase awareness and education in that part.

Dr. Del Rivero is one of several people working to address these challenges. She was recently involved in writing a whitepaper that provides guidance for palliative care for NET patients, both during treatment and in a hospice setting.

As a patient advocate, Josh Mailman was also instrumental in writing this paper.

**Mailman:** I probably work with at least, you know, a patient a month around the country who is going through end-of-life. And we'll have things like Sandostatin or Lanreotide or, or Pelotrostat or other drugs that manage symptoms. taken away from them in order to go into end of life care.

NET patients can share this whitepaper with their hospice agencies to ensure more appropriate care. You can find a link to it in the show notes, and at NETRF-dot-org.

And despite these challenges, most hospice agencies are committed to doing what they can to get patients the care they need.

**Fosdick:** If we have tried other things. Nothing's working. We know this med has worked in their past. We're going to do everything in our power to get a medication, even if it is expensive, to get it covered.

And hospice care includes so much more than medications. It is interdisciplinary and holistic by design. Each patient works with a team of people who care for the mind, the body, and the spirit.

**Fosdick:** So, your core team that every hospice patient gets is a medical director, a social worker, a RN case manager. A chaplain, and those are your four core team members.

The medical director is in charge of the interdisciplinary team. They facilitate communication between your doctor and hospice staff, and consult on matters of palliative care.

The social worker is focused on psychosocial aspects of care.

**Fosdick:** So, their interpersonal relationships, their family dynamics, they're focused on that. If they do have, like, insurance questions, money questions, they can help with that if they have FMLA paperwork, maybe they want to take off time for work to care for their loved one.

These are things that you can go to your social worker with and say, ‘Hey, this is what I'm thinking. Can you help me, guide me through this?’ And they're there, they're experts in all of those things.

The RN case manager might also be called a "hospice nurse." Their job is to focus on symptom management. They also bring in other members of the care team when necessary

**Fosdick:** And so it's important to tell them what you're liking and what you're not liking or what you need more help with, because they can really direct your care and help you get the right person in front of you.

Finally, the chaplain is there to care for your spiritual well-being.

**Fosdick:** And that is so important at the end of life. They're non denominational, whatever church you're affiliated with, they'll make sure to make those connections for you.

They're there to pray for you, or not pray for you, but pray *with* you. They're there to just talk. You can talk to them about anything. You can talk to them about your fears of your diagnosis. Your fears of what you're leaving behind. Maybe, what you've done in your past. You feel like, am I going to go to heaven or hell?

Maybe those are beliefs, maybe not, but even patients that don't have beliefs. still need spiritual care at the end of life.

All of these individuals are available to patients and caregivers throughout hospice. People can form strong bonds with their nurses, social workers, and chaplains as they go through what can be a very vulnerable time.

And as a patient gets closer to the end of their life, the hospice team is there to guide the process.

**Fosdick:** Towards the end of life, our clinical staff does see changes and we educate every step of the way. And those changes could be breathing changes. Definitely they start eating less, maybe drinking less. And so we're there, at the bedside, educating you every step of the way.

If I were to see those changes, I would say, you know, we're probably looking at the last week of life. And then as we see more dramatic changes, you can guess more hours to days, it's hard to pinpoint the exact moment that it's going to happen.

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**Ludlow:** I'm Suzanne Ludlow. I live in Silver Spring, Maryland.

In 2012, my husband had surgery to remove tumors in his liver and they were diagnosed as neuroendocrine tumors.

The– the death certificate says pancreatic neuroendocrine cancer, but it didn't start in the pancreas, I'm pretty sure. It was all in his GI system, but it took a long time to try to figure out where a primary tumor might have been.

His name was Vince Taylor. He's African American. Grew up in the Washington, D.C. area. Liked to write. He went to Oberlin College – his mom had gone there before him. And I met him; he was a senior, I was a freshman. He graduated just after his mother died of cancer.

He was a journalist for a number of papers, ended up being a newsletter editor for many years.

He was pleasant to be with. He liked to cook or listen to music. He was private, but he made me laugh every day. He cared about other people. Everybody who knew him kind of thought of him as a friend.

So my husband was relatively fortunate in that he did not seem to be in pain, most times. He was able to work until three months before he died. when he was in pain – it cracked me up – when he was in pain, he would take one Ibuprofen.

So he really didn't need palliative care for a very long time. He simply, he went to his scans and his doctor's appointments and he tried to eat well and that was fine. Over time, he– he got a lot of tumors. In 2014, he went in for surgery to try to remove what was probably his primary tumor, which was right between his stomach and his small intestine. And it was not possible to remove it.

And so, you know, basically the care was to kind of tamp down the tumors. He had liver directed therapy to try to reduce tumors in his liver. He had other kinds of medications that would slow any growth, that kind of thing. bBut, but he was living with the tumor. And there was a point where there just were a lot of tumor. And

so the options were waning about what new steps to do.

So it was in February of 2017, the doctor said, I think you need to start thinking about choosing a hospice care agency. And that was very stunning to my husband. Um, I don't think it came as a surprise to me. But– but it, it was a bit abrupt.

The concern at the time was this was February. Our son was graduating from college in May, and my husband was going to see him graduate. There was– his mom couldn't see him graduate. He was going to see our son graduate. And the doctors reassured him that he would live long enough to do that.

So we took a few days to kind of just let it settle in. And I was fortunate to be able to talk to a friend of mine who, who– she hadn't faced hospice care herself, but a close friend of hers had.

