Caring For A Partner With Dementia
This podcast does not provide medical nor legal advice. Please listen to the complete disclosure at the end of the recording. Hello, everyone, and welcome to Everyone Dies, the podcast where we talk about serious illness, dying, death, and bereavement.

I'm Marianne Matzo, nurse practitioner, and I use my experience from working as a nurse for 44 years to help answer your questions about what happens at the end of life. And I'm Charlie Navarette, an actor in New York City, here to answer questions that you may have while listening to our podcast. We are both here because the more you plan, the better prepared you will be to make life-altering decisions.

So please relax and get yourself something to eat and drink, and thank you for spending the next hour with Charlie and me in our multiverse as we talk about loving and caregiving for a partner with dementia. In the first half, Charlie talks with us about the death

of the Pennsylvania's forgotten funeral pie, the sweet and somber treat of extravagant 19th-century funeral feasts. He also has our recipe of the week, and I bet you cannot guess what that's going to be.

Wait, can I guess? In the second... Huh? Can I guess? No. How many guesses do I have? In the second half, I'll be talking about what can be involved when caring for a partner with dementia, and we have an interview with Michael Porter, who talks about his experiences caring for his wife, Janet, with Huntington's disease. So Charlie, the funeral pie has died? Oh, actually, yes.

It's not impossible to find, but near impossible to find. It's dead. It's like poor Jed in Oklahoma.

It's dead. It was... Poor Jed is dead. Oh, Jud, not Jed.

Yeah, there we go. Mr. Theater. Yes.

Yeah. It just, you know, fell out of flavor. Flavor.

Maybe flavor, too. But yes, nowadays, people pretty much have to have it. You have to order it.

You just can't go to your grocery shelves anymore. So with that, let's delve into the history of this bad boy. Live from Castro Obscura, the death of Pennsylvania's forgotten funeral pie, the sweet yet somber treat of extravagant 19th century funeral feasts.

In August 1880, a coffin containing the body of Christian Eyre led a procession of 1,500 relatives, friends, and members of the congregation to the Old Mennonite Church in Millersville, Pennsylvania. Additionally, many funeral runners, a type of mourner that often popped up at Pennsylvania German memorials in the 1800s. These attendees weren't there to pay their respects.

They were there for the food. Culinary historian William Woys Weaver states, it was so common that you didn't even raise an eyebrow. The star of the funeral banquet was raisin pie, a dish so tied to the event that it became a euphemism for death itself.

When an ailing member of the community took a turn for the worse, you were sure to hear someone say, there'll be raisin pie soon. In 19th century Pennsylvania German homes, raisins meant one thing. Death was near.

Friends and neighbors would cook, clean, and bake raisin pie, which became known as funeral pie. Nancy Schmeichel, a historical reenactor, bakes her own raisin pie in an open hearth at the Landis Valley Village and Farm Museum, much the same way the site's founders baked a funeral pie centuries ago. Her recipe combines a flaky, lard-based crust with a subtly sweet, inky black filling of raisins, sugar, lemon, egg, and flour.

Raisins were a luxury in the 1800s. Prior to the seeding technology, producing raisins meant a thorough process of removing grape seeds by hand. Memorial banquets would feature multiple raisin pies and each recipe called for a pound.

Schmeichel says it was an absolute labor of love. Breaking bread after the death of a community member is an ancient tradition that transcends cultural and geographic boundaries. The meal was a way to socialize with the community, to bring everybody together under one roof and feed them.

This was tied to the social mores of the era. Providing the meal was part of an unspoken rule of hospitality. Since many guests were making the journey from far away, it was only right to host a mega-sized feast.

Funeral attendants would often number in the hundreds, occasionally in the thousands. People commonly ate in shifts. Generously feeding these large groups was also a display

of status, but people who didn't have the means either went into debt or leaned on contributions from neighbors to achieve a respectable spread.

Families were bankrupting themselves on these funerals, Weaver adds. But funeral feasts continued, although with altered menus. By the mid-1900s, mainstays like funeral pie had begun to fade away.

Today, most descendants of Pennsylvania Germans have swapped out raisin pies and stewed chicken for a casserole or pizza. As raisin pie disappeared from funerary tables, it has also faded from Pennsylvania's cultural consciousness. By the 1910s, younger generations no longer associated it with death.

