TRANCRIPT, NETWise EP 58: Nutrition and Neuroendocrine Cancer

Jessica Thomas, LCSW, Director of Patient Education at NETRF
A cancer diagnosis can change something as familiar as deciding what to have for dinner. You may be wondering what you should eat, what you should avoid, or whether a food could make your cancer worse. And if you are living with neuroendocrine cancer there may be another question underneath all of that: What can I eat without feeling sick?

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.

Today on *NETWise*, we're talking about nutrition and neuroendocrine cancer—the questions, the fears, and how to find your balance with food. We'll hear from three dietitians who work with people with neuroendocrine cancer, and from a chef and culinary educator who's also living with neuroendocrine cancer, bringing both a professional and personal perspective on how cancer can change our relationship with food. Together, we'll explore how to stay nourished and find advice that fits your needs.

Melanie Underwood has spent decades teaching people to cook. She also lives with a neuroendocrine tumor in her lung. Before her own diagnosis, she was a daughter trying to help her mother eat during cancer treatment. As a chef, she could prepare all kinds of meals. Her mother wanted something much simpler.

Melanie Underwood, Chef, Culinary Educator & Founder, Nourish and Gather
For me personally, like, the backstory is a little bit of being complicated because I saw my mom sort of wasting away from not being able to eat, and I wanted her to eat anything. And she wouldn't eat, like, food that I prepared because she didn't want it. What she truly wanted was Campbell's cream of mushroom soup. And her taste buds were getting dulled from chemo, so that's why.

Jessica Thomas, LCSW, Director of Patient Education at NETRF
That story raises a question for patients and caregivers alike. When cancer changes eating, what does good nutrition actually look like? Madelynn Strong is a registered dietitian and board-certified specialist in oncology nutrition at Mayo Clinic in Rochester, Minnesota. Her answer begins with the person.

Madelynn Strong, MS, RDN, CSO, LD, Oncology Dietitian, Mayo Clinic
Yeah, and I think that varies so much from person to person. There's really not a one-size-fits-all approach in terms of nutrition. So, you know, what means good nutrition for one individual might mean a very different thing for another individual, even with that

same cancer type. Things like past medical history, type of treatment, you know, overall health and wellness can really influence, you know, what is good for that specific individual. And even, you know, what is good nutrition at one point for an individual might change and evolve over time. You know, might look different in six months or a year or years down the road. You know, typically during treatment, good nutrition involves making sure we're getting enough calories, enough protein, and enough fluid to help us maintain our weight and tolerate treatment well.

Jessica Thomas, LCSW, Director of Patient Education at NETRF
During treatment, getting enough nourishment can sometimes take priority over what we usually think of as the healthiest meal.

Madelynn Strong, MS, RDN, CSO, LD, Oncology Dietitian, Mayo Clinic
Sometimes patients are surprised when I tell them that it might be a time when we have to put some of those healthy eating guidelines to the back burner. You know, right now we're going to focus on getting enough calories and protein and fluid. And if some days that means, you know, my win is that I eat a chocolate milkshake for breakfast, you know, that can be a win. Versus, I have other individuals I work with that, you know, they're doing great in terms of getting calories and protein and fluid. And, you know, we might be thinking about: How can we make some healthy swaps within our diet to improve the overall quality of that diet?

Jessica Thomas, LCSW, Director of Patient Education at NETRF
The milkshake is an example of how priorities can change when eating is difficult. What works for you will depend on your needs and what you tolerate. Meghan Laszlo is a registered dietitian, board-certified specialist in oncology nutrition, and a clinical nutrition coordinator at Cedars-Sinai Cancer. She looks at how someone is eating, their treatment, and the symptoms they are experiencing.

Meghan Laszlo, MS, RD, CSO, Clinical Nutrition Coordinator, Cedars-Sinai Cancer
It's so much more than calories. I mean, we want to assess each person as an individual and explore their individualized needs, what their eating patterns are like, and their habits, what supplements that they're using, if any, and their understanding of what their needs are during treatment. And that can vary quite a bit in individuals with with neuroendocrine tumors because they can be so different and impact the body in so many different ways. So we really want to recognize that each different treatment may impact each different person in a different way, and supporting individuals through making changes to their diet to help manage treatment- or disease-related symptoms or side effects. And really, the ultimate goal is to help each person be as well nourished and strong as possible so they can get through the recommended treatment with the best possible outcomes. We want to prevent and address malnutrition and muscle loss as important parts of that, and really support the patient with that being the primary goal, is for strength and good nutrition.

Jessica Thomas, LCSW, Director of Patient Education at NETRF
For Meghan, protecting muscle is a key priority.