And this friend had told her that it was really good to reach out to a hospice agency early on, before it was last minute time, because you could learn more about their services and you could get a nurse that you liked or that fit you and if you didn't care for them or their structure, you could go to someone else.

And so after my friend told me that, I told that to my husband. And he appreciated that. I don't think he would have agreed to really start calling around, having us call around to the agencies, until that made sense to him. And so a day or two later, I was checking in and doing some background checks of these agencies and contacted one. And we set up a visit, a home visit, with the nurse that would be assigned to Vince. And she was awesome. And so that was a relief.

And we started this system where she would come once a week, take his vital signs, check on him, that kind of thing. They would sit and chat about cooking. Or whatever. And it was something my husband looked forward to. And it was, so it was a good thing.

By mid-April, the nurse was coming more than once a week. Checking on him. But he was cooking, and he was taking walks. But he was more often falling asleep in a living room chair. He couldn't write very much before he fell asleep. He was listening to podcasts, and he was listening to music, and mostly doing okay.

The other thing that was really great about hospice was they were really helpful when we needed to go from Maryland to North Carolina for our son's graduation. They helped get the contacts in each of the places so that if we needed help anywhere along the road, they had kind of other agencies that they had agreements with that we could contact. You know, the supplies we needed, they had for us. And so we were able to go to our son's graduation in mid-May, and it was really nice. So that, that was just such a positive thing.

When we came home, I noticed that he just was sleeping more and more. So he would, he would do things, but he was– he was a lot quieter.

And, so one day my husband, who always would wake up in the morning, get breakfast, he had a little routine, didn't get out of bed this one morning. And I went in to check on him and he said, yeah, he's getting up, but you know, and then he fell back asleep. And another hour... So I went to check on him again and he was the same. He talked to me. He was fine. He just– it would be a bit.

I called the hospice nurse because it was just different than his normal routine. And she's like, ‘would you like me to come and check on him?’ And I said, ‘yeah, yeah, I would like that.’ And she came. And she spoke with him and checked him. He stayed in bed and she came out to me and said, ‘I think you should get your son home.’ And, he came home the next day. And, and we knew that it wasn't long.

Fortunately, two of my nieces who love their uncle very much, came to help me during that time. So we basically had a four-person circle of love with my husband. And, they did an early birthday party for me so that he could be there. It wasn't very coherent, but, but it was nice. And my nieces made nice dinner for me.

And, uh, we celebrated an early Father's Day, tried to get it all in, and, then over time, over time he passed.

After my husband passed, we called again, the hospice care and our nurse came to help basically declared the death, and clean him, and prepare him. It was so tender. It was very nice.

We were exhausted, I have to say. Nobody, nobody fully can appreciate how physically and mentally exhausting it is, even when it's not drama. And so, it was really, it was, it was quite an experience, but it was also.. I felt more part of the universe than I ever had. There was something spiritual, with a little S, but spiritual about the whole thing for me, and for all of us.

And it was remarkable. It was positive and uplifting. And I know my nieces and my son and I will never forget how meaningful that was to be there and to see it be peaceful. And I hope that for everyone.

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**Fosdick:** When I first was at a death in hospice. Um, it changed my life. We were honoring the patient and the life that they had lived. So, I sat there with the patient, and the family. We were all holding hands. We knew that the end was near, but it was special.

So it's why I'm so passionate about hospice, is because we get to guide these patients towards the end of life, and when the end comes, it ends up being special and rewarding. And it's just a complete honor to be at the bedside with these families and these patients as they say goodbye.

The death of a patient is the end of one journey, and the beginning of many others. One additional benefit of hospice is that it comes with access to counseling for family members, both before and after the death of a loved one.

**Fosdick:** And that follows your loved one's death 13 months after a patient passes away. And then there's also something that's called anticipatory grief. And hospice often has support groups available to family members, to patients, that are dealing with that anticipatory grief.

So that bereavement support will be tailored to what your needs are. And even if that changes throughout the 13 months after your loved one passes, maybe you just have a rough week and you need to talk to someone, that hospice is always there to support you.

**Ludlow:** Both my son and I were able to continue to get counseling with the counselors of the service, and I found it very helpful. I know my son did as well. But I had thought, stupid me, I had thought, well, I've known that my husband was terminal for six years. And that I was prepared for his death, and I was not.

It came as a punch in the stomach afterwards. It was like, oh my god, you know, here we've been doing all this stuff, and we prepared, we had hospice care. But just, there was an emotional hit that I really appreciated talking about.

From advance directives and palliative care, to hospice and grief, end-of-life care comes up at many stages throughout a patient's NET journey.

And there comes a time when all of us will face the end of our lives – whether we are NET patients, doctors, advocates, or voices you hear on a podcast. And no matter how prepared we may feel, it can be frightening to think about.

But Suzie Ludlow told us something her husband Vince once said to her -- he said that dying is natural. In other words: it’s *part* of living. And we have the power to exit this world with as much grace as we have lived in it.

**Hallet:** Because this is a long and protracted course of disease, a lot of patients are able to come to terms with what's happening to them. They're about. They're able to, quote unquote, see it coming, and they show incredible courage and grace, in, in very difficult situations.

And to me that's very inspiring and extremely touching to see and it's also a privilege that people allow us to be there in those moments.

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Thanks for listening to NETWise. I’m Jessica Thomas, Director of Patient Education for the NET Research Foundation.

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