Episode 24:
Gynecologic NETs
Transcript

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Welcome to NET Wise. This is a podcast for neuroendocrine cancer patients and caregivers that presents expert information and patient perspectives. My name is Jessica Thomas, Director of Patient Education at the NET Research Foundation.

Today, we're going to pick up again with our series looking at all possible NET primary sites, with a conversation about one of the very rarest forms of NETs - those that originate in the female reproductive organs.

Here's Dr. Michael Frumovitz, a gynecologic oncologist who serves as Chief Patient Experience Officer at MD Anderson Cancer Center in Houston, Texas. He's regarded as one of the leading experts in the country on gynecologic NETs

> ***Frumovitz:*** *"It's really rare. So, if you think about gynecologic oncology and the areas that we take care of, it's vulva, vagina, cervix, uterus, ovary. Of those five, the cervix is the most common place for us to see neuroendocrine*

> *carcinomas, and it accounts for about 1%, maybe 2%, of cervix cancers in the United States.*
>
> *If you think about cervix cancer as a fairly rare disease to begin with – about 12,000 cases a year in the United States – and then you think, okay, 1 or 2%, you're looking at maybe 150 to 200 cases a year in the entire country for cervix. For uterus, ovary, vulva, vagina, it's even less: for those uterus is probably 20% of that, ovary probably 10% of that. With vagina, we see maybe 50 to 100 cases a year. So even across all the gynecologic organs, it's an incredibly rare disease."*

And these diseases almost always behave very differently from many of the more widespread forms of NETs, like those with primaries in the GI tract. For one thing, these NETs almost never express somatostatin receptors, which means that a wide range of popular NET treatments – like somatostatin analogues and PRRT – would not be effective, nor would gallium 68 dotatate PET CT scans.

> ***Frumovitz:*** *"We actually did a small study here where we did immunohistochemical staining for the somatostatin receptor on 25 or 30 neuroendocrine cervical cancers, and it was like 0% expression of that receptor. There doesn't seem to be a lot of that applicability of what they're doing in the GI NET tumors."*

Other differences between these cancers and more common forms of NETs is that they often appear in younger people - frequently women in their 20s, 30s, and 40s - and they are often discovered because of uncomfortable physical symptoms. A common one is vaginal bleeding after sex.

> ***Frumovitz:*** *"There doesn't seem to be a premalignant state for the neuroendocrine carcinomas. Occasionally they're picked up on Pap smear, but more frequently it's symptoms. These usually*

present as bleeding or discharge. The kind of classic sign is post-coital bleeding."

And with the exception of ovarian NETs, which can occasionally be low-grade, gynecologic NETs are almost always high-grade and extremely aggressive.

> ***Frumovitz:*** *"These are almost 100% high-grade neuroendocrine carcinomas, either small cell, large cell, or not otherwise specified. In fact, if a patient has a low grade – like a carcinoid or an atypical carcinoid on their cervix – you have to basically prove that it's not starting somewhere else before you can say it started on the cervix. And I would say in my 20 years doing this, I've only once seen a true carcinoid of the cervix in all that time. So, if you have a lower grade net tumor, it's almost always going to be from somewhere else."*

As you may have noticed from that "small cell/large cell" terminology, Gynecologic NETs do resemble another kind of NETs - those that start in the lungs.

> ***Frumovitz:*** *"They do look the same under the microscope. They do behave equally aggressively. And if you look at the history of how we've treated these diseases in the gynecologic tract, it's always been from taking paradigms that they use in lung cancer and applying them to these patients."*

This treatment regimen will often begin with surgery, if possible, and then move immediately to the kinds of treatments we most associate with aggressive cancers - chemotherapy and radiation. In what follows, we'll mostly concentrate on describing a treatment course for cervical NETs, but the courses for other kinds of gynecologic NETs are generally quite similar.

