

Episode 45:
Financial Toxicity
Transcript

If you're new to NETwise, we highly recommend you go back and listen to the first episode in this series. It goes over the basics of neuroendocrine cancer and how it's treated. And you can find a whole library of episodes on different topics at netrf.org/podcast, where you'll also find infographics and videos that expand on this material.

If you have a story to tell about your own neuroendocrine cancer journey, please email us and let us know - podcast@netrf.org.

In 2023, Matt Skinner went to the doctor. His wife had had a heart attack not long before, and once she was doing better, they thought it was a good idea for Matt to get checked out himself.

Matt Skinner: *So, I went in and got a, um, heart calcium exam test, whatever you want to call it. And they found a tumor on my lungs.*

When he heard this news, Matt, who's a Colorado-based filmmaker, was shocked. He went to see a lung specialist, who performed a bronchoscopy.

Matt Skinner: *It's when they go down there and look in your lungs. Did some tests. Yes, it was there.*

He learned that he had neuroendocrine cancer, with one tumor in the lung and another in his mid-gut. In December 2023, he had surgery to remove his lung tumor. He and his doctor are keeping an eye on the other one. And these days, he's feeling pretty good.

Part of what makes that possible is the fact that he hasn't had too many expenses. Cancer comes with an extremely high price tag, which can be an enormous burden to patients and their families.

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Matt's been lucky – insurance has covered a large portion of his testing and treatment.

Matt Skinner: *There were some things that would be out of pocket, but it was not the kind of out of pocket that would cause you to say to yourself, 'do I move forward with this? I can't afford this,' you know. I was able to move forward with my medical help with a minimal cost that it was compared to the gigantic cost that it would have been.*

You're listening to NETWise. I'm Jessica Thomas, Director of Patient Education at NETRF.

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

One of the major challenges of cancer is the financial strain caused by the disease. Fortunately, there are resources to help patients and their families reduce that burden.

In this episode of NETWise, we've teamed up with a FLAnet Carcinoid Community to unpack some of the significant costs that come up throughout the neuroendocrine cancer journey, and share some tools for navigating them.

Welcome.

Cancer is expensive. No matter how many resources you have, or how comprehensive your insurance coverage may be, the financial burden of this disease is extremely high.

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Motz: *It's very much like a secondary diagnosis on top of having cancer.*

Mysti Motz is a nurse at the University of Miami Sylvester Comprehensive Cancer Center, where she supports patients in the Neuroendocrine Tumor Program.

Motz: *So just finding out you have cancer costs money, even if it's as simple as a blood test or a scan, anything along those lines, you have to have money or insurance to get to the next steps. And you cannot see someone that can even help with the diagnosis and treatment until you have had these tests.*

Once you've had these tests and know you have cancer, it costs money to see an oncologist.

Motz: *If you have a rare subset of cancers, like with neuroendocrine cancers, you need a specialist that highly is specialized in those cancers because they respond differently.*

So there's two forms of specialists that are even more money on top of, you still have to see your primary provider to get your regular medications and vaccinations done through them.

So there's so many barriers just to start that involve money.

After diagnosis, there are costs associated with appointments, scans, surgeries, and medications. Treatment can be incredibly expensive, and it might involve travel or time away from work.

Motz: *So that is: you're losing money that's coming in, so you still have to pay the bills at home with that loss of income. And then if there's anything else going on in your family, if you have small children, there's going to be times where they have to miss school or someone else*

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is taking off of work to help you with your appointments. So there's multiple variations to where the money can come out of pocket.

With neuroendocrine cancer, people often live for many years with their disease. This means navigating all these costs over a prolonged period of time.

Samantha Powell is a social worker licensed in Utah and Iowa, who has worked with neuroendocrine cancer patients.

Powell: *Because neuroendocrine can be a longer term cancer diagnosis, it's almost like a chronic illness. And so it's really not just about like, okay, what's your treatment cost, but also how are you advocating for yourself if you're still working? Or if you can't work, how do you advocate for benefits and resources? So it's really complex in that way.*

There's a term for this: financial toxicity.

Sasha Watson is a clinical pharmacist at the University of Miami Sylvester Comprehensive Cancer Center.