Meghan Laszlo, MS, RD, CSO, Clinical Nutrition Coordinator, Cedars-Sinai Cancer
My concerns for patients often differ from their concerns for themselves, and I always try to address both. But one of my top concerns is loss of muscle because we know that muscle loss is an independent predictor of poor treatment outcomes. If someone is losing muscle, they're going to have potentially less response to treatment. They may not be able to withstand more treatments. They're at higher risk for complications after surgery or other sensitive situations. So we want to make sure that someone is getting enough protein to protect their muscles and and fuel their muscles, and that they're also getting enough calories so that they don't have muscle loss because of inadequate calorie intake. And then, at the same time, we want to make sure that someone is exercising and doing resistance exercise as much as possible during treatment to also build and maintain muscle mass and physical strength.

Jessica Thomas, LCSW, Director of Patient Education at NETRF
With neuroendocrine cancer, figuring out what to eat often starts with understanding what is happening in your digestive system. Luz Chavez is a dietitian at the University of Chicago Medical Center who has worked extensively with people with neuroendocrine cancer and other digestive cancers. She says the same symptom can have different causes, especially with diarrhea.

Luz Chavez, MS, RD, CSO, LDN, Manager, Clinical Nutrition & Diabetes Patient Education, UChicago Medicine
Especially with patients who are diagnosed with a neuroendocrine tumor, diarrhea is such a horrible symptom. I mean, there's really no other way to put it. I mean, it really is a very, like, inconvenient, sometimes embarrassing symptom to have to deal with. And even though your everyday person may think of, you know, “Oh, just diarrhea, you know, it's loose stools.” The cause of the diarrhea is what's going to dictate the diet with this patient population, especially. So knowing that root cause is what will really kind of dictate the diet even further for this patient population.

Jessica Thomas, LCSW, Director of Patient Education at NETRF
In some patients, diarrhea is caused by hormones released by the tumor, particularly serotonin, as in carcinoid syndrome. Medications such as octreotide and lanreotide can help control these hormone-related symptoms. But diarrhea can also result from problems with digestion and nutrient absorption, sometimes following surgery or treatment. Meghan explains why this treatment history matters.

Meghan Laszlo, MS, RD, CSO, Clinical Nutrition Coordinator, Cedars-Sinai Cancer
You know, for individuals that have undergone surgery, it really depends on where… you know, which parts of maybe the small bowel they had removed. You know, are they having digestive issues because of that? You know, was it an extensive surgery? Do they have short bowel syndrome or other factors impacting their digestion and absorption? So each- each treatment can- can vary quite a bit. And when we look at the treatments like somatostatin analogs, like lanreotide and octreotide, those greatly- can greatly impact how the body utilizes nutrients. You know, is the body able to break down fat and digest it while on those medications? Is it able to utilize glucose effectively while on those medications?

Jessica Thomas, LCSW, Director of Patient Education at NETRF
Malabsorption means the body is not absorbing nutrients as it should, and that can include important vitamins. For people living with neuroendocrine tumors, certain surgeries and long-term treatment with somatostatin analogs can increase the risk of vitamin B12 and vitamin D deficiencies. People with carcinoid syndrome may also be at risk for niacin, or vitamin B3, deficiency, because their bodies use more tryptophan to produce serotonin. That doesn't mean everyone needs to start taking vitamins. Your care team can assess whether you're at risk for deficiencies and recommend testing or supplementation when appropriate. Understanding whether malabsorption is happening, and why, can affect the plan. Luz describes how the care team investigates diarrhea while trying to preserve nourishment.

Luz Chavez, MS, RD, CSO, LDN, Manager, Clinical Nutrition & Diabetes Patient Education, UChicago Medicine
So, for example, you know, with neuroendocrine tumors, you could have fat malabsorption being, like, the cause of that diarrhea. You could have, like, bile acid malabsorption. So, in each of those situations, for example—and that's not even considering the side effects from the meds; you know, that's a whole other kind of category—you know, with even just the bile acid malabsorption and the fat malabsorption, there is a common theme there where, you know, reducing fat could be helpful. But, you know, we we still want to take into consideration the fact that we don't want to over-restrict our oncology patients because they need that to really fuel them and be strong for any kind of treatments they're going to be receiving. So our work is really to know that cause, try to adjust the diet and not limit it. You know, so we may reduce certain fats to make it a little bit more tolerable, but that's where the oncology dietitian will also kind of work with the oncologist and the patient, you know, probably recommend to keep a food log and see if there are some other components that we can add in, like supplements, like whether it's pancreatic enzymes or a bile acid—what's called a bile acid, like, sequestrant—so that we can also minimize the diarrhea from, like, a supplement perspective, but then also try to give the patient as much nutrients as we can without overly restricting their diet. And it really is a phased approach, and that food log can be very, very eye-opening because if we do find that this combination of

recommendations isn't quite working, that's where we may consider, like, pulling back on a little bit of fiber, adding in certain kind of fibers to bulk. So it is a very complex kind of tumor diagnosis, unfortunately, and it really does take a multidisciplinary team with a few different factors being taken into consideration to help the patient.