> **Frumovitz:** *"We think about patients in four groups: local and small, meaning on the cervix only, and small, less than four centimeters; local and big, like on the cervix only but bigger than four centimeters; locally advanced, which means spreading out past the cervix and limited to the pelvis, so even lymph node spread we would say is locally advanced; and then metastatic or distant. So in those four groups, the stages 1A through 1B-2, which would be the local and small – less than four centimeters – those we start with surgery almost always, and we'll start with the radical hysterectomy."*

Hysterectomies are one of the most common surgeries performed in the United States – around half a million every year – but we haven't had a reason to discuss them yet in this series, so let's talk a little bit about what they are. To do that, let's start with a little anatomy.

A woman's reproductive system has six main parts: first the vulva, which is the externally visible part of what most people call the vagina, and then the vagina itself, which is an expandable hollow tube, also called the "birth canal", behind the vulva. Then at the other end of the vagina is the cervix, which is a kind of muscular gate blocking the entrance to the uterus, an open area where conception happens and a fetus can grow. Then there are two sets of Fallopian tubes which connect the uterus to the ovaries, the twin organs that store a woman's eggs and produce several important hormones, including estrogen.

A hysterectomy is surgery to remove the uterus, and there are three main kinds: a "partial" hysterectomy removes just the uterus; a "total" hysterectomy - also called a "simple" or "complete" hysterectomy - removes the uterus and cervix; and a "radical" hysterectomy removes the uterus, cervix, and part of the vagina, as well as surrounding lymph nodes and other tissues. It may or may not also remove the ovaries and Fallopian tubes, depending on the circumstances.

These are major surgeries, and they have significant consequences for the women who have them. When you've had a hysterectomy, it is no longer possible to bear your own children, and if your ovaries are also removed then options like surrogacy are also no longer available, unless there was time to surgically harvest and store your eggs before operating. Removal of the ovaries also has serious hormonal implications – basically beginning menopause early, with all the symptoms that entails.

And unfortunately, this surgery is almost always only the beginning of a very grueling treatment course for women with these NETs.

> ***Madsen:*** *"My name is Stephanie Madsen and I live just north of Austin, Texas. I'm 35 and I will be 36 in January. So, I was diagnosed at 25 with a large cell neuroendocrine cancer in my cervix.*
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> *So, I was obviously very young, and I was symptomatic for a year and had been to several different doctors. I had cramping. I had stomach pains, back pains, lethargy… very exhausted. My immune system was shot. I had bloating. I had vaginal bleeding after intercourse – just so a bunch of symptoms that I guess if you take one and you say, 'I'm exhausted' as a 23-, 24-year-old, a doctor could say, 'Well, you know, slow down, maybe don't work so much'. Or if you're having stomach cramps, you know, 'Let's talk about your period and get that figured out with birth control', or 'You're newly married and so you're adjusting to emotionally, like, being in somebody else's space and they're being in your space'.*
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> *But in my gut, I just knew something was going on. After a year of not getting any answers, I was just basically pleading*

with doctors, like, 'Please, can you do a scan? Can you do an ultrasound?' By the end of the year, I started homing in, just personally feeling that it was in my reproductive system, like something was going on down there. And so, I eventually got a different gynecologist who did the exam and did a normal Pap smear, and she found what she initially thought was a fibroid, and it was essentially coming through my cervix. So, my cervix was a little dilated with what turned out to be the tumor. Her initial diagnosis was stage 2B cervical cancer.

Two weeks later, I had a radical hysterectomy. And so, when they did that, she tested off all the tissues and stuff and found that it had spread to one lymph node, I believe… one or two. And then obviously I was diagnosed with high grade stage three large cell neuroendocrine carcinoma of the cervix.

Radical hysterectomy… immediate chemo as well as external radiation. And then I was… I had a clear PET scan. And then within three months, I felt another mass in my stomach. And at my next scan I had a softball size tumor on one of my ovaries. Biopsy came back… same high grade neuroendocrine. So, my first recurrence was the softball size on my left ovary. The second recurrence was, I believe, a pea- size on my right ovary. Third was the left adrenal gland, so they ended up taking my left adrenal gland. And with each recurrence I would have intensive surgery, usually like a week stay in the hospital, and then would recover for about two weeks and then go straight to chemo again.

