



Episode 16:  
NETs and Nutrition  
Transcript

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Welcome to NETWise. This is a podcast for neuroendocrine cancer patients and caregivers that presents expert information and patient perspectives. I'm Elyse Gellerman, from the Neuroendocrine Tumor Research Foundation.

They say you are what you eat, and on today's episode, we're going to look at all the ways that NETs interact with nutrition - both how having a NET can affect your body's ability to take in and use nutrients properly, and also how what you choose to eat can help or hurt your NET treatment and quality of life.

Here's Greta Macaire, an Oncology Dietician/Nutritionist at the University of California, San Francisco:



Episode 16:  
NETs and Nutrition  
Transcript

**Macaire:** *"The studies that I've seen, it's estimated that up to 40% of neuroendocrine tumor patients have poor nutritional status, and poor nutritional status is linked with lower overall quality of life. It's linked with poor response to treatment, longer hospital lengths of stay, more treatment complications, and actually lower overall survival."*

And here's Dr. Michelle Kang-Kim, a gastroenterologist who is Co-Director of the Center for Carcinoid and Neuroendocrine Tumors at Mt. Sinai in New York City, followed by Leigh Anne Burns, a registered dietician with decades of experience working with NET patients in clinical settings. She's now in private practice in Louisiana.

**Kang-Kim:** *"We certainly strive to improve quality of life and be able to have people be able to live and work and be as free as they can within the context of their medical conditions."*

**Burns:** *"The biggest thing we can do is improve the quality of life, and in oncology it's all about quality of life. That's the name of the game for us."*

Of course, NETs and NET patients vary quite a lot from one to the next, and the best approach to improving your nutrition varies just as much.



Episode 16:  
NETs and Nutrition  
Transcript

**Burns:** *"Everybody's different, everybody's symptoms are different where you have your tumors are different, situations you live in are different. So the better we manage meal plans and manage personal needs for nutrition, the better we can make that patient."*

**Macaire:** *"Obviously we have some patients who are completely asymptomatic and they're going to be, we're going to be focused much more on just overall, you know, how can you eat as healthfully as possible, and optimizing your diet. But then we're going to move into those patients who are going to have a lot more issues related to what they can eat, how they can eat, how they digest."*

The most common NET-related symptom that wreaks havoc with the digestive system is diarrhea. It can be caused by NETs in a variety of different primary sites - most especially those in the digestive tract - and also by several NET treatments as well. Diarrhea can be disastrous to your nutritional status, because it causes food to leave your system too quickly, before the body has time pull the nutrients out of it.

The tricky part is that diarrhea can be caused by a variety of things.

**Kang-Kim:** *"There can be so many reasons for symptoms and for diarrhea. And so being able to separate out what is related to the neuroendocrine tumor perhaps itself, and might require, you know, pharmacologic treatment, perhaps*



Episode 16:  
NETs and Nutrition  
Transcript

*with somatostatin analogues or other things like that; what perhaps might be related to a surgery or a treatment; and then I guess the last category is that you may have diarrhea unrelated to the NET or the surgery or the treatment. And perhaps it's a completely, you know, different reason like C. difficile or some other type of reason. And so, you know, having the experience to separate all of that and to understand that, actually, a lot of times there is a little bit of each, and perhaps even a key component of irritable bowel syndrome that can add to that, is part of the experience, I think, you know, being a gastroenterologist and seeing just, you know, hundreds and thousands of patients with these different things to different extents.*

The medical treatments for each of these can be quite different.

**Kang-Kim:** *"So for instance, for those patients, let's say who have a small bowel resection, particularly if it's in the terminal ileum, a lot of those patients could have a bile acid diarrhea. And so actually those patients respond really beautifully to something like cholestyramine. So that's often part of our armamentarium. What we also see is those patients with pancreatic resections or those patients who are often on somatostatin analogues like octreotide or lanreotide, a lot of times their diarrhea will change. So what started out perhaps as a very watery, secretory kind of diarrhea actually changes more to what we call a steatorrhea, which is more of a malabsorptive type of*



Episode 16:  
NETs and Nutrition  
Transcript

*diarrhea. And so then actually pancreatic enzymes work very well for that."*

Other kinds of treatments and dietary guidelines can help with diarrhea, no matter the cause.