Watson: *So one thing I always talk about is toxicity from treatments. You know, whether that's nausea, diarrhea, fevers. But in recent years there's been this term coined called financial toxicity, which was something that was developed to really capture this whole side of the financial burden that's placed on patients.*

Financial toxicity is an unfortunate reality. But it's not something you have to face alone. There are people and resources at every stage in your cancer journey that can help you along the way.

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Nurse Mysti Motz described financial toxicity as almost a secondary diagnosis, on top of having cancer. That's because this disease and the costs associated with it go hand in hand from the very beginning. And just as you want to start treatment for your disease as soon as possible, it's important to start thinking about finances as soon as possible, too.

In the days and weeks following a neuroendocrine cancer diagnosis, there are three important conversations to have.

The first conversation is about personal finances. Take stock of your financial situation: what are your expenses? What is your income? Do you have savings? Do you have any debt? If you have a partner, what is their financial situation? When you have a sense of what your treatment costs might look like, how does that factor in?

If you have a financial planner, this would be a good time to meet with them. If you don't, it could be a good time to find one. They can help advise you on your particular situation.

Watson: *Some cancer centers even offer their own financial planners or financial advisors when it comes to medical specific treatments. So I think that's always a good idea.*

Being honest about money with yourself and your family is essential: if you know your financial starting point, you will be better prepared for the road ahead.

The second important conversation is about work.

If you are currently employed, it's very likely that you will need to take time off for appointments and treatment. That could range from a lot of time upfront, to more sporadic days and weeks -- or both.

Watson: *Depending on your exact situation, you might have to come in to receive treatments frequently. Or, if you*

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receive treatments at home, you know, you might not feel well every day. And try to see if your job can offer you some flexibility in that, because if they still expect you to show up every single day at the same exact times, that's probably not feasible.

It's important to understand what benefits you have access to at work. You can learn more about this by consulting your employee manual, if you have one, or talking with your manager and with HR.

If you work for an employer covered by the Family and Medical Leave Act, this is also a good time to fill out FMLA paperwork. This allows eligible employees to take up to 12 weeks off work for certain qualifying reasons, including serious illness.

Powell: *There are some requirements such as you've had to be there a year, but this is the federal protection for your job. And I always tell people, especially early in diagnosis, I'd rather you have it and not need it than need it and not have it.*

Caring for a parent, child, or spouse with a serious medical condition also qualifies someone for FMLA.

Powell: *That's why it's the Family Medical Leave Act. So if you are a loved one of somebody with a neuroendocrine cancer, and say you're the driver, or you're helping with treatment or you have to take them to scans because X, Y and Z, make sure you fill that out too.*

The third conversation that's important to have is about insurance. This is complex and individualized, and will depend on your particular disease, treatment plan, and insurance coverage.

The place to begin is by understanding your current plan. Joanna Doran is the CEO of Triage Cancer, a national nonprofit

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that provides free education on legal issues that may impact people diagnosed with cancer.

Doran: *So what type of insurance do you have? What are your out of pocket costs? Because even if you don't know what your treatment is actually going to cost, you can find out things like your out-of-pocket maximum, which is the most that you'll pay out of pocket for your medical care based on your policy. So you can start to plan around a worst-case scenario.*

For some people, it may make sense to explore different insurance plans. There are lots of options out there, and for those 65 and older or who have a disability, there is also Medicare.

It can be worth comparing options to see if there's a plan that will cover more of your treatments, or cover treatment at a hospital closer to where you live.

Motz: *Some people are not aware of when you have certain life changes, you can change - it's not always, but sometimes you can. So that type of insurance you have is very good to look at.*

If you are exploring new options, be sure to meet with an insurance advisor or someone within the cancer center where you are getting treatment.

It's also important to notify your care team ahead of time.

Watson: *We've sadly had a few patients, you know, switch their insurance plans on their own and they end up picking a plan that actually doesn't even cover their current oncologist or cover their current treatments. So that's something very important: if you're changing insurance plans, always speak with someone first.*

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All of this is very specific to each individual patient, where you live, and your disease. The important thing is to start all of these conversations early, to make sure you have as much information as possible so you can make informed decisions as you move forward in your neuroendocrine cancer journey.