My fifth time through this last time was in the muscle of my back. Which, yeah… which left my doctor very… scratching his head as to, it's… we like to joke I'm like the rarest of the rarest because of just how mine has moved. And I'm thankful in that regard because, well, all of my recurrences and tumor sites are in removable parts.

> *So, the quickest way to say this is I have been fighting on and off for the last 10 years. I have had 83 chemotherapy treatments. I've had 28 external radiation treatments and five major surgeries. I'm currently almost the longest I've been cancer free, which my… I call it my 'PR' with my oncologist – 'I'm about to hit, my PR' – is three and a half years. And so, my three-and-a-half-year mark will be in April sometime."*

After surgery, or if surgery is not possible, the next steps are almost always chemotherapy and radiation therapy. Let's talk about each in turn.

Chemotherapy drugs are basically controlled poisons that kill cancer cells by damaging their DNA. The ones most commonly prescribed for gynecologic NETs are medicines we've heard about in previous episodes as treatment options for other kinds of high-grade NETs.

> ***Frumovitz:*** *"So we use, for almost all of our… regardless of the gynecologic site, we usually use cisplatin and etoposide. That was stolen from the lung literature, but it seems to work.*
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> *Cisplatin, as a drug is very mitogenic, so it can cause a lot of nausea. What I tell patients is If we don't do anything you're going to have a lot of nausea, so we're going to do a lot to prevent it. So, it's not that if you get nauseous, take these medicines' we tell patients, 'take these medicines so that you don't get nauseous'.*
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> *Unfortunately, hair loss is another side effect that we see. And then the other main one, for the combination at least, is toxicity in the bone marrow. So, low white counts, which can make a patient susceptible to infection; low red counts, which*

is anemia, which can make patients fatigued or tired; and then low platelet counts that can make patients susceptible to bleeding, if they… if the counts go really low."

Madsen: *"Chemo hit me hard. It hit me hard.*

Initially when I was diagnosed and going through chemo, I had no clue what to expect. In my naivete, I thought, 'Okay, I'll get chemo. I'll get surgery, I'll be done, and we'll just go forward with life, and it'll be great', and that's what it would be. So, I'm thankful I didn't know that that's not at all what it would be like.

My life kind of stopped in that regard. I stopped working. I just really was full-time focusing on healing my body and being in chemo and doing what it took to, to get better and to be cancer free.

So, I would go from chemotherapy in the morning for four hours, and right afterwards I would go up to the second floor of the hospital and then go straight into radiation. And I did that for 28 consecutive days. And so, I was already tired and exhausted from chemo and just bloated and yucky. When people who have never had cancer want to know what chemo feels like, I say it's like the worst hangover of your life. And I was also on Neulasta and Neupogen, which is its own thing. That's a medicine that boosts your white blood cells in your bone marrow. So, it quite literally feels like your bones are exploding and… and I would just feel like I got hit by a semi-truck. But I had to get up every day and go to chemo and go to radiation and do it again, because you do what you got to do.

So my first round through chemo – my first, I call them seasons, because I feel like there's just been so many – my first time through chemo, I lost my hair. The second time *through chemo, I lost my hair. Third, same. Fourth, same. So that was a whole nother experience. I think there's a big, attachment as people in general, but especially women have to their hair. So that was a big, grief and a big loss to lose my hair at 25 years old.*

And then this fifth time that I went through chemo, I actually did 'cold capping' this last round. Which, in a nutshell is you put a freezing gel cap on your head, and so there's no heat in your scalp when it's freezing and there was less blood flow, so the chemo couldn't go through that space. And so, it essentially preserved my hair. So, I did lose about 50% of it, but I have very thick hair, and so I could get away with just wearing hats and nobody really would be none the wiser. I still lost my eyebrows and my eyelashes and all the rest of my body hair. But that for me was a whole new experience this last time doing cold capping because it really, it saved my hair.

And it was brutal to go through. When people ask me like, 'was it worth it?', I say yes, but that's a twofold answer because it took a lot of effort. I had to have a partner come with me to chemo every time, so whether it was my husband or my brother or a friend, and they would have to rotate out these cold caps every 15 minutes for the duration of my chemotherapy, and then six hours after chemotherapy. So I would be in a freezing cold cap – and I mean freezing – so I would have to wear, like, wool socks and wool coat in the middle of therapy just so that I wouldn't, like, essentially get hypothermia.