Jessica Thomas, LCSW, Director of Patient Education at NETRF
These are examples of different approaches to managing diarrhea, depending on its cause. For patients whose carcinoid syndrome-related diarrhea remains poorly controlled despite treatment with somatostatin analogs, their care team may consider adding a medication called telotristat ethyl, also known as Xermelo, which reduces serotonin production. Other treatments, such as pancreatic enzymes or bile acid sequestrants, address different digestive problems. Changing your diet alone may not solve the issue. If diarrhea is persistent or worsening, or you're losing weight or struggling to stay hydrated, bring that to your care team.

Luz Chavez, MS, RD, CSO, LDN, Manager, Clinical Nutrition & Diabetes Patient Education, UChicago Medicine
I always say that, especially outpatient dietitians, and especially those that are dealing with a lot of symptom management, like in oncology, we really are detectives because we are starting with kind of that, you know, initial consultation and that initial diet plan. But then there is a lot of follow-up and really getting to know that patient because the symptoms that follow after that initial recommendation are going to tell me so much information about how their digestive system is tolerating that food. So that food log is really a, like, window to what they're experiencing and will help me then customize their diet even further. So there's a lot of follow-up, a lot of checking in, really getting to know the patient and their symptoms, and getting the patient to be comfortable with poop talk because your poop is going to tell me a lot about what you're going through.

Jessica Thomas, LCSW, Director of Patient Education at NETRF
That work depends on being able to talk openly about symptoms. It also means questioning whether restrictions you find online actually apply to you. Madelynn sees patients who have removed foods they may not need to avoid.

Madelynn Strong, MS, RDN, CSO, LD, Oncology Dietitian, Mayo Clinic
The type of tumor, the location, whether it is, like, a functional tumor—is it making hormones, for example? Have we had a surgery, especially if a surgery to our digestion, our gastrointestinal tract? Medications can all have a big influence. And I think even, you know, kind of the idea of there's not a one-size-fits-all is important there because I've worked with individuals with neuroendocrine tumors that, you know, come in and they say, you know, “I went to Google and I searched what I should eat, and it says I should avoid all these foods. Is that true?” And, you know, this is an individual, for example, that perhaps is not having a lot of side effects, doesn't have, you know, a functional tumor, doesn't have carcinoid syndrome, and really doesn't necessarily need

to follow that type of a restrictive diet. Where, on the other hand, that type of diet might be a lot more beneficial for someone who's having, say, flushing or diarrhea related to carcinoid syndrome. They might be looking at, you know, “How can we tweak our diet? What types of triggers am I having that I can modify to help improve those symptoms?”

Jessica Thomas, LCSW, Director of Patient Education at NETRF
Meghan suggests gathering some information about your own experience.

Meghan Laszlo, MS, RD, CSO, Clinical Nutrition Coordinator, Cedars-Sinai Cancer
I think, you know, there are resources out there. There's not one guide I would point to, but I think one of the most valuable resources is actually a food journal and tracking symptoms and writing down what you're eating, what your experience is like. Are you having flushing? Are you having diarrhea? How much did you eat? Because that's often a factor more than the food itself, and really tracking those symptoms to try to come up with the correlation there for when there is one with diet. At the same time, I hate to acknowledge this, but it's not always the food that's causing the symptom, as well. And it could be stress. It could be exercise. It could be other things that are triggering it too.

Jessica Thomas, LCSW, Director of Patient Education at NETRF
A journal can help guide a conversation. It does not prove that every symptom came from food. And if tracking becomes stressful, Madelynn says there are other ways to share what is happening.

Madelynn Strong, MS, RDN, CSO, LD, Oncology Dietitian, Mayo Clinic
My patients do a variety of things in terms of how they might track their intakes. A lot of them don't necessarily track in- in any formal way, and so when I see them, we might do what I would call a diet recall. So, you know, tell me about a typical day recently. What are you eating and drinking? And we'll walk through that day. I do have others that prefer to track. It helps keep them accountable even between appointments, where they might track using electronic software that can tally their calorie and protein intake. I have others that will just jot down in a notebook, and I do tell my patients, you know, I don't want that to be a source of stress. So if, you know, writing it down or tracking is becoming cumbersome, that's something I'd want them to- to pause to, you know, focus on eating. I don't want it to take away from eating.