**Macaire:** *"Usually the cornerstone, when things are moving through too quickly, is using antidiarrheals or gut-slowing agents just to help slow things down so that they can spend a little bit more time in the digestive system and improving absorption. So things like Immodium, and taking that regularly, and taking it even before meals, like 30 minutes before meals, to kind of slow things down.*

*But diet can make a difference too, so generally, you know, smaller meals are going to be important. The simple act of chewing food really well is helpful, and taking a little bit more time to eat. We find that separating meals from liquids is also very helpful because, if, I mean, you can sip a little bit of fluid just to wash your food down, but if you're drinking a lot of liquids when you eat, you know, you kind of might just be pushing everything through in terms of speeding up the transit time with liquids. So we try to separate those out. And then certain foods are better for sort of slowing down the gut."*

**Burns:** *"I put people on a diet that's going to reduce the transit as much as we can with diet. Reduce as much of the movement created by foods that tend to cause more movement.*



Episode 16:  
NETs and Nutrition  
Transcript

*Some of those are concentrated sweet and sugary foods. They tend because the osmolality of the GI tract. I use a lot of soluble fibers – that's inside of the fruits and vegetables – and I reduce the outside. I would take the skins and the peels away, especially right after surgeries, and for the most part, until I get the GI tract absorbing enough nutrients."*

**Macaire:** *"So if we're thinking of an apple, the soluble fibers in the flesh of the apple – so that would be something like applesauce or the cooked, fleshy part of a potato or a sweet potato. The skins and the seeds are more the insoluble fiber, and that is like – I think of that as like a broom sweeping through your digestive system. So kind of like pushing things through faster. So, generally, cooking fruits and vegetables and peeling them just helps with that situation."*

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This list of foods to avoid grows when the patient is dealing with carcinoid syndrome, because choice of diet can also affect the other symptoms of carcinoid syndrome, such as flushing and fatigue.

**Macaire:** *"For carcinoid syndrome, there are certain types of foods that could potentially increase their symptoms. And these are foods that have something called amines in them. So it's tyramine and dopamine, and these are*



Episode 16:  
NETs and Nutrition  
Transcript

*compounds that can cause the tumor to secrete more serotonin basically, and cause more of the symptoms like flushing and diarrhea."*

**Burns:** *"Tyramine is an amino acid, and it converts to tryptophan. So if it has problems with the tryptophan conversion, it can cause the flushing and the diarrhea and it can have an effect. So that's one of the amino acids that we do watch, and it comes from the aging process of foods. So aged foods tend to be troublesome for neuroendocrine patients that are having carcinoid syndrome."*

**Macaire:** *"So it would be things like aged cheeses, aged meats, and fish. So that's like smoked, cured, salted meats, alcohol. Those are kind of the highest foods. Generally we also just find larger meals – people report that as triggers; fattier meals... so kind of avoiding really fatty greasy foods, large meals, and alcohol are kind of common triggers for most people. But again, it's individualized."*

These triggers can also change over the course of a person's disease.

**Macaire:** *"I think it can change over time. I have seen that I've seen sometimes when maybe their disease is more active or progressing that they may be more sensitive to triggers. Or, if, say they've started somatostatin analogs and things*

*are a lot better as far as symptom management goes, they may be able to eat more of those foods and not be, not really see them as triggers."*

Carcinoid syndrome can also cause a problematic deficiency in vitamin B-12, also known as niacin.

**Macaire:** *"Normally we have this at the amino acid, tryptophan, and normally 1% of it goes to making serotonin and 99% of it goes to making niacin, which is a B-vitamin. And with somebody that has carcinoid, that number's going to shift a lot. So now we've got maybe 60% of it – the tryptophan that we eat, it comes from protein in our diet – 60% of that might be going to be making serotonin because the tumor is producing serotonin and now a lot less of that can make that B-vitamin niacin. So we can have these patients that are developing a niacin deficiency, and some of the symptoms of niacin deficiency are diarrhea. So that would be something I would address, in terms of making sure that they are getting a higher protein diet. And then also, you know, we just usually routinely recommend that they take a niacin supplement, and this would be a fairly low dose. It's not a high dose of niacin, but it's about 25 to 50 milligrams twice a day.*

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What all of this adds up to – diarrhea, vitamin deficiencies, and so forth – is an overall state of malnutrition. This is when





Episode 16:  
NETs and Nutrition  
Transcript

the body just isn't getting the nutrients it needs to be healthy.