Once you have assessed your personal finances, worked things out with your employer, and gotten a handle on insurance, you'll be in a solid position to move forward with treatment. This is where the costs that you've prepared for really begin to kick in.

The most significant cost is treatment itself, which comes with a high price tag.

Motz: *Astronomical is the word that comes to mind.*

This expense comes from a combination of the cost of doctors' visits, tests, procedures, and medications. With neuroendocrine cancers, there may be several specialists involved, which can increase costs even more.

Motz: *There are patients that are getting biweekly treatments, or every three weeks, and that is a doctor's visit, labs, and the treatment. Sometimes multiple days. There's multiple visit charges for the nursing staff and everything. So easily hundreds of thousands.*

If there's a surgery, that costs money. So do the drugs that are often used to treat neuroendocrine cancer.

Watson: *So somatostatin analogs like octreotide or lanreotide injections, those are very expensive medications. Some of the oral chemotherapies are cheaper, like capecitabine, temozolomide, those have been around for a bit longer.*

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But some of the newer drugs, you know, if you think of like everolimus, cabozantinib, those are more expensive. And then if you're also looking at like lutathera treatments, those are expensive.

Insurance tends to cover a large portion of these costs. But even if you have the best insurance plan possible, and you have done everything you can to minimize your out of pocket costs, you're still going to face medical bills.

Watson: *You're likely still going to be charged a copay or have to meet part of your deductible for surgeries, for coming into the doctor, for getting labs, for getting the drugs, for getting infusions or injections.*

When you do get these bills, there are a few things you should keep in mind.

Joanna Doran with Triage Cancer says that it's a good idea to keep track of all these charges, to make sure you only end up paying what you actually owe.

Doran: *So you're going to get communication from your insurance company and you're going to get communication from your providers, which is the bill. And the communication that's most important from your insurance company is the explanation of benefits, which explains how the insurance company handled that claim from the provider.*

You want to wait to pay the bill from the provider until you have that explanation of benefits, and compare the two.

These charges should line up. If there are any mistakes, you'll want to address those before paying the bill.

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It can also be worthwhile to keep track of what you are paying for out of pocket, to see if you've met your deductible and your out-of-pocket maximum.

Doran: *You might be in a situation where you go to a provider's office and the provider lets you know that you have a \$25 copayment. Well, if you've already met your out-of-pocket maximum and co-pays are included in your out-of-pocket maximum, you actually don't have to pay any additional money for the rest of the plan year.*

So you can let the provider know you've already met your out-of-pocket maximum, you don't owe anything else.

Even if you keep careful track of your bills, costs are likely to still be high. Fortunately, there are a few actions you can take to combat financial toxicity.

If you have a surgery, you can often break the payment up into installments.

Watson: *Most cancer centers and hospitals offer things like payment plans, so you can meet with the financial team and ask, you know, 'Okay, can I split up these payments over the next several years?' You don't necessarily have to pay all of that upfront.*

When it comes to paying for drugs, there are ways to alleviate the burden of a high copay. This might include options such as copay cards.

Watson: *So that's something that drug companies offer to help bring that copay down, potentially all the way to zero.*

It is quite nuanced, so if you have commercial insurance, you can use copay cards. If you have any type of government insurance, whether it's Medicare or Medicaid,

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you typically cannot use the copay cards, so that's something to keep in mind.

Your care team can help you find out if there might be a copay card available to help pay for your treatment.

If that isn't an option, they can also help you find out if there is a patient assistance program available from the drug company.

Watson: *So these are programs that you apply to, to receive the drug or treatment completely free.*

Motz: *Your social worker will know about them. A lot of the time, the pharmacist that is also helping with your treatment plans will know how to access them and they can try to help guide and give you information. Generally, your provider's office will be the one that helps apply for that. So they are a great person to ask about it.*

These options may be helpful for some patients dealing with burdensome copays.

However, insurance is a tricky business. They can sometimes entirely deny coverage for treatments, even when your care team has determined that those treatments are the best option. This can be complicated by the fact that neuroendocrine cancers are uncommon, and each tumor is so unique. An insurance company may not have a solid understanding of what is medically necessary.