Jessica Thomas, LCSW, Director of Patient Education at NETRF
When meals repeatedly cause discomfort, eating can start to feel uncertain. For some patients, that began long before their NET diagnosis. Luz has worked with people who spent years trying to manage symptoms they had been told were caused by something else.

Luz Chavez, MS, RD, CSO, LDN, Manager, Clinical Nutrition & Diabetes Patient Education, UChicago Medicine
When I started in this, I mean, I really leaned on, like, the medical providers to learn about this and how to reach out internationally. And what I found is that many patients were being diagnosed initially with IBS. You know, they were being misdiagnosed for the longest time because neuroendocrine tumors is just, you know, it was just seen as rare. You know, providers weren't as well versed on it, and I will say, earlier in my career with this patient population, I saw a lot of that. A lot of patients coming to me that previously were diagnosed with IBS, and that… I almost always kind of saw this fear of eating because of, like, the digestive symptoms. And, you know, patients would try the FODMAP diet, you know, these things that are recommended typically for IBS, but they couldn't understand why things weren't working, you know. Why aren't they not getting relief? So it really did create a lot of, like, food aversions, which is kind of what we call, like, this fear of eating certain foods. So earlier on, when I started counseling these patients, it was a lot of, like, counseling to kind of rebuild that trust with food and kind of show them that, you know, unfortunately, because of the misdiagnosis, you know, that was more so the reason for that, you know, like, lack of effectiveness for their food restrictions. And then building that trust in those first few sessions, and then getting patients to kind of reintroduce foods that was… that were appropriate for, like, the symptoms that we're experiencing.

Jessica Thomas, LCSW, Director of Patient Education at NETRF
There can be another kind of fear: that eating something will make cancer worse, or that food caused it in the first place. Madelynn hears that concern even in conversations about an ordinary bowl of ice cream.

Madelynn Strong, MS, RDN, CSO, LD, Oncology Dietitian, Mayo Clinic
I think when we get that cancer diagnosis, we have friends or family members, even others that have good intentions that want to try to share some advice and say, “Do this,” or, “Don't eat that.” And it creates this fear of eating, where we're fearful that if I eat something, it's going to make our cancer worse or grow, or perhaps even that, you know, something we ate caused us to get cancer. When, you know, in reality, I think that, again, nutrition often is a little bit more simple. It's not just, “I ate, you know, food X and I got cancer because of it.” You know, I always encourage my patients to view food as fuel and nourishment. I never want them to feel guilty about eating. In fact, there's even been times I've been talking with- with individuals about, you know, “Tell me kind of what you typically eat in a day.” And, you know, they're listing off some of the foods and meals, and then they get a little bit more hesitant to mention, you know, “Oh, after dinner I might have a little bowl of ice cream.” And they- they think that, as their dietitian, I'm going to get mad at them for that. And that's often when I throw in, you know, “Can I tell you my favorite food?” Chocolate and ice cream are my favorite foods, and I know very well that those are not necessarily, like, the top number one, like, healthy food out

there. But I think it's all about balance or moderation. Don't feel guilty about eating food. Food is fuel and nourishment for our body.

Jessica Thomas, LCSW, Director of Patient Education at NETRF
For some people, the guilt goes beyond what they're eating now. They look back at how they ate before their diagnosis and wonder: Did I do something to cause my cancer? You may replay choices you made years ago, or wonder whether eating differently would have changed what happened. Those questions can carry a lot of pain. And advice about what you should eat now can sometimes sound like a judgment about how you ate before. Luz hears that self-blame from patients. She says understanding the feelings attached to food is part of caring for the whole person.

Luz Chavez, MS, RD, CSO, LDN, Manager, Clinical Nutrition & Diabetes Patient Education, UChicago Medicine
So it is a lot of counseling, but then you do have those group of patients that do question, like, "Was it something that I did?" You know, you know, "Oh, I used to eat, like, a lot of processed meat. You know, was that the cause of it?" And it always comes up, and not even just for this patient population. I will say, for most cancer diagnoses, it really is a common theme, and I think it's important as clinicians to really kind of listen to that and, you know, just be mindful in terms of, you know, that emotion tied to eating. Because a lot of folks, I don't think, realize outside of the food realm how food really plays a factor in someone's life, and it is regardless of the reason, whether it's, like, they think they did something wrong or whether they're coming in with food aversions from a misdiagnosis. At the end of the day, that counseling is rebuilding that trust with the food and really kind of letting them know that it, you know, there's so many factors that go into a cancer diagnosis, and it's not necessarily anything you did wrong.