**Burns:** *"That's what we're trying to do, is either repair or prevent malnutrition, and malnutrition is basically when the body is unable to absorb the nutrients. Either you don't get enough of an intake – you don't consume enough calories and protein, and these nutrients in foods and fluids – or your body can't absorb, it can't uptake these because of something, whether it be the disease, the treatment, the altered structures, or medications that have changed those things. So when that happens, that's when we come in."*

Some of the most troubling cases of malnutrition from Small Bowel or other GI NETs can come from bowel obstructions, caused by either the tumors themselves or scar tissue that can develop after surgery.

**Kang-Kim:** *"My patients who are malnourished, I will say that I think it's honestly many times because those patients have partial small bowel obstructions as a result of their disease. However, their disease has progressed and perhaps with or without treatment, or perhaps without adequate treatment, that they have just not been able to eat. And so, I guess what I'm trying to say is that, in those cases what I find is most helpful is actually a second opinion, or a third opinion, or whatever the opinion is to see if there is any way to have the GI tract work*

*better. And so then that is largely a collaboration with our team here – our, you know, terrific multidisciplinary team. It's often a conversation with the surgeon saying, you know, "What can you do to help these patients? They're vomiting, they're having complete or partial small bowel obstructions." And boy, these patients can be very sick because they have often been suffering for a long time. And that, you know, some of these patients do end up getting admitted to the hospital, but that can have a really nice response if that specific issue is able to be pinpointed and addressed by surgery or by whatever modality we see."*

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And actually, many of the surgeries that are performed to treat NETs – particularly surgeries in the GI tract – can also have an effect on digestion and nutritional status.

**Kang-Kim:** *"This is generally a very individualized question because people respond differently to having a portion of their stomach or their small intestine removed. In general, of course, there is always an acclimation period, right after the surgery, where all bets are off and you can have all kinds of symptoms that you didn't have before the operation. But then, generally, as you get further from the operation, you know, the acclimation continues, but you start to have more formed and normal bowel movements."*

**Macaire:** *"We can see things like vitamin B12 deficiencies develop in patients that have had their ileum removed,*



Episode 16:  
NETs and Nutrition  
Transcript

*which is the lower end of the small intestine. Or, if they've had their stomach removed, or part of their stomach, again, we're going to be looking at vitamin B12 as typically needing to be supplemented. Sometimes iron absorption can be a problem, especially with stomach resections. So we need to monitor their vitamin levels.*

*Now, with larger portions of the intestine removed, we can see increased diarrhea just from rapid transit, to things... you know, food and fluid are moving through too quickly. All the way to 'short gut' where, you know, it's very hard to absorb most nutrients."*

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When a NET develops in the pancreas, surgery is often performed to remove the tumor and part of the pancreas with it. The pancreas produces several enzymes that the body relies on for good digestion, so when part of it is removed, those chemicals can be lacking. Thankfully, this can be very successfully treated with pancreatic enzyme replacement therapy.

**Kang-Kim:** *"So what that is, is essentially a pill that you can take several times a day with every meal and every snack. And so we often recommend five or six times a day, assuming, let's say, three meals and also two or three snacks. Sometimes even for bigger meals or celebratory meals, we recommend taking two or more. And this is to help the gastrointestinal tract deal with the bolus of food that is coming their way and that, you know, normally they would*



Episode 16:  
NETs and Nutrition  
Transcript

*be able to handle with pancreatic enzyme secretion, but that they're not getting.*

*And so these pills that you take with food can really help with these symptoms. Not perfectly, but often taking the edge off so that patients can feel a little bit more free to travel and to go out to restaurant meals and other things that, you know, should be part of a normal, happy life."*

An insufficiency of pancreatic enzymes can also be caused by one of the most commonly prescribed medications for NETs - the somatostatin analogues octreotide and lanreotide. This is also treated with oral pancreatic enzyme replacements.