If your insurance company denies a treatment, you can appeal that decision. The appeals process depends on your insurance -- and there are resources out there to help you navigate it, like Triage Cancer.

Doran: *We have a lot of resources to help people understand the step-by-step appeals process based on the type of insurance that they have. But if somebody doesn't*

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remember that Triage Cancer exists, they can always start at their state insurance agency, which can guide them towards the process based on the insurance that they have.

And of course, it's important to talk to your care team. They can be one of the most helpful resources to navigate medical bills: they can help you with an insurance appeal, and you may have access to a financial advocate at the hospital.

As a clinical pharmacist, Sasha Watson is part of this process all the time.

Watson: *Let us know, and just know that we are here. We want to help fight for you and fight with the insurance to let them know why we think you need this treatment. Like, even today, I was able to get a patient's treatment approved.*

Paying for treatment can be complicated, but your care team will work with you to make sure the cost is as manageable as possible. The most important thing is to talk to them about it.

Watson: *Tell us, tell your treatment team if you are having financial issues. We don't want you coming back to clinic and saying, 'I have huge debt now, I ran out of money. I can't afford my rent because I paid for my last month of my oral chemotherapy.' You know, that's really devastating. And we want to do everything we can to help prevent that.*

Of course, medical bills are not the only part of cancer treatment that costs money. Other major costs could include things like travel, lost wages, childcare, and mental health support. Piling these on top of medical bills can make an already stressful situation overwhelming.

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Fortunately, there are some resources to help with these costs, too. These might be available through your hospital, community, or state, and will vary depending on where you live.

Motz: *I would make sure that you're asking the questions through the social worker, the pharmacist, and your primary oncologist about not only patient assistance programs for your medications, but if there are resources for transportation assistance or childcare assistance, how to get assistance with different types of regular-day life.*

One kind of assistance you may be able to access is for travel. With neuroendocrine cancer, you may need to travel a long way to see a specialist or get a procedure done. Some hospitals offer resources like gas cards or lodging assistance.

Some employers may also have programs that can help with travel costs.

Motz: *There was a program through one of the insurance companies, at a previous employer that I had that they actually would help cover like the maintenance of the vehicle if they had to travel so far for treatment because we lived in a very rural state where it could be a two-hour drive for treatment.*

Sometimes a spouse's employer will cover some of these costs as well.

There's also the Hope Lodge program, which offers cancer patients and caregivers a free place to stay during treatment. There are more than thirty Hope Lodge locations around the country.

Powell: *You do need a referral from your treatment team, whether that's a nurse, provider, social worker, they'll*

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send that referral to Hope Lodge, just verifying your appointments. And you can stay there the night before any appointments and the night following any appointments.

If Hope Lodge isn't available, there are often other local options.

Powell: *Ask if they've got something. If it's not a Hope Lodge, they might have something else.*

In addition to help with travel costs, there are many different kinds of financial assistance programs out there that you may be able to access. Joanna Doran with Triage Cancer encourages patients to think as creatively as possible when exploring their options.

Doran: *Sometimes when people have high medical bills, they're only looking for financial assistance that help with medical bills. But if you qualify for a utility assistance program where you live, maybe you can get help with your utility bills and be able to use that money that you're saving for your medical bills.*

No matter what your financial situation is, there are resources out there to help alleviate the stress that comes with cancer.

Doran: *I think many people assume that they don't qualify for assistance programs, and we always take the opinion that it never hurts to try. It doesn't hurt to apply for programs or to look into the options that might be available to you and to not assume that you don't qualify.*

Just like with treatment costs, the most important thing is to start the conversation with your care team. They can help direct you to the resources that will be most helpful to your specific circumstances.

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Motz: *It's not about how much you have to pay. It's about getting the help you need during a time that everyone wants to be able to help.*

Once you have navigated paying for your initial treatments and the related expenses, there's a third stage of financial well-being to consider: long-term planning.