Jessica Thomas, LCSW, Director of Patient Education at NETRF
Meghan hears it, too: patients blaming themselves for foods they ate, or foods they think they should have eaten. She wants them to have support in the present without carrying that blame into every meal.

Meghan Laszlo, MS, RD, CSO, Clinical Nutrition Coordinator, Cedars-Sinai Cancer
It doesn't show a direct cause between those things, and while I think that has value, I think we need to release ourselves from that… from placing the blame on ourselves, from saying, like, "Oh, I didn't eat enough salad," or things like that. I think that's an important thing to let go of and to really focus on what you can do right now to support your body, and in many different ways in your mind too, and knowing that that doesn't need to be perfect. It doesn't need to look like someone's Instagram feed. It needs to be what's right for you in the moment, and that you're well supported in your choices, and that your choices are practical and sustainable to support the body. But I hear the guilt quite a bit from folks, and that place the blame on maybe foods they had or didn't eat, and I don't think that–that's not founded– scientifically. It's not one food that you didn't

eat. You know, our changes, our dietary habits are important, and they influence our lives, but I would take the blame off when it comes to pointing at food.

Jessica Thomas, LCSW, Director of Patient Education at NETRF
You can care about nutrition without turning it into a judgment about yourself. Having cancer does not mean you failed to take care of your body. And getting nutrition support now is not an admission that you did something wrong before. If guilt is making it harder to eat, or making you afraid to enjoy food, that deserves attention, too. You can bring those feelings to your dietitian, your care team, or a mental health professional. You deserve help with the burden as well as the meal. One claim that can fuel that fear is the idea that you can starve cancer by avoiding sugar. We asked Madelynn what that leaves out.

Madelynn Strong, MS, RDN, CSO, LD, Oncology Dietitian, Mayo Clinic
The kind of, the question of “Does sugar feed cancer?” is by far and away the most common question that I get from my patients, and I think a lot of them are surprised to hear that it is a myth. You know, oftentimes when we are diagnosed with cancer, we have, you know, well-intending family members or friends, or maybe social media that tells us we should be avoiding sugar, when, in reality, sugar can fuel every single cell in our body, cancerous or not. But there's really—there's no compelling evidence that eliminating sugar from our diet is going to treat or cure our cancer. And in fact, we could even argue that, you know, if we're too restrictive with our diet and really eliminating too many foods, that that could actually be more detrimental, and that could make us more malnourished and, you know, could negatively impact our, our treatment tolerance.

Jessica Thomas, LCSW, Director of Patient Education at NETRF
Part of the confusion comes from what we mean by sugar. Madelynn explains how carbohydrates from many different foods become fuel for the body.

Madelynn Strong, MS, RDN, CSO, LD, Oncology Dietitian, Mayo Clinic
So sugar, or we might even call it glucose, is kind of like that fuel for our cells, for our body. It's kind of like, you know, the gas for our car. Gives us the energy, so we–we need some sugar, and in fact, sugar could even come from a lot of healthy, nutritious foods. Things like fruits, vegetables, grains, beans, all contain carbohydrates that ultimately are broken down into sugar in our body to act as a fuel source.

Jessica Thomas, LCSW, Director of Patient Education at NETRF
Your own carbohydrate needs still matter, including if you have diabetes. But cutting out sugar is not an established cancer treatment. Madelynn distinguishes that idea from being thoughtful about added sugars.

Madelynn Strong, MS, RDN, CSO, LD, Oncology Dietitian, Mayo Clinic
You know, I tell my patients that sugar doesn't feed cancer, but I still say it's a good thing to limit our intake, especially some of those added sugars. Added sugars generally refer

to those that are added to a food. People often think of, like, cakes and cookies and pies. You know, those are are some of those kind of extra foods. I say we eat them because they taste good. We don't eat them necessarily for the nutritional value, and so we say limit those types of foods. But they can certainly still be included as part of an overall healthy eating pattern.

Jessica Thomas, LCSW, Director of Patient Education at NETRF
Promises about supplements deserve a closer look, too. A product described as natural can still affect your treatment or medications.