**Kang-Kim:** *"This is an extremely common medication that we prescribe, and I would say that the vast majority of it - of the reason for the prescription - is because of patients being on octreotide or lanreotide. And so I think a lot of patients and a lot of doctors who prescribe those medications are aware of this... not everyone though, as I found out when some of my patients have come in with really glaring pancreatic insufficiency and not a clue in the world that one of their medications was contributing to this.*

*Essentially what happens with octreotide or lanreotide is that it blocks the ability of the pancreas to secrete the normal enzymes that you would have for the pancreas to help*



Episode 16:  
NETs and Nutrition  
Transcript

*digest food. And so you get this sort of very smelly and very strange pale-looking diarrhea called steatorrhea, and that is very effectively treated with pancreatic enzyme supplementation."*

Another surgery often associated with NETs is removal of the gall bladder. This is frequently done because somatostatin analogues have a tendency to cause gallstones, which can be extremely painful and also cause nausea, indigestion, and vomiting. Losing your gall bladder, though, can sometimes cause poorly-controlled rushes of bile through your GI tract, which can cause diarrhea and other issues. This can be treated with medication and diet.

**Burns:** *"That's why we use cholestyramine, you know, is to bind that bile, because that bile runs rapid, and it's going to run straight through you. It will push everything else in your GI tract through until it gets out. (Laughs) It's a stubborn material. And I know that absolutely, for fact. I live with... I had a gallbladder taken out, a great surgery, I needed to have it done, I was having a lot of trouble with it, but I've had to modify my own diet."*

All of these factors - hormonal and physical; caused by the cancer itself, and caused by related issues - can add up to eating problems that can last a long time and be very tricky to properly diagnose and treat.

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Episode 16:  
NETs and Nutrition  
Transcript

*Patient Story #1:*

*"My name is Devon Billings. I live in Mendocino, California, which is north of San Francisco along the coast. I was diagnosed in 1984 and so I have been living with NETs for over half of my life. I am 72 years old. My primary was in my appendix, and it created an intestinal blockage. It's a long and lonely journey, or it was for me. I never even spoke to a person who had NETs until after I'd had it for 22 years - because I wasn't treated, they just cut it out and said, 'you're cured.' And it was only when symptoms started happening that I realized that there might be something wrong.*

*It's a slow growing, you know, sort of tumor for me. And I bet I've had it since I was a teenager. Anyway, I was 35 when it came up. But once - the more you learn about the symptoms, the more you learn that actually they were there. You just didn't notice them, or didn't know what they were. I mean, I've had eating problems my whole life. I had a lot of pain in my stomach as a child. Food never tasted good because it made me feel sick. I would get really bad pains in my stomach. And, you know, just being a little girl, they just thought you were imagining it and being dramatic. Because I didn't have any guidance, you know, I had to make it up as I went along for years.*

*I could eat, except that I could not eat anything with heavy fiber because adhesions are one of the side effects,*



Episode 16:  
NETs and Nutrition  
Transcript

*or companions to, neuroendocrine tumors. Adhesions are – what I call it are 'overenthusiastic healing.' But it's scar tissue. It's that sort of heavy fibrous tissue, basically. And I would often get backed up. And so I found that I could not eat celery, grapefruit, oranges, corn... anything with heavy fiber. The idea of living my life with on white rice and bananas really was not attractive.*

*And I finally had them cut out in 1989. They removed my ascending colon and about 30 inches of my ileum. I had an ileostomy. It was a five-hour surgery, and the doctor threaded, basically NG tubing in my intestines to create a cage so that the adhesions worked for me. It was after that surgery, and then the ten weeks later removing the tubing, that I could actually eat like a normal person. And I haven't had any problem with adhesions and twisted guts and any of that since then. So '89 was the real turning point for me. It was kind of liberating to be able to, you know, have a Bloody Mary and chew on the celery. Couldn't do that before. So it was just, it was... it was very nice.*

*I was rediagnosed in 2006 and then started being treated. By and large, I can eat pretty much what I want, I just eat 'em carefully. I'm very selective about what I eat.*

*For your health and your sanity, what you have to do is you have to take care of yourself and you have to keep a food log. And you record any responses, or no responses, and figure out what works for you and what doesn't. I pay*



Episode 16:  
NETs and Nutrition  
Transcript

*attention to everything that goes in my mouth, and sometimes I know going in ahead that there could be problems. And then it's just trial and error, because if you can get a handle on what your triggers are, you can minimize your symptoms, you can improve your quality of life, and you'll be a happier person."*

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An interesting theme in all of this is that the things that make a normal, healthy diet for a normal, healthy person - fiber, whole grains, raw fruits and vegetables - can be very problematic for someone with gastrointestinal issues like the ones caused by some NETs.