It can be hard to find a raisin pie in bakeries today. Even in Pennsylvania Dutch country, you need to special order it. Mr. Weaver says it's nice to enjoy a slice without the traditional accompanying sadness.

It's great, he says, but I don't want to have a look at a dead body while I'm eating one. I'm sure Mr. Weaver meant the pie, not a dead body. I hope.

So, please go to our webpage for the recipe for raisin pie and additional resources for this program. You know, many of you have let us know that Marianne's expertise has helped you to better understand how we die and how to get there. So, we ask you for your support in the form of a tax-deductible contribution so that we can continue to offer you quality programming.

Thank you in advance for going to our website to make your donation, as well as following us on Facebook and Instagram. Visit us at www.everyonedies.org. That's every, the number one dies.org. Marianne? Thanks, Charlie. You know, as we head into our fourth season of Everyone Dies, we're beginning a series about caregiving for people diagnosed with dementing illness.

For the last two weeks, we've talked about frontotemporal dementia and we've previously produced podcasts about Alzheimer's disease, Huntington's disease, Parkinson's. As a nurse practitioner, I've spent a lot of time caring for people living with dementia, teaching nursing students how to care for people living with dementia, as well as supporting their care partners in their caregiving by facilitating support groups. The real experts about caring for people who are living with dementia, though, are the family members who do the caregiving 36 hours a day, every day.

So in talking about caregiving, we have a series of interviews for you with Michael Porter, who's allowed us to see what life is like and what he's learned about being a caregiver for his wife, Janet, who's living, who at the time we started these interviews, was living with Huntington's disease. If you don't know about Huntington's disease, please listen to our podcast about that disease. But

the Reader's Digest version of Huntington's is that it's a rare inherited gene defect.

There are about 200,000 people diagnosed with it a year, there is no cure, and there are about 10 to 30 years between diagnosis and death. The primary symptoms are dementia, movement issues, which are kind of similar to Parkinson's disease, and people also go through a violent period in the course of their illness. Many people do, not everybody.

In Michael's case, Janet had been living with the disease for 12 years, and at the time of the interview that I'm going to share with you today, was receiving hospice care at home. One thing I asked Michael about was how he balances his role as a spouse and as the primary caregiver. I think it's very worthwhile to listen to his answer about his feeling of his loss of place in his relationship with Janet.

He talks about the need to cultivate a new relationship with her, that of caregiver, and his need to pull away from his role of spouse, or

as he put it, he puts that role of spouse in a box and puts it on the upper shelf of the closet because it's just not used anymore. To him, the role of spouse is gone and replaced by the caregiver role. So let's have a listen to what Michael has to say.

Today we're going to be talking about a disease, and I don't know if a lot of people know of the disease or know what it's called, but we're going to be talking about a disease called Huntington's disease. And Huntington's is pretty rare. Statistics are there's about 200,000 cases per year in the United States.

So this rare inherited disease causes a progressive breakdown or a degeneration of nerve cells in the brain. Because it's happening in the brain, there are huge changes to the person, both in how they're able to function, take care of themselves, movement, thinking, and psychiatric disorders. Now, this is an inherited gene

defect, and it's what's called an autosomal dominant disorder.

There is no cure for this disease. What they can do is manage the symptoms as it goes along, but there isn't a cure. The numbers are kind of varied.

From diagnosis to death is about 10 to 30 years. Some people say 15 to 20 years, but people tend to be diagnosed younger. It can be actually anywhere between 6 and 80 years old that you can be diagnosed with this disease.

Now, childhood Huntington's is a whole kind of different disease outside of what we're talking about today, because today we're talking with Michael, and Michael's wife has Huntington's disease. Her name is Janet, and she was diagnosed 12 years ago at the age of 58. She has two siblings, and both of them have Huntington's.

Michael is now caring for Janet full time with hospice support. She's been on hospice for about a couple of months. So, Michael, welcome to Everyone Guides.

Thank you. So, I guess what would be interesting to our leaders is if you wouldn't mind talking about Janet's kind of lead up and diagnosis to Huntington's, because it's really kind of hard to exactly put your finger on that this is Huntington's. Now, if you know it's been in your family forever and that that could be a possibility, it might kind of say, oh, maybe we should look at that.