Madelynn Strong, MS, RDN, CSO, LD, Oncology Dietitian, Mayo Clinic
I would say if it sounds too good to be true, odds are it's too good to be true, and—and but if they're probably selling something. That's a big red flag for me. You know, if they're trying to promote something and they say, “Hey, also buy this,” you know, they've got some financial motive for you to—to buy into what they want. And I think they're, you know, on social media and, you know, the internet. There's a lot of push to do some certain types of things like supplements, for example. You know, supplements are a huge multi-billion-dollar industry, but really, when we look at supplement use in cancer, especially, like, cancer prevention, the research is actually pretty disappointing. We don't see a lot of that same reduction in cancer risk that we would see with a healthy diet with supplement use. In fact, there, you know, can be times when supplements could actually be more detrimental. To give an example, cold and flu season, I often see individuals that, you know, are wanting to take high doses of vitamin C to hopefully help prevent that cold. But during chemotherapy or radiation, there's concern that, you know, is that high dose of an antioxidant actually going to negatively impact the effectiveness of that treatment? And many people view, you know, supplements, especially, you know, vitamin C—it's naturally found in food—as something that must be, you know, pretty harmless, or a lot of more than naturally derived types of supplements. But in reality, they actually can be harmful at times or can interfere with the treatments or medications that we might be receiving.

Jessica Thomas, LCSW, Director of Patient Education at NETRF
It's also important to understand that dietary supplements are regulated differently from FDA-approved medications. Unlike those medications, supplements are not reviewed and approved by the FDA for safety and effectiveness before they're sold. Instead, manufacturers are responsible for ensuring their products are safe and their claims are truthful, with the FDA able to take action against products that violate the law. Just because a supplement is available in stores or online doesn't mean it's been proven to work or is safe to take during cancer treatment. Before starting a supplement, bring the label to your team. Ask what it is for and whether it could interfere with anything you take. A product recommended for a particular nutritional need is a different decision from taking something because it is advertised as fighting cancer.

Then there is the daily work of eating. What happens when nothing sounds good, or a whole meal feels like too much? Madelynn helps patients find a manageable place to begin.

Madelynn Strong, MS, RDN, CSO, LD, Oncology Dietitian, Mayo Clinic
I hear that all the time: “Nothing sounds good. I just don't want to eat. If I could go all day without eating, that would be best.” And, you know, sometimes I encourage those individuals to to reframe how we think about eating. We think about nutrition as food or fuel for our body. So we might eat because we know we need to eat. We might even, at times, set reminders on our phone. You know, if food just doesn't sound good, we might be a lot more flexible with what we eat. You know, that's where maybe if that chocolate milkshake does sound good for breakfast, absolutely, let's eat that.

Jessica Thomas, LCSW, Director of Patient Education at NETRF
She also offers a way to include protein in those smaller opportunities to eat.

Madelynn Strong, MS, RDN, CSO, LD, Oncology Dietitian, Mayo Clinic
And it might even be even smaller amounts throughout the day too, where sometimes it's less overwhelming to think about, “I'm going to eat a snack right now rather than a meal.” You know, if I have a small plate, I can finish that. It kind of gives me this feeling of a success or a win. And if I can maybe do that a little bit more often during the day, I can still get that fuel that my body needs.

Jessica Thomas, LCSW, Director of Patient Education at NETRF
Smaller portions can make eating feel more manageable. Madelynn also suggests thinking about what goes into those smaller meals

Madelynn Strong, MS, RDN, CSO, LD, Oncology Dietitian, Mayo Clinic
If you're struggling to eat today, some of the things that I would encourage you to do are think about eating five or six smaller meals and snacks. And if you can, try to include a source of protein with each of those meals and snacks, just because we know we—our bodies need a little bit more protein. And if we can spread it out throughout the day, odds are we're going to get a little bit more protein. So, could be incorporating things like some of the meats, or eggs, or dairy products, or nuts, seeds, beans, for example. Whatever protein products are sounding best, try to incorporate those into your meal.

Jessica Thomas, LCSW, Director of Patient Education at NETRF
These are examples to consider alongside what you tolerate. A nutritious food is not useful to you if you cannot comfortably eat it. Melanie does not personally experience carcinoid syndrome, but people with trigger foods have asked her for help finding recipes they can enjoy. Her culinary approach is to look for what else might work.

Melanie Underwood, Chef, Culinary Educator & Founder, Nourish and Gather
I mean, I do believe if you have functional NETs and that you can't eat certain foods, there- there are many ways to bring other foods in that you can enjoy, and also to not think of it so much as eliminating. Because I think when we think about, “Oh my God, I'm taking out this food that I love because it's causing me severe health issues,” it's really not about eliminating. It's about, “Okay, this makes me healthier to take this out of my diet, but what can I bring in that would make me feel good about not having that in my diet?” And everybody does have… I mean, a lot of people that I've worked with have different triggers, so it's about finding those sort of individual needs to meet that person.

Jessica Thomas, LCSW, Director of Patient Education at NETRF
For caregivers, watching someone eat less can be frightening. Encouraging one more bite may feel helpful. Madelynn says that pressure can sometimes have the opposite effect.