So, it was worth it to me, but it's not the best choice for everybody. and you just kind of… I think you just have to make the best decision for you in terms of any care and treatment and moving forward in your care plan with cancer."

Often, chemotherapy is administered in conjunction with radiation therapy, which can be an extremely challenging experience for patients.

> **Frumovitz:** *"When we talk about radiation for cervix cancer, it's in two, kind of, phases. There's what's called 'external beam', which is where the patient comes, they lie on the table, the machine goes on, around them or on top of them, beams the radiation through the tumor sites. That's about half the treatment, is that external beam, and then half the treatment is what's called 'brachytherapy' or 'internal radiation', where we're able to give very, very high doses of radiation right up against that tumor by putting radiation into the vagina. And we're able to do that and for the most part spare the surrounding organs of the bowel and the bladder and the other things that limit the amount of radiation you can give in other manners."*
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> **Murphy:** *"I'm Danielle Murphy. I live in Dacusville, South Carolina, which is a small town right outside of Greenville, South Carolina. I am 39. I'm a nurse, and I have two girls, 19 and 11. I was diagnosed with high grade small cell neuroendocrine carcinoma of the vagina, stage 4-B.*
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> *So, in March of last year, I was kind of worried because I started losing weight. So, by July, I had lost like 20 pounds, and then by the end of June, I found a mass. It felt like I had a tampon in, and I knew I didn't, so I just stuck my finger, and I found a lump. And of course, got out the mirror, as us nurses do, and I saw this growth there, and I was like, 'this is not normal'. So then I went to my doctor, and they biopsied it. And then they called me on July 6th to tell me that it was metastatic cancer.*

I was numb. I was just like, 'Oh my God'. Like, I've seen this so much in my practice – patients going through treatments and cancer – and I was just numb. I hung up the phone. I called my husband, and his exact words was, 'Well, that F-ing sucks'. I said, 'Yes. Yeah… yeah, it does'.

So, I started… got my diagnosis July 6th. PET scan, July 8th, which was the Friday, and then Monday I saw my OB-GYN, and Friday I was getting my port. And then I started chemo on July 18th, the day after my 39th birthday. We did chemo – it was three cycles, so carboplatin and etoposide – on Wednesday, and then just etoposide Thursday and Friday. And the plan was to do that Wednesday, Thursday, Friday regimen every 21 days, you know, with lab work in between and all the things, and then to start concurrent radiation treatment.

So then I met with the radiation oncologist the next week, and then she proceeded to tell me that it was going to be the worst experience of my life. It's going to be horrible because of the dose that she was going to have to deliver. We started talking about sitz baths and Vaseline, like, creams. I was like… I froze. And I said, 'Hold on, wait a minute'. I said, 'Radiation burns – that's what you're talking about?' and she said yes. Just weeks before I saw a patient with severe radiation burns to their perineal area and… - their bottom - and that was actually the worst radiation burns I'd ever seen. I said, 'I'm not doing this. I will do the chemo, but I'm not doing the radiation'. And she looked at me – she was an ICU nurse before she was a doctor – and she said, 'Nurse to nurse, you will do this. You're going to do it. You're going to do it for your kids. Let's just make the most of it'. So, I lost it… you know, cried… you know, all the things. And so there we went on our radiation journey.

I started August 18th with radiation, which was a couple days after I'd had chemo. And I will tell you, chemo's bad. Chemo… I had hyperemesis with my pregnancies, so I vomit nonstop. Like, sometimes I've slept on the bathroom floor. Like, chemo's bad, but the radiation burns? That's the part that nobody talks about. If I was not a nurse, I would not have correlated radiation treatment with burns. I don't know why… you just don't think about it like that, because you hear radiation, and you think 'X-ray'. X-rays don't burn.

The exhaustion, the burning. I mean, it felt like my vagina was on fire."

