Episode 272: Amanda’s mom slipped away

Scott
sometimes something can be wrong with a person someone you love and you don't realize it right away my mom has been on this podcast in a couple of past episodes just in the opener not as a featured guest and i can tell you she remembers things This past summer, she turned 84, and she still knows the birth dates of everyone in our family, including some who are no longer with us. For me, that's what Google Calendar is for. But for a lot of people, as their parents age, you start to notice some changes. Maybe they forget something they wouldn't normally forget. Or perhaps they ask the same question more than once.

Scott
Or they could just get confused about something that should be completely familiar to them. At the beginning, you don't immediately think, uh-oh, something is seriously wrong. You just think, hmm, that's a little odd. That's what started happening with Amanda's mom. And it didn't make sense because she was only around 50 years old. But those little things didn't go away. Instead, they became more frequent. This wasn't just normal forgetfulness. Amanda realized something much bigger was happening. And their family was faced with some big decisions.

Scott
In what you sent me, one of the words you used to describe your mom was fancy. What was your mom like when you were growing up?

Amanda
She had a really big personality. And yeah, I would call her fancy. She owned retail stores for over 20 years and she was. department store manager before that. So I think that's kind of where she gets some of her fanciness from was that she worked at a department store. So she's all about designer clothes and fancy shoes and handbags, things like that. And I think that also gave her like a really, she was a really outgoing. person. And I think she kind of just had to naturally have that personality as a department store manager and store owner.

Amanda
But I would say one of the things that people that didn't know her as well probably remembered about her was, I don't know if I would say fancy, but just how well put together she always was. You would notice when she walked into a room because she was just dressed, always dressed from head to toe in something really nice.

Amanda

Her hair always looked really nice she did her nails all the time and with that type of stuff i wouldn't even say she was like high maintenance like she wasn't a go get a mani pedi and go get your hair done at the salon type lady like she did it all herself and kind of prided herself in that one of the things she always bragged about to me was that even on her own wedding day, she did her own hair and makeup and stuff. So she was very put together. I would say she was a head turner when she walked into a room. So I guess that's why I would say fancy.

Amanda

I remember like as a mom, when I got old enough to like wear makeup myself, I was never really into it. I'm very different than she was, but I can still hear her in my head saying like anytime I walked out the door, she would yell something like, oh, at least throw some lipstick on because I just wasn't on the same page.

Scott

She couldn't imagine going out without lipstick or everything.

Amanda

No, perfectly put together all the time.

Scott

Did you still live at home with your parents when all of this started?

Amanda

No, I was actually talking to my dad recently, and he said that he started noticing signs when she was 52, so that would have been around 2009, and that's the year that I graduated from college. So he started to kind of notice things, I guess, like when I was college age.

Scott

What were some of the early signs that things were not quite right?

Amanda

The first thing that my dad noticed, he, at this