**Macaire:** *"You know, the healthy diet advice that we hear for the general population does not apply to everybody."*

**Kang-Kim:** *"And I think, you know, a lot of neuroendocrine tumor patients are very educated and very well-intentioned and trying to eat healthy. And they tell me about how healthy they are, and sometimes actually very healthful diets can actually have a lot of adverse effects on the gastrointestinal tract."*

**Burns:** *"People associate healthy with green (laughs). With spinach or greens, and cleansing. And sometimes this is... if you have a patient that has had six to eight stools a*





Episode 16:  
NETs and Nutrition  
Transcript

*day, they're plenty cleansed! (laughs) They don't need any more cleansing done!"*

**Macaire:** *"It doesn't mean don't eat fruits and vegetables, it just means maybe change the form that you're eating them in. Sometimes people do a lot better with blended fruits and vegetables. So blended veggie soups, or blended smoothies... It's not that you can't eat those foods, they're still very important to eat, it's just, you know, if you're eating big salads or apples with the skin, it just may kind of go right through you, so to speak. And so it's important to look at ways to optimize that."*

The opposite is true, too - foods that have been labelled "less healthy" for the general public may be the best and healthiest choice for someone struggling with these kinds of symptoms.

**Burns:** *"People say white potatoes are bad for you. Well, not if you're in this situation, because I need something that's easy to absorb in that GI tract, and potatoes have a lot of nutrients in it, and it's broken down very easily. And again, very good for my patients that I'm trying to get nutrients in."*

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All-in-all, managing your diet as a person with NETs is largely a question of trial and error: paying attention, keeping notes, and really noticing what triggers particular symptoms and when. It's a hassle, but it's important, because mismanaging or



Episode 16:  
NETs and Nutrition  
Transcript

mistiming certain foods and treatments can lead to repercussions that can have a real impact on your life.

**Burns:** *"Understanding what's going to do it and how to manage your life accordingly. If you're going to go out to eat dinner and you're on something like a pancreatic enzyme or you're on cholestyramine, and you need to know how to time it before that meal, so you can affect that meal, so that you don't have to leave during that meal, or you don't have to be interrupted and embarrassed. I think that the quality of life and what we don't talk about is probably what I'm saying now - is there's a lot of personal management to it because there's a lot of embarrassment to this disease, because it causes a lot of gas, and it causes a lot of diarrhea unexpectedly, and fat malabsorption is hard to control, and it makes you very worrisome. And the more you worry, and the more stress you have makes that bowel worse, and you can get so worried on the days that you travel that you create your own problems. So learning how to control situations... and we do that. I mean, as dieticians we do that. You know, it's not all just food put in your mouth, it's learning how to adapt to the situations that we're put in and the challenges."*

**Kang-Kim:** *"And, again, I think there are some things that are very common culprits and triggers. So for diarrhea, it can definitely be the fruits and vegetables. It can also be the artificial sweeteners, which can really give a lot of bloating and gas and diarrhea. The dairy products, the milk*



Episode 16:  
NETs and Nutrition  
Transcript

*products, can definitely also be a very common trigger. And, you know, it's a matter of figuring out what are the symptoms, what are the things that are preceding it? Have I been having this for just a few days, because I had perhaps a trigger of some sort, or is this something that has been going on for six months and perhaps it relates to the start of a treatment or relates to a recent surgery or medication?"*

And with careful observation and management of your diet, foods you enjoy but thought you wouldn't be able to eat anymore can sometimes be brought back.

**Macaire:** *"What I like to do for patients is to not say that, you know, these foods are off the list for you forever, because I feel like they've oftentimes been restricting foods for years, because they've been trying to figure out what is going on with their digestive system before they were diagnosed. So I usually have them do like a two-week period where they eliminate those foods, go on sort of an elimination diet, restrict those foods, and then assess - how is their body responding to that? Are they having less diarrhea symptoms? Are they having less flushing? And if they are, that's great, now we can try to maybe add in small amounts of something that they enjoy eating that's been off the list, and see if they can tolerate it. And hopefully they can figure out what their individualized triggers are."*

*Patient Story #2:*

*"Well, I'm Cindy Abel and I live in West Lafayette, Indiana. I am 63 years old, until a couple of weeks. (laughs) And I believe I was diagnosed in 2017. It started out that I was diagnosed with lymphocytic colitis. And then we found out that we had the neuroendocrine tumor of the stomach. Did not need surgery, just went through many years of 'there was nothing wrong with you,' you know... and it took a long time.*