Madsen: *"I was not in the slightest prepared for radiation. I got external radiation and it was horrific. I mean, it was right in my pelvis area. So, radiation goes in and then it has to go out. So it… it would go in, zap everything up, but then the light would have to escape. And so I had a char mark – literally singed skin – right above my butt. And it was as awful as you can imagine just the description of 'charred skin' being. It was awful. So there was that.*

Because it was also radiation in my pelvic area, it stripped all of the tissues down there. So when I would pee, I would be screaming in agony. Because again, you don't know until you know, and I didn't know that your… our urine is highly acidic, and when you don't have tissues to protect your organs while you are urinating, it feels quite literally like acid coming out. That was probably my most brutal experience, was just the feeling of urinating acid. I would have to get ice packs. I would have to, like, talk myself up to go pee. It was a whole thing. And that's just a daily task that you take for granted. I mean, you know, you have to go pee. But when I was in radiation, it was definitely quite the feat to do."

> ***Murphy:*** *"So me and my peri bottle got very close. I did Epson salt baths with green tea bags. It was a recommendation. it helped… it definitely helped soothe. I made green tea and put it in my peri bottle. And they have spray Aquaphor now, so I used that - Dermoplast, the spray that a lot of moms know because they've had vaginal deliveries… but I had C-sections, so I didn't know, I never went through anything like this in that area. My daughter, who was 19, was pregnant, so she was on pregnancy TikTok, and she's, 'Oh mom, they have this stuff, like, after I deliver, if I tear, then use the stuff'. And so, we went on a search for Dermoplast, and sure enough, there's like 17 different kinds… but that really, that really helped.*
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> *Completed radiation October the 25th and… a two-week period after, the ulcers started healing up and the sores were gone. I do still have the tanning, which they said may or may not lighten. The fatigue is getting better slowly, but of course I'm still doing chemo, so there's those… but the good thing about that is it's every 21 days, so I do have some time in between now that I'm just doing the chemo to recover more. So that's nice.*
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> *The main tumor on my vagina had resolved and then the lymph nodes from my groin, my abdomen, my chest, my hilar lymph nodes, all those were clear on the CT scan. So that was great. The one nodule that was on my lung has gotten smaller. We did incidentally find more scattered micro nodules, they called them. We decided that we are going to continue with the chemo and do three more rounds of chemo and then do another scan and see what happens."*

For a long time, those really have been the only three treatment options for these cancers - surgery, chemotherapy, and radiation. But now there is some promising clinical research being done into the effects of immunotherapy.

(Patient Story #3)

Wilkinson: *"My name is Courtney Wilkinson. I am located in Dallas, Texas. I am 32 years old. I was diagnosed when I was 28 – so July 2017 – with small cell neuroendocrine carcinoma of the cervix.*

I actually was misdiagnosed. Originally, I was diagnosed with uterine cancer. I went for a second opinion at MD Anderson. They discovered that it was cervical and small cell, and things moved really quickly after that. That was on a Thursday. The following week on Wednesday I was having a radical hysterectomy.

It was a lot to take in. I've always wanted children and so that was a really, um… I didn't have time to freeze my eggs or do an egg transport, I think that's what they call it. So, I didn't have any of those options and things moved very quickly.

It was really scary. A lot of praying happened, a lot of reaching out to my close friends. But yeah, it was quite terrifying and I'm very much of a control person, and it was hard grasping that I'm not in control of this.

After my first surgery, we were going to – with it being as rare and aggressive type of cancer as it is – throw the kitchen sink at it, so to say. And then this year, 2022, I started in March, I started on immunotherapy.

As far as I'm aware, I'm one of the first people that have done the immunotherapy with my type of cancer, or at least with my doctor… and kind of both went in blind. Why I went to immunotherapy is that chemotherapy was starting to get really