But if you don't, you might not stop to think, oh, maybe that's what this is. So, she was diagnosed pretty late kind of in life for Huntington's. Can you tell me about how that was discovered and how that was determined? Well, Janet was diagnosed as a result of the, excuse me, as the physical symptoms.

Her feet were twitching, her hands and arms were twitching. I mean, I tell people one of the big disappointments in my life was I'd be lying in bed next to her and I thought she was getting frisky and she was just sick. But they, you know, they tested her.

At first they thought it was recessed leg syndrome, then they thought it was this, then they thought it was that, then they thought it was something else. And finally, we went to a doctor and he was explaining all the symptoms she was seeing. And he said, no, there's something more involved here.

You need to see a neurologist. So, we went to see a neurologist and this was in Washington, PA. And I always like to give a shout out to Dr. Brian Katugna in Washington, PA.

He's like a, he was like a bulldog in a white, in a lab coat. He looked at her and he says, there's something going on, neurological. He says, I will figure out what it is.

You know, and I mean, she was tested for absolutely everything under the sun. And finally, you can't, we went in for a meeting and he says, look, he says, there's one disease we can look, we can still test for. It's called Huntington's disease.

And it's bad. And he gave us just a little bit of an intro to it. He says, it's hereditary, it's degenerative, there is no treatment.

But he says, go home, read up on it, get online, read up about it, and then come back and tell me whether or not you want to test for it. And so, is he going to do genetic testing? Is that what he was saying? Yes. Yes.

Okay. Yes. Yeah.

Unlike some other neurological diseases, like, well, Huntington's and Parkinson's, actually, there is a definitive test for Huntington's. And he, so we went home, we looked it up and we decided, well, you know, whatever it is we

need to know. We went back and she was tested and came back positive.

Yes, she does have Huntington's. But back before the physical symptoms started, back as long as Jack and I have known each other, and in fact, for as long as our children have been alive, we realized that there has never been a time when they did not know their mother when she was not experiencing symptoms from Huntington's. Really? Yeah, shortness of, yeah.

But then it showed up prior to the onset of the physical symptoms. It was emotional, mostly emotional, a few cognitive things. Emotional in terms of she, you know, very short flashes of temper, where she would get angry and would just blow up and two minutes later, it would be all gone.

Just like a firecracker going off. And then there's a symptom called perseveration, which is, it's like where your mind gets stuck on an idea and you just go back, going back

to it over and over and over and over again. And that was very prominent in our relationship, earlier relationship and in the kids growing up.

In fact, when the first conversation I had with my son about Huntington's, I was telling him about the symptoms that she was experiencing and that I was noticing. And his reaction was, well, yeah, but Ma's always been that way. Wow.

You know, and so it was just, you know, one of the advantages, if you can call it advantages, I mean, when Janet got her disease, got her diagnosis for the disease, it gave people a new perspective on her father. Because her father was probably the one she inherited it from. Yeah, really? Yeah, people just universally assume that her father was a ass.

He was a jerk. And everybody just assumed that's who he was. And then when Janet got her diagnosis, and they started looking at

what the symptoms was, it's, ah, well, maybe he was sick after all.

Maybe he was sick too. Was Janet an only child? No, she's got two siblings. So did anybody, oh, yeah, you told me both of the kids, both of her siblings did have, do have the disease.

Yeah, yeah. And so it's, and that's the thing about it. I mean, you have, if you, you know, you get, you inherit it from one of your parents, and you have a 50-50 shot of inheriting it.

And it was, I mean, most times people know about it, it's because they're musicians, basically, or they have somebody in their family with it. I say musicians, because Woody Guthrie died of Huntington's disease. And yeah, and it's a terrible condition.

And his wife, Marjorie, basically established what is today the HDSA, Huntington's Disease Society of America. And she founded

it, pushed for it, funded it. And it's a wonderful organization in the United States here.

But the thing about Huntington's is that even if you, is that it has a lot of diseases in, or a lot of symptoms, rather, in common with other conditions. For instance, dementia is a major issue. And, which it obviously holds in common with things like Alzheimer's and Lewy body and, and those sorts of things.

And then you have the uncontrolled body movements, which it has sort of in common with the, with Parkinson's. Parkinsonian movement is different, though it tends to be more like tremors, you know, fine motor issues. Whereas Huntington's tends to be large, you know, more gross motor movements, like uncontrolled shrugging, or your whole arm or your whole leg flopping around.