Neuroendocrine cancer can take many different forms, which come with many different costs. If you have a more aggressive cancer, you may pursue an intensive treatment plan that frontloads these expenses. However, many kinds of neuroendocrine cancer are slow-growing, and can be kept at bay for years with regular treatment.

Motz: *So because they are slower growing, you have much longer treatment timeframes. There are patients that are getting 20 and 25 years of taking an injection for this treatment, and it's a monthly injection.*

This, of course, costs money. There are also expenses related to scans, bloodwork, and other appointments.

Motz: *So this long-term planning takes more money over time.*

Planning for these costs is like budgeting for any large expense, like a mortgage, car payments, or saving for retirement. *Unlike a house, a car, or retirement, no one expects to have to pay for years of cancer treatment.*

Adjusting to this new reality can be a huge shift, and it can be helpful to work through it with a financial planner.

Motz: *They would be very helpful, I think, for making sure that what you need over the next 10, 15 years can be addressed without draining savings and retirement funds that you're going to need even though you have to since you're living longer, you're going to want those, you're*

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still going to want to retire and enjoy your family and traveling and doing those things. You just are going to do it with this treatment and this long-term plan.

There are a number of organizations that offer pro bono financial advising for people living with cancer and other diseases.

And you can find more advice for your specific situation by talking to others who are going through the same thing.

Motz: *There are multiple support programs that our patients have utilized and they've just, in a normal support meeting, have had a conversation with another person that, 'Oh, well, I'm a tax guy and I do my taxes this way, and this could actually benefit you if you would, if you listed your treatments in this way.'*

So there are different resources inside of your support groups that you may not have known about or thought about and talking to others and seeing what they have done because they've been living with it is your biggest resource, especially when it comes to money and long-term treatment plans.

Some people may be able to continue working, but for others, this becomes challenging. If you are unable to earn a living the way you did before your diagnosis, it may make sense to explore disability insurance. Disability insurance benefits are offered by the federal government, some state governments, private companies, or through employers.

Like with many of these options, it will depend on your unique set of circumstances.

Powell: *Neuroendocrine cancers are not, unfortunately, an automatic qualifier for social security disability, so it's a case-by-case basis depending on the impairments that the cancer has.*

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To learn more about all the options that might be available to you, we will link in the show notes to many of the resources we've talked about in this episode. They'll provide more specific information about programs and assistance that might be available to you.

We'd also encourage you to visit Triage Cancer's website, where you'll find a comprehensive guide to navigating employment, insurance, & finances, among other resources.

Doran: *We do a lot of vetting to make sure that we're pointing people towards financial assistance resources that are going to be useful to patients and their families. So if people do have questions about their individual situation, they can find that information on our website. People can attend our educational events for free. And then we also have a free legal and financial navigation program where people can contact us with their one on one questions about their individual situation.*

Matt Skinner, the filmmaker we met at the top of the episode, recently had a meeting with his financial advisor. He was diagnosed with neuroendocrine cancer a few years ago, and has been in a pretty good place following his treatments. But the way he thinks about his life and finances has changed completely.

Matt Skinner: *You know, the question comes up, how long will I be fighting this? Can I get 5 years, 10 years, 20 years? You know, how long will I live? Then how will my finances come into play for that?*

And I still don't know what will arise. And at what point does insurance, you know, when did things change with insurance? When does that battle become more intense? I don't know.

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Matt says the future can be scary, especially when it's this uncertain. But he works hard to live as fully as he can, and not let worry take over.

Instead of saving every penny for potential medical expenses, he and his wife decided to go on a trip to Europe together. And he focuses as much as he can on the world around him: nature, art, and most of all, other people.

Matt Skinner: *Nobody's going to remember what movie you made 10 years down the road, what your salary was 10 years down the road. They're not going to remember that award you got at work 10 years down the road.*

The only thing that matters that I have found are the relationships that you have with family and friends, those that are rowing the boat with you. And it's so important because that will affect the quality of your life.

And one of the best things about all that, Matt says, is that it doesn't cost anything at all.

Thanks for listening to NETWise. I'm Jessica Thomas, Director of Patient Education at NETRF.

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Special thanks to everyone we interviewed for this episode. We are grateful for your expertise.

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