*He told me that I'd probably had this for years, and I can go back to remember when I had the diarrhea and the fatigue, things like that, was probably seven years before I was diagnosed. It was a lot of nausea, vomiting, stomach pain, loose stools, diarrhea... just cramping. But I think the worst part was the fatigue. I was really tired. I felt like I was like a space cadet. Most of the time, my brain just didn't seem like it wanted to function. That's probably because I was crapping all my brains out. I don't know. (laughs)*

*And so I've been, nutrition wise, I was dealing with diabetes, gastro-paresis, lymphocytic colitis, and the NETs. I can go through, 'this is what this diet says you can have, this is what this diet'... nope. 'This diet says you can't,' you know... So trying to put all of those*



Episode 16:  
NETs and Nutrition  
Transcript

*together was just overwhelming. The biggest thing was a lot of heartburn, a lot of really bad heartburn, to the place I thought I was having a heart attack.*

*I received a book from the NETs Foundation that would tell me all of these things that, like the amines that were in there, and these are not good for you, and other things... and it's like, 'Oh! Okay! Maybe this is a problem!' So by starting to cut some of those out, it seemed like that helped.*

*The tomatoes was a big one, you know. I love pizza. Couldn't do the tomatoes. Raw vegetables was a hard one for me - very, very difficult, because, being a diabetic, at night, I always get the munchies at night. So I would sit around and munch on, you know, like carrots or celery or something like that. Well, I can't do that anymore. I can't go out and have corn. Salad... we have a place here in Lafayette - 'course, there's a few all over Indiana - called Arnie's. It's a pizza place. And they make these salads called Arnie's Juniors. It had lettuce, and it would have mozzarella cheese, and ham, and turkey, and you would get your dressing and garlic bread and stuff like that. I used to eat those all the time.*

*It's mostly been trial and error. You know, like, the other day I really wanted to try a spinach and artichoke dip, and spinach is on the list of things that you really shouldn't*



Episode 16:  
NETs and Nutrition  
Transcript

*have, but I wanted to try it. It's been a disaster, you know, but it was so good. (laughs)*

*I think it's, a lot of it is trial and error. Just keep a log of what you ate, or what you eat. And this is something that I did even as a diabetic and I would turn these into my dieticians. When I say this is what I ate, it can't just be 'Well, I ate a ham sandwich.' No. I ate the bread; what kind of meat did I have? What kind of toppings that I have? What else did I put on it? You know, did I eat a half? Did I eat a whole? Clear down to the point that I - what I drank down to the... if you drank a bottle of water, put that on there. The time. The day. By keeping that, you can go back and say, 'Oh, I had this. Maybe that was that. Let's take this off for a while and see what happens.' "*

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Living comfortably with some NETs can require changes in a patient's diet and lifestyle that are quite significant, and it can be a challenge for a care team to convince a patient to make these changes, even when they know it will make them feel much better.

**Macaire:** *"You know, as dieticians, we're always taught to meet patients where they're at, and start with something. And I think that if we can start with something that's going to help somebody feel better, and they actually feel better, they're probably going to be more motivated to do the next thing.*



Episode 16:  
NETs and Nutrition  
Transcript

*So sometimes it's hard, if you're only seeing somebody once or twice, to really work with them on making little changes that can then add up to producing big results. But if you have that opportunity - which, in the outpatient setting, which is what I'm in, it's kind of, we can follow up with patients and we can build a relationship. The hope is that we can just start making little changes and then they're going to feel better, and I think that's motivation for people."*

Changing your diet, though, can be easier said than done. Not everyone knows how to cook, and even good cooks might be less motivated to prepare healthy meals when they don't feel well.

**Macaire:** *"It can be very challenging for people. I think family and friends and support people are really key, as far as just helping with cooking and shopping and things like that. Not all of us have family support, but when we do, this is a good thing to ask people to help with because it definitely can be helpful.*

*The second thing is maybe looking at things like where you can save time and energy. That could be like grocery delivery. I know with COVID, everybody's gotten used to grocery delivery now. It used to be like a rare thing, but now it's very common, so a lot more people are used to grocery delivery. But that can be a big energy saver, when*



Episode 16:  
NETs and Nutrition  
Transcript

*you don't have to actually go out and put in all the legwork to go to the grocery store.*