And I've seen, you know, folks with advanced stages of Huntington's in special wheelchairs

that they literally had to be strapped into. Otherwise, the convulsions would have basically thrown them out of the chair. Now, did Janet progress to that, that movement beyond just her hands and her feet? Not really.

I mean, it grossly affected her balance, her sense of balance. She also had, at one point she had, was constantly biting her tongue, and, or biting the inside of her mouth, which is, again, very common with HD. Her symptoms were primarily not physical, though.

Her primary symptoms were, was emotional and cognitive. I mean, there were, who I refer to as there was her violent period, where she would get angry. And I got punched, I got scratched, I got cut, I got bit.

And I mean, there were times when basically, I would just grab her, hold her in my arms, hold her like a bear hug until she calmed down. Because, you know, to protect, keep

her from injuring herself or somebody else. Thankfully, that period passed.

But then there's another portion of stuff, like, you know, you're dealing with, and by the way, I guess this is common with dementia patients in general. But she would get in my face, and she would just yell, you know, how much she hated me. And how, what a mistake it was that I should, that, you know, she married me, you know, and these sorts of things.

And- Even though you know, it's the disease talking, it still must hurt your heart to hear that. Oh, yeah. Yeah.

And it's such a common thing. Yeah. I got a, you know, I'm constantly seeing notes on the, on the support forums.

And for, you know, Huntington's, as well as Alzheimer's, and Parkinson's, and Lewy body, vascular dementia, and just, you know, dementia forums. And, or people saying, you

know, how do you deal with it? And I said that you, it's really, really hard, but it requires a carefully cultivated lack of emotional connection. Because, and the way I explain it is, you know, you have, you know, you have whatever your old relationship was, say, a spouse.

All right. And, okay, where, you know, you're, the one you're caring for is your husband. And so your, your relationship has always been wife.

Okay. But now, because of the disease, you have another relationship that is coming into the, coming to the fore, which is caregiver. And the problem is, is that sometimes the wife relationship can get in the way of the caregiver relationship doing what it needs to do.

Right. And so what you, and I said, I know it's incredibly hard to do, but you need to be able to figure out how to sort of take that role, that wife role, put it in the box and put it up on a

shelf for a while. So you can concentrate on being caregiver.

Because you can't do both at the same time, because one will get in the way of the other. Michael, do you think that you ever then get to take the box of being a spouse down again? Oh, yeah. Oh, yeah.

I was reading a book about a woman whose husband was suffering from Alzheimer's. And the way she dealt with it is she took her wedding ring off, literally put it in a box in her bedroom. And then at the end, after he passed away, and she had done everything she could care for him, then she took the box down, put her ring back on.

And now she's no longer caregiver. Now she's widow again. Now she's a widow.

But what I'm what I'm asking, for her, for her, that was, yeah, that was, that was how she dealt with it. But I mean, on a shorter time

basis. Do you ever get to take the box down and just be Janet's husband? Yes.

Yeah. And it hurts. And, and you do.

And I mean, those are the times when, when you just sit and you cry your eyes out, remembering. And, but the important thing is to remember, not just the pain and not just the sorrow, but to remember all the good times and, and to sort of be in that place. In other words, people tend to remember, like say their weddings, people remember their weddings, but it's overshadowed by what comes, came later.

Okay. And that, you know, the trick is to, to learn to, to, to, to remember those memories and be in the place of those memories. In other words, be with them on that wedding day.

There is no future yet. There is no Huntington's disease yet. There is no Alzheimer's yet.

There's no, there's none of the family problems that everybody always has yet. All you have is one other person in your love and you're getting married, you're exchanging vows. You know, and learning to be in, be in that moment with them right then.

So can you tell me, you know, I don't, I don't know if this is too personal, but when, in Janet's current situation, when do you get to take the box of being her, her husband down? Oh, in the evenings. When, recently, I, I wrote about, she went into a, into a five-day, well, it turned into a six-day, you know, temporary inpatient hospice. And so, my daughter Frances and I, we had six days where we didn't have to take care of mom physically and, and emotionally too, for that matter.