Madelynn Strong, MS, RDN, CSO, LD, Oncology Dietitian, Mayo Clinic
I think caregivers have the best of intentions of—of wanting, you know, what's best for their family member or loved one. But sometimes I think that the pressure that caregivers put on loved ones actually backfires a little bit because when we make eating stressful, it actually can make our appetite worse, and we might even eat less then. So kind of take a step back. You know, give your loved ones some grace. Try to make eating a non-stressful thing. Make it a relaxing environment, and that might mean playing some of their favorite music. Maybe looking at the food that we're serving and the colors and textures and flavors. Maybe it's using some nice table settings at times too to make, again, that meal more relaxed. When we feel more relaxed, we'll eat a little bit more. And even looking at the amount of food that we put on a plate, if your loved one isn't really hungry and you make this big, huge Thanksgiving-style plate, that's going to make them feel, odds are—or I should say—the make them feel a little bit worse about that meal in terms of they're not going to want to eat as much. They're going to say, “I can't finish it, so I might as well not even try.” Versus if I can do just a small amount of food, maybe more like a snack-like meal, and say, “Hey, I made you a little snack. How about trying this?” they're going to be much more likely to eat that.

Jessica Thomas, LCSW, Director of Patient Education at NETRF
Melanie's advice to the person preparing the food is direct.

Melanie Underwood, Chef, Culinary Educator & Founder, Nourish and Gather
Put your ego aside and ask the person, “What would you like to eat? What can I make for you that would be helpful?”

Jessica Thomas, LCSW, Director of Patient Education at NETRF
Asking leaves room for the person's symptoms, appetite, and preferences. And when food is working for you, pleasure can be part of the picture. For Melanie, a regular family outing meets another need, too.

Melanie Underwood, Chef, Culinary Educator & Founder, Nourish and Gather
And if you're like, “Oh God, I ate gelato on Sunday night,” you know, that's sort of a ritual that I have with my family. We go get gelato on Sunday nights, and I also have a nutritionist, and she's like, “You don't need to feel bad about that.” I'm like, “I—I don't, don't worry.” But that's because that's meeting another need. Not only, like, do I love gelato, but my family and I are going out together and having this experience, and I don't know that it would be as enjoyable if we were going out and having, like, a broccoli pancake or something.

Jessica Thomas, LCSW, Director of Patient Education at NETRF
Connection does not require an elaborate meal. Melanie encourages people to make room for company even when they do not have the energy to host the way they once did.

Melanie Underwood, Chef, Culinary Educator & Founder, Nourish and Gather
I think try to surround yourself with people that love you, and from all different angles, right? Just… food is a common denominator, and food brings us together. And it doesn't have to be anything fancy. It can just be, like, whatever—a soup and salad, or something simple, coffee cake—and just invite people over. And if you're tired and you are like, “I can't do this,” ask someone to do it for you. And I really, really know that people are like, “I can't have people over because my house is a mess,” or, “I don't feel like getting makeup on. I don't feel like getting dressed.” Those things don't matter. Nobody actually cares, and it's a huge piece of not connecting, being worried about those things… no one cares. No one cares what your house looks like. They really just want to spend time with you, and just enjoying the moments that we have because that's—that piece of gathering helps our emotional nourishment in ways that nothing else can.

Jessica Thomas, LCSW, Director of Patient Education at NETRF
She also teaches mindfulness. These are optional suggestions for making a meal feel more comfortable, rather than another set of rules to get right.

Melanie Underwood, Chef, Culinary Educator & Founder, Nourish and Gather
Two or three tips that I would give about mindful eating would be, first and foremost, expressing gratitude for the food. Gratitude does go a long way. It's cumulative to help us with our happiness. And then also chewing slowly. This might seem like something—I get pushback from people all the time—but chewing slowly allows you to digest your food easier. But also, it really helps with the mindfulness piece so much. And then, I mean, I think this goes without saying, but not using devices at the dinner table, and even if you're living alone and eating on your own, putting your device away.

Jessica Thomas, LCSW, Director of Patient Education at NETRF
There may be days when sharing a meal feels good, and days when the goal is simply getting something down. If eating has become difficult, or you have begun doubting your own experience, Luz wants you to know those concerns belong in your care.