*And then even kind of looking for healthier prepared items. So for people that don't have the energy or the ability to cook, I'm often recommending things like frozen vegetables. Frozen vegetables are cut and chopped and cleaned already, and so that saves a lot of the prep work there, and they typically have no additives in them and they're picked to kind of their freshest point and frozen at that point. So they're going to be equally, if sometimes even higher in nutrient content, than fresh that has been sitting, you know, in the grocery store for a long period of time.*

*So looking for frozen options, looking for things that could be time savers. So, you know, some grocery stores or delis have like good roasted chickens that you can get with, uh, you know, take the skin off, but it's all cooked and it can be, you know, just basically cut up and used in different ways. So we need to look at time-saving techniques like that. Batch cooking or meal prepping, so when somebody does have enough energy to prepare something, they're preparing something that they can then eat, maybe, you know, several times throughout the week or freeze portions of it and have it two or three weeks later. So I think we kind of need to be creative in that way."*

As you're figuring out the diet that is right for you, please keep in mind that what is important is identifying particular





Episode 16:  
NETs and Nutrition  
Transcript

foods or ingredients that are triggers for your particular symptoms, not following any one specific diet or meal plan. These are principles that can be applied to just about any style of food that you like to eat.

**Macaire:** "Because people will say, 'What is the right diet?' And I really feel like it's got to be individualized. There is no one diet for neuroendocrine tumors."

**Burns:** "I think that the biggest misconception is that you need to change everything you're doing in your present life. I think it's sometimes that they want to overcorrect from the normal lifestyle. And I think that that's why it's so important in taking care of cancer patients that you really meet them where they are. You want to make sure that you don't change anything you don't have to."

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The biggest challenge for good nutrition can come in the later stages of a NET journey, when someone can be so sick that they really don't feel like eating at all. This can lead to rapid weight loss and significant deterioration of health and wellbeing.

**Macaire:** "That's really hard. I mean, when somebody is feeling so sick that they don't want to eat at all, then, you know, it can be really hard. When somebody doesn't have an appetite, it's not as easy as 'Just eat a little bit



Episode 16:  
NETs and Nutrition  
Transcript

*more... eat a couple more bites,' you know, it's easier said than done. So we do need to get kind of creative and looking at things that they can do to make every bite count. And so my main strategy for somebody when they're really having a hard time eating is to focus on frequency, not amount of eating, because I feel like, if somebody is not feeling well, it's a lot easier to take two bites of something than it is to sit down to a full meal. And even though two bites isn't that much, if they can eat two bites every hour... sort of, like, food is medicine and it has to be something that you do like you're taking your medicine at these times of day. If we can just set up an eating schedule where maybe every one to two hours, they take a couple bites of something, you know, at the end of the day, that is going to add up to a significant bit of nutrition."*

More frequent, smaller meals can also be better for patients who are experiencing abdominal pain.

**Burns:** *"That's one reason we change meal plans. With this patient, type of patient, we'd need six small feedings throughout the day, smaller types, and keep feeding throughout the day, so they never distend that GI tract too much, and try to reduce the pain... [This] also reduces gas and complications."*

One good strategy when it comes to timing might be to have several small meals pre-set and ready to go, to eat during the



Episode 16:  
NETs and Nutrition  
Transcript

windows of the day when they are feeling hungry, without having to wait for the food to be prepared.

**Burns:** *"One thing is that, when patients with cancer get hungry, that hunger is very limited, usually about 15 minutes, and then they're not hungry anymore. So if you don't have something that they can get to very quick, in that 15-minute period, then they're not hungry anymore. So what we see is that they say, 'Oh, I'm hungry'; someone, their caretaker goes and tries to prepare that meal, and it takes them 30 minutes. They come back with it. The patient's no longer hungry. The caretaker's frustrated because they've tried to get something into the patient. The patient feels bad because they weren't able to consume it. So next time, the patient doesn't ask for it anymore. And so what happens is we see a lot of frustration in the family setting."*

**Macaire:** *"And then when they are eating, let's make the most of it. So let's make sure that there's some protein in there and some good, healthy fats. I'm not talking French fries and pizza, but I'm saying, add a little bit of extra olive oil to what you're eating. If you can eat avocados, add some avocado. Add some almond butter or something. These high-calorie-density foods go a long way."*

*And then, some people that don't like eating, they do really well with more liquids. Sometimes it's easier to drink your nutrition than it is to eat it. So that could be*



Episode 16:  
NETs and Nutrition  
Transcript

*– smoothies can be a really good way, and we can fortify those with different types of protein powders or nutrition supplements... soups, blended things... sometimes when you're not hungry, it's easier just to sip on something. So just really try to implement those types of strategies to improve their nutrition."*

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Then there are all the herbal compounds and nutritional supplements that are marketed as having a positive impact on good health in general or cancer specifically. It's important to be cautious when adding these sorts of products to your diet, because some may have a positive impact; some might be a waste of time and money; and others might even be harmful when taken in large quantity or combined with certain medicines.