But it's, and so there was a time for, you know, for that, you know, being able to relive and rethink some little things and remember. But, but like, but also for me, and the one,

one advantage, one outlet that I have that a lot of people may not or don't, is that I write. And so a lot of times, my writing, it's an opportunity to take that box down, open it up, put all the good stuff in it, and to, to relate some of those things and to replay some of those things and to remember all the good things, you know, that, that my wife did, that my wife accomplished.

Like for instance, you know, if, if, if you ever, if you're a woman and you enjoyed playing sports in high school or in college, and you live in the era of Title IX, then you have, you owe Janet a debt of gratitude. Because in the 1970s, when Janet was teaching school, middle school in Massachusetts, she was, she worked, of course, for the implementation, for the creation of the Massachusetts State equivalent of Title IX, which then became the model for the federal Title IX law. And, you know, my, my Janet, all five foot four inches of her, she, she coached girls basketball.

And it was- I'm only laughing because it must have been kind of cute, you know, somebody so little. Oh, yes, yes, yes. And it was, her, her, her idol was always, there was a, a really short guard, spud something, I forget his last name.

But, but he would always, you know, he maneuvered so well and got around, you know, the big men couldn't stop him. He literally would run underneath them. But, but, you know, but I, and, and Janet was always, was always involved with politics and, and she's addressed, at the state level, she's addressed, you know, legislative assemblies and, and hearings and these sorts of things.

Back when, you know, the, before you had computers and the internet and whatnot, she taught ninth grade math. And she would sit every night and he would, she would put together an individualized lesson plan for every one of her, every one of her students with no computers, no laptops, no PCs, no internet, nothing. Geez Louise, how did she

ever do that? Well, it was just, I mean, she worked just unbelievable hours, but that's who she is, you know.

And, and I mean, you know, one last example is the other day we were talking and she asked me about her neurologist, Dr. First, First Eming. And she said, how's Dr. First Eming doing? I said, fine, she's doing well. I said, why is this? She isn't, she isn't feeling bad or anything, is she? I said, well, why would she feel bad? Is this because I'm dying? Because she wasn't successful? And I said, what was, you know, it just made me cry.

She was, she's, they're literally lying on her deathbed and she's worried about her, about the emotional state of her doctor. How incredible. She sounds like an incredible woman.

She was, she is, she still is. It sounds like other, you know, because with late stage dementia, you wouldn't have that kind of

conversation with somebody. So is she still cognitively intact? There are big holes.

Okay. It's sort of, it's just like, it's like Swiss cheese. I mean, it's not like, at least in Janet's experience of it, dementia isn't like this metal gate coming down and you don't remember anything past four days ago, four days ago or something like that.

It's like Swiss cheese. There are things she remembers clearly and there's things that she doesn't remember at all. Like family relationships.

She, the other day, she was talking about our two daughters and we only have one daughter. And I said, you know, our daughters? She says, Franny and Catherine. Well, Franny is our daughter.

Catherine is my daughter from her previous marriage. And it's like, she's in her mind and in her heart. She has adopted Catherine as her daughter.

Really, really sweet. Yeah. And it's, and so it's just, and there are like, one of the things I've noticed recently is she sort of lost contact with her I don't know how to explain this other than like sense of place.

She'll be lying in bed. She'll ask me to come over and help her. I said, what do you need? She says, well, I need help lying down.

Well, you are lying down. Oh, I'm lying in the bed? Yes. Why does it feel like I'm standing up? Well, I don't know, but you're not.

You're lying down in bed. Oh, okay. Thank you.

So she loses track of things like that. And considering she had like the balance problems as part of her symptomatology, it kind of makes sense, the particular, you know, place of damage in her brain. That makes sense, right? Oh yeah.

I mean, one of the things you understand is that anything that affects your brain is going to, it's like, you know, modern cars have this, have the black box that's under the hood that controls absolutely everything. Yeah. And because everything goes to that same box, you can have bizarre symptoms that make absolutely no sense.

I had a car the other one time where if I turned on the right turn signal, the radio would turn off. It made absolutely no sense. And I, and I went in the dealer and said, you know, you're going to think I'm crazy, but you know, every time, but every time I turn the, put on the turn signal, the radio goes off.

He says, the right turn signal, right? He says, yeah. He says, yep. Know what the cause is? It's because everything runs, ran through that box.