> *hard on me, and I was not really tolerating it very good. I was staying in bed a lot of the time. I was having a reaction where I had open wounds all over my body. I was having to get in and out of… help out of bed. I was going into the hospital a lot and they weren't able to figure it out. And so, we were looking at a couple of different treatment options and insurance only approved this one.*
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> *I do immunotherapy every two weeks currently. And there's a lot of side effects that come with it. From what I was told there could be a reaction with your thyroid, inflammation in your… inflammation all over your body, but especially your eyes that could change your vision or blur your vision. The only side effect that I have really had, since I've been doing it since March, is fatigue. I spend my lunch breaks taking naps. I take naps on the weekends. That's been my big one.*
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> *I am feeling a lot better now, and last week I just had my first 'No Evidence of Disease Anywhere scan'. Yes, very happy news. And I'll stay on the… treatment plan right now is to stay on this immunotherapy for two years. So, I don't know long term if I'll stay on it longer, but right now, two years is the point that they keep you on it and adjust if you're doing well."*

It's good that new therapies are being researched and developed, because unfortunately the current long-term prognosis for women with gynecologic NETs is not what we would hope for.

> ***Frumovitz:*** *"The cure rates are… they have a lot of room for improvement. So, for those patients who have disease that's found early - so small tumors limited to the cervix - the cure rate is somewhere between 55 and 60%... somewhere in there. If you compare that to the more common squamous and adenocarcinomas of the cervix: those patients, the cure rate*

> *is probably closer to 95%. So it's still… It's better than 50%, but it's not nearly what it is for other types of cervix cancer.*
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> *For those patients with the locally advanced disease – the patients who are going to get treated with radiation and chemotherapy and no surgery – it's probably in the 20 to 25% range. And those patients who have metastatic disease, it's less than 5%."*

New research is being done, though, and particularly in the last decade, progress has been made.

> ***Frumovitz:*** *"So, I would say that this tumor or this tumor type 10 or 15 years ago was essentially completely… no one knew what to do with it. And when you showed up to your doctor… and I heard this from a lot of patients, they said, 'I would show up to my doctor and he'd say', or she would say, 'I've never seen this before. Let me call around and see what I might want to do', which is never reassuring for a patient when their physician says, 'I've never seen this before. I don't know what to do'.*
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> *I think in the last 10 or 15 years, there's been a lot of research on this. These tumors… there's been a lot of publicity about these tumors. I think it's pretty rare now for someone to show up to their physician and their physician to say, 'I've never seen this' or 'never heard of this'. and I think we've – because we've been able to put a little bit of a spotlight on the disease – we've been able to improve outcomes. I think patients are living longer now after diagnosis is being found earlier and therefore more treatable, and I think there's a lot of resources for patients now once they're diagnosed, and there's a lot of support out in the community for them. Being diagnosed today, your prognosis and*

> *your support are much better today than they were 10 years ago."*

One of the most promising breakthroughs on this disease is actually not in treatment, but in prevention. Perhaps uniquely for neuroendocrine tumors, there is very strong evidence that these cancers can be prevented by taking an existing and widely available childhood vaccine.

> ***Frumovitz:*** *"We think more and more now, even the neuroendocrine tumors of the cervix require an inciting event, and that inciting event is an HPV infection. Like squamous cell carcinomas or adenocarcinomas, we say HPV is 'necessary but insufficient', meaning all of those cancers will have had an HPV exposure, although not all people who get HPV will develop cancer.*
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> *The HPV vaccine was originally developed and marketed as a cervix cancer vaccine, but we now know there are lots of other HPV associated cancers, such as not just gynecologic cancers – vulva and vaginal cancers – there's also penile cancer, head and neck cancers… HPV associated head and neck cancers. And one of the big studies, their summary conclusion was HPV vaccine will prevent these neuroendocrine cancers, just like it prevents squamous carcinomas or adenocarcinomas. So there's lots and lots of reasons to get the HPV vaccine.*
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> *There are a lot of vaccine skeptics out there in general. With the… with all of the politization of the COVID vaccine, there have been more vaccine skeptics. but the HPV vaccine should really be a no-brainer for anyone who has children between 12 and 26, basically, both boys and girls."*

If you're living with gynecologic NETs, please keep this progress in mind, and remember that you’re not alone. Treatment options will continue to improve, and even now, women are living longer and stronger with this disease than they ever have before.

Please keep in mind also, that sometimes what seem like firmly closed doors can find new ways to open.