**Macaire:** *"I find that people have tried a lot of different supplements. They're taking a lot of supplements. So I just try to be very open and just find out what they're taking, and not in a judgmental way, but just to say like, 'Hey, I can look into all of these for you, give you some feedback as far as maybe this is safe, maybe it isn't safe. Why are you taking it?' A lot of people don't really know why they're taking any things, they're just taking them because they heard it was good, you know, at one point in time, and they've just added all these supplements on.*

*And there's generally going to be truth and myth to all of the fad diets or supplements that come out, basically. And*

*the truth is that a lot of compounds that you can take in a supplement – turmeric being a good example – have some basis for some anti-cancer properties. Because turmeric, for example, is very anti-inflammatory. It can downregulate processes that promote cancer... but most of the studies are at a cellular level. So we're in a petri dish in a lab, and we're applying turmeric to cancer cells. And so does that translate to what happens in the human body as we digest and absorb? And that's where there's a lot of unknowns."*

**Kang-Kim:** *"Human beliefs are a very powerful thing, I will say. And especially, I think, when you have cancer, there are so many things that you're not able to control. And one of the things you can control is what you eat. And I've certainly seen in many people that focus on their diet can sometimes be helpful to them, because, again, there is a feeling of control and a feeling that they are helping to make things better.*

*In my personal opinion, however, I will say that my advice is to have a well-rounded diet, not to have too many extremes, whether a lack of or a surplus of any one thing. And that, you know, for any sort of a supplements, that certainly they at least have a conversation with their NET specialist or their primary care doctor to discuss that. There can be many harms in some supplements, and these are not regulated the same way as medications are. And so I would just hate to see someone having an overdose or an*



Episode 16:  
NETs and Nutrition  
Transcript

*adverse effect from a supplement that's just not very well studied. Again, you know, a moderate amount of anything I don't think is too harmful, but I think you just want to be careful about very regular intake of anything without running it by healthcare providers first."*

**Macaire:** *"You know, we don't really always realize that just because it's natural, or it's a supplement, that it could couldn't have some negative effects in terms of interacting with medications or causing some side effects. So I usually recommend, like, 'Hey, when you're seeing this information, whether it's somebody telling you, or whether it's online, or where you're getting the information about a supplement, what is the source of the information?' You know, always looking at: Who's saying it? What's their motive for saying it? What are their qualifications of saying it? That kind of thing.*

*Memorial Sloan Kettering Cancer Center in New York, they have a website called About Herbs that I recommend to patients a lot. You can really look up many dietary supplements, and it's nice because it gives you references as far as what the safety is, any kind of interactions with medications, what the evidence is for - and it'll tell you, this is in a cell study, this was done in humans. So I feel like that's a pretty good, user-friendly website."*

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Episode 16:  
NETs and Nutrition  
Transcript

It can really be a tricky process to figure out the way of eating that is best for you and your NETs long-term. The good news is that you don't have to do it alone. There are more resources for patients and more experts in the field than ever before.

**Kang-Kim:** *"This is often a lifelong process. This is not something that is a short-term sprint, and therefore, patients need to be able to live long-term with these kinds of diets, and then also long-term with the types of symptoms that they have, and therefore it's got to be sustainable, and something that fits with their life. There is art to the science, and there's not a perfect outcome or a perfect situation, but really it's about helping patients to live as best as they can with these conditions. And so I think just making well-informed decisions, seeking second opinions... There are a number of specialists who are available, particularly in this era of telemedicine, and that patients should feel free to reach out."*

**Macaire:** *"The number one thing I would say is if you can meet with a dietician to get an individual plan, especially somebody that has neuroendocrine tumor experience, I think that's the best way to go, because it's very individual and specialized and unique."*

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Thanks for listening to NET Wise. My name is Elyse Gellerman, and I'm CEO of the NET Research Foundation. This episode was



Episode 16:  
NETs and Nutrition  
Transcript

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