Luz Chavez, MS, RD, CSO, LDN, Manager, Clinical Nutrition & Diabetes Patient Education, UChicago Medicine
Probably would just want them to know, like, you know, it's truly not in their head. You know, I feel like sometimes there's a lot of doubt, as if to, like, especially with the symptoms, just because I'm always thinking of how symptomatic this patient population can be, you know. And there's sometimes, like, doubt as to, like, you know, “Am I over-focusing on this?” You know, just knowing that, like, oncology dietitians, we're here to hear you out. Like, you know, bring us your concerns. Like, we want to hear it, and we're here for you, to be quite honest. I mean, we can be your biggest allies and really helping manage some of those symptoms so that—they can live a more complete life. Because the over-restriction that can happen without having that knowledge is something that does kind—that does break my heart. To be quite honest, you know, I don't want anyone to live in fear of, like, eating food, and that is really what happens. You know, they don't have to live in fear. We're here for them.

Jessica Thomas, LCSW, Director of Patient Education at NETRF
You do not have to wait for a problem to become severe. Madelynn would like patients to have nutrition support earlier.

Madelynn Strong, MS, RDN, CSO, LD, Oncology Dietitian, Mayo Clinic
I think it's very appropriate to see a dietitian from diagnosis onward. I think kind of the misconception is that you should wait to see a dietitian until symptoms are quite severe or you've lost a lot of weight. But meeting with that dietitian and intervening early is actually going to help improve some of those outcomes. And I think, you know, even from the time of diagnosis, separating some of those facts and fiction, you know, can help you maintain good nutrition and be able to eat a variety of foods without some of that guilt or that pressure.

Jessica Thomas, LCSW, Director of Patient Education at NETRF
Ask your cancer care team for a referral to a registered dietitian who works with people with cancer. If there is not someone at your center, ask about other options. Meghan suggests a credential that can help guide the search.

Meghan Laszlo, MS, RD, CSO, Clinical Nutrition Coordinator, Cedars-Sinai Cancer
So I have a board certification in oncology nutrition. I think that's a great place to start. Someone that has experience in oncology is- is most likely to have some experience with- with NETs, although I acknowledge it- it can be limited, but at least they can be connected to the right resources. So searching for somebody—for a dietitian that has CSO after their name—you can do this on the Academy of Nutrition and Dietetics

website. For those that don't have connection to a dietitian at their, their—their treatment center, then it could be worth looking either for those in a private practice or some of these telehealth companies like like Nourish or Berry Street or some of the other companies that have dietitians that can offer telehealth services. And insurance is usually much more streamlined with those, and I think there could be a benefit there in searching for an oncology dietitian on those services and platforms.

Jessica Thomas, LCSW, Director of Patient Education at NETRF
Ask about their experience with neuroendocrine cancer and how they would work with your care team. You can begin with the question that matters most to your daily life. Madelynn's advice is to start small.

Madelynn Strong, MS, RDN, CSO, LD, Oncology Dietitian, Mayo Clinic
I'd take a step back from the noise. I know there's a lot of pressure. You know, it's a really scary time. A stressful time. We feel like we need to make changes now to help improve our health. But give yourself a little bit of grace. Think about, "What can I do today or tomorrow or this week to help fuel and nourish our body?" And those changes don't have to be, you know, a huge, dramatic overhaul. It can be small little changes. In fact, kind of those baby-step changes are more sustainable over time and usually a lot more realistic as well.

Jessica Thomas, LCSW, Director of Patient Education at NETRF
Getting support can help you understand which changes serve your needs and which restrictions you may not need. The goal is to nourish your body while making room for the other things food can give us: comfort, and pleasure, and connection, and a sense of normalcy when so much has changed. You deserve that, too. And you don't have to figure it all out on your own.

For those interested in learning more, we've included links to two scientific publications in the episode notes: a European Neuroendocrine Tumor Society position statement on nutrition and an American Society of Clinical Oncology guideline on managing symptoms of certain neuroendocrine tumors. These resources are written primarily for healthcare professionals, but may help you explore questions to discuss with your care team.

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 **Lantheus, Novartis, Boehringer Ingelheim, Exelixis, and ITM**. *NETWise* is produced by Deren Abram at Two24media. Special thanks to everyone we interviewed for this episode. For more information, visit our website at NETRF.org. You can find a whole library of *NETWise* episodes on different topics at NETRF.org/podcast, where you'll also find infographics and videos that expand on this material. And if you would like to join NETRF in our mission to fund research for neuroendocrine cancer or help support educational

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Additional Scientific Resources

For those interested in exploring the research and clinical guidance discussed in this episode:

- ENETS: Controversies in NEN: An ENETS Position Statement on Nutritional Support in Neuroendocrine Neoplasms — Addresses nutritional assessment, malnutrition, vitamin deficiencies, and individualized dietary support.
- ASCO: Symptom Management for Well-Differentiated Gastroenteropancreatic Neuroendocrine Tumors: ASCO Guideline — Covers management of carcinoid syndrome, diarrhea, and other symptoms associated with gastrointestinal and pancreatic NETs.