And there was a known failure mode in that model car in that, with that particular model of controller, something would fry on the

inside where you turned on the right turn signal, it would cause the radio to go out. And the guy had seen it before. It was, it was a known, it was a known problem.

And so you have, you can have a situation like that in where things that make, seem to be totally disconnected, suddenly have an impact or suddenly matter. There was a young African-American man in our local support group that what hunting, one of the things that hunting did for him is it totally messed up his body thermostat. You know, I've, I've seen him sitting in a 72 degree conference room in a hospital, just sweating bullets.

I mean, just water just coming off him, just in rivulets, you know, because he was, he was feeling so overheated and he was, I mean, he would, the way he was, was getting by is he would have these ice packs that he would strap to his chest, keep his core body temperature down. Otherwise, otherwise his body temp would have gone up to like 104,

105 and just stood there, stayed there until he died. You know, then you have the physical symptoms, you have the emotional system symptoms.

There, there's a story, you know, you get 12 Huntington's patients in a room and you'll have 12 completely different sets of symptoms. Right. Right.

There'll be some commonalities across some of those people, but it's a whole, it's a whole different story. And sometimes it depends on the day, you'll get a whole different story too. Oh yeah.

Yeah. And I mean, this is why, you know, when I first started writing, I wrote about, I wrote about Huntington's and then I started realizing that people who are dealing with Huntington's, people who are dealing with Parkinson's, Lewy body, what, you know, the results in England is called vascular dementia. What it is, is in the United States, it's the from like a stroke.

Right. And see, but all these people, you know, they're confronting a lot, 99% of the symptoms that they're going to be experiencing are going to be the same. So I started, you know, getting into contact with these other groups on Facebook and I'm getting tremendous response to folks that have, are dealing with all these, you know, different, different forms.

I mean, one thing that was amazing to me is the number of different conditions, medical conditions that can produce dementia. Right. Yeah.

It's mind boggling. Yeah. Literally.

Right. The other, the other thing too, is, you know, what we were just talking about, how you cope with that is you said, you know, you can, you put that role of spouse in the box and you put it away when you're being the caretaker. And I used to facilitate an Alzheimer's support group.

And one of the ways that the group would conceptualize some of the ugly things that their significant other was saying to them was that they would say, that's the disease talking. That's not, you know, that's not Janet, that's the disease talking. And then that, you know, and it kind of results in the same sort of thing, like what you're talking about, in that you separate yourself from them.

Like they're, they're not, you know, because you see a lot of daughters and daughter-in-laws who are caretakers to wives. And, you know, when somebody's screaming at you, how much they hate you, or like, you know, you said, you know, I shouldn't have married you, you know. If you take that as they're really saying that, it breaks your heart.

But if you're able to realize the disease is talking, and it's not being very nice right now, you kind of shut that off and, you know, have

a key line or something, some way that you respond when your feelings are being hurt. Does Janet realize or remember when she has those kind of outbursts? Sometimes, sometimes she has in the past. And a couple months ago, she, as the, her angry phase was sort of tailing off.

And one day, she, she was talking to me, and she says, you know, I just want you to know that I really do love you. You know, I know I've said some things in the past, but I do love you. And, you know, there are, there can be moments of clarity.

And I mean, they're priceless, when they happen. And, like, when Janet's dad was dying, Janet and I had gone to see, visit him with Janet's mom. And we, we, at that point, we did not know about Huntington's at all.

And we were, we were in his room. And, and he said, you know, Meena, his wife, Meena, why don't you take Janet downstairs and show her the cafeteria in this place? They got

a really good cafeteria. And I was like, cafeteria, really? Just go show her.

Okay. Not sure what this is about, but okay. So, as soon as they're gone, he called me over, and he held his hand out, and he says, Mike, I just wanted to say I'm sorry.

You're a good man. Thank you for marrying Janet. And he shook my hand.

And, I mean, this is a man who, at one point, had declared very loudly that he wasn't even going to attend our, our wedding. And had thrown fits about, you know, that. But it was just, you know, and the thing, the thing is, is that, you know, one of the things I've learned is that it's a matter of education.

It's a matter of learning what's going on. Like, for instance, at one point, when our son, Michael, was a little, like, four or five, he, he did something. Grampy got angry.