> ***Madsen:*** *“When my husband and I initially got married, I think we talked about having children, or starting to try to have children, and so we were simultaneously in the process of actually conceptualizing what that would look like to try to have a child when I got hit with my diagnosis.*
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> *And because my initial diagnosis only led to a radical hysterectomy, and they tried to preserve my ovaries, there was still hope that I would somehow be able to harvest eggs later and go through a surrogate or something like that. So, I remember checking my… having my oncologist check my FSH levels, and all of that, right after my first season through chemo. And… was still very hopeful, l and was like, ‘It's not going to be the way we thought it would be, but there still might be a chance’. And then when my levels came back and she said, ‘Even though we moved your ovaries, like, all the treatment you've been under… it's not going to be really conducive to harvesting any viable eggs’.*
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> *And so that also switched our perspective, but I will say we have always thought about adoption and we are now parents, through adoption. So, we have a four-and-a-half-year-old, who is amazing, and the long story short is to say, you know, we always had that dream of being parents and we were determined to be parents and we thought it would be one way, and it wasn't that way, and it was something else.*

And that makes us sit… very often we will have a moment of reflection where we'll look at each other and say, 'Can you believe we're here'? My doctor gave me nine months to live 10 years ago, and not only am I alive, but our marriage is thriving, and we have a four-year-old.

A lot of plans got put on pause when I first got diagnosed, and now to just look at the big picture and see, like, what your life would look like, and maybe dream about your future life, but really like it's just going to fall into place how it's going to fall into place. We ultimately don't have a hundred percent control. And if you have the perspective to view it as - and this doesn't take away the pain or the trauma or the heartache or anything - but as an adventure of 'what doors will open'? We thought it would be one way, and it's a million times better in many aspects than what our tiny little baby brains could have thought when we got married at 23 and 24.

And I have high hopes that I will be a grandma one day and my husband and I will… 20, 30, 40 years look back and be like, 'Wow, can you believe that'?

Wilkinson: *"We got married after the initial diagnosis. My husband proposed after my first scan came back good in 2017. And I was so worried that if it came back that I could ruin his life… or I guess… I don't want to say run his life, but definitely it would affect his life a lot more. And I knew what the recurrence rate was and it also became more real after the dust settled that, you know, I couldn't have children of my own, and so I was really nervous about that.*

And so we got engaged in December and then we had a small wedding. I wasn't looking what I wanted to look like on my wedding day. I had no hair, hardly, and I just didn't feel *what I thought, I was going to look like getting married one day and… yeah, it was wonderful. it was a beautiful wedding and we're still happily married and living life.*

I just didn't know, kind of, what life would lead. And like, getting a stage-four cancer and knowing that I was going to be on treatment all the time, I was like, 'I'm not going to be able to live a life'. But like I said, I still am able to work. We go on vacations and travel together and still have fun times with our friends. We can't go on every trip and night-outs with our friends, we might start dinner at six o'clock instead of eight o'clock. And I… we don't go out with them maybe all night, but we're still able to live a pretty normal life. For that I'm thankful."

Murphy: *"Some weeks I have more good days than bad days. And in those weeks, I feel like I accomplished my goal. Like, I defeated it in a way. You know, it didn't get me this week. And I have… I keep track of it on my calendar. I have a green smiley or a red smiley face to monitor what's going on.*

I did say to my daughter yesterday morning, on the ride to school, I said, 'It sucks having cancer'. I said, 'You know, I'm about the bright side of things', and she's like, 'Well, you know, Mom', and I said, 'I still get to spend the days with you guys'. And you know, she just loved that. You know, she's like, 'Oh God'. She says, 'How long are you going to be home? When do you get back to work, Mom'? So, you know, we're just looking towards the future and living one day at a time right now, sometimes one minute at a time, and just really… being hopeful."

Thanks for listening to NETWise. I'm Jessica Thomas, Director of Patient Education for the NET Research Foundation. Our Production Partner for this series is CitizenRacecar. This episode was written and produced by David Hoffman; Post-Production by José Miguel Baez; Production Manager, Gabriela Montequin. It was made possible by the generous support of Ipsen. If you would like to join NETRF in our mission to fund research for NET cancer or help support educational programs like this NETWise podcast, please go to netrf.org/donate

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