Just blew up at him. Said, said something nasty. And Michael just ran off crying because, you know, how could Grampy say that, right? Well, I went to, went to check on him, and one of his older cousins, who was, well, there was two of them.

One was 10, and one was 10, and one was like 12. And two of them had him sitting in, they had him sitting down in one of the backbridge rooms and explaining to him the facts of life. They, okay, Grampy said something upsetting.

Don't worry about it. He, sometimes he just gets upset. But give him a couple minutes, and he'll be fine.

And that'll be, you know, and they were explaining, you know, they, they had no idea about hunting them or anything else. But they just, they had this, they had a sense of, all right, this is what happens. We don't know.

It doesn't, don't, not sure why it happens. Doesn't matter. But, you know, give him a couple minutes, and he'll be okay.

And there, and they did a good job, as good a job talking to him as, as I ever could have. But, you know, that, one of the things I've noticed about, about Huntington's, is that when you get your, your diagnosis, it's half, oh, no, and half, oh, yeah. Where suddenly things that, things start making sense.

Yeah. Why things happen, you know, like Janet's older brother, who has since died of a unrelated heart condition. Everybody thought he was a drunk, because he wouldn't, and they think, they said, well, he came to his daughter's wedding, it's not, you know, intoxicated.

And then the wedding was at like nine o'clock in the morning. And, and what it was, was the chorea, is a very common symptomology, is people would have these very broad movements, and they look like they're drunk.

And, and so everybody looked at the way John was moving, and the way he was acting, and his speech was slurred.

And they said, oh, he's snoggered. How could, you know, what kind of a drunk is he, come to his own daughter's wedding? You know, and, and then, but then after Janet got her diagnosis, she would call, talk to his wife, explain the situation to her. And so John went in, which by the way, you're seeing one of the main neurologists at Mass General.

I mean, it was, I mean, this was not like, you know, some guy at a little country clinic somewhere. I mean, this is like one of the foremost neurologists, probably in the United States at Mass General. And it hadn't even occurred to him to test John for Huntington's.

Because, you know, when Jenny said to him, we need you to test him for this. And he says, what for? Did you realize how rare a disease that is? And she says, yes, and his younger

sister just got diagnosed with it. Oh, so yeah, let's, we do need to test for that.

You know, so I mean, it's, it's, you know, Janet's neurologist here at, in Houston, a doctor for stemming. She, she teaches at the McGovern Medical School here in Houston. And she set up a session where Janet could come, or Janet and I both would come and talk to her second year medical students about Huntington's.

Perfect. And, and just so they could see that, and she allowed herself to be examined, and you know, the neurological tests and all that kind of stuff that they do. And basically be shown off like a prize guinea pig.

And she, but she did that because she's, she's a teacher. And students will never forget what they learned from her either. All right.

Oh, absolutely. You know, I, I, one thing they're asking, asked me to comment, and

one thing I said, for one thing, for Pete's sakes, don't ever just play the odds. Is that there may be, you may have a situation where you have a disease like Huntington's, where there are like 30,000 cases in the entire United States.

That person sitting in front of you might be one of those 30,000. You don't know. Don't ever just play the odds.

And it's like the clinic Janet goes to covers the western half of Louisiana, and, and, and all of southeastern Texas. And the clinic has about 100, 100 or so patients coming to it every month. I mean, that large of an area is, I mean, that's what you have.

Well, you know, Michael, this has been such an incredibly fascinating chat. And you're so articulate with what's going on with Janet and even what's going on in your own head. And I really appreciate you letting our listeners hear, you know, about this story.

And I think there's so many other parts to the story that maybe we can get you to come back and talk more. Yes, absolutely. I would enjoy that.

And I want to let our listeners know that Michael has a blog that he does. It's called reaching out in love. And you can find it reaching out all one word re a ch i n g o u t dot l o v e. And go read his blog.

He's as good a writer as he is in terms of telling his story. So Michael, thank you. Thank you to Michael for that interview.

And please stay tuned for the continuing saga of Everyone Dies. And thank you for listening. An octopus's garden is unlike sand through an hourglass.

This is Charlie Naborette, and from poet E.E. Cummings, unbeing dead isn't being alive. And I'm Marianne Matzo, and we'll see you next week. Remember, every day is a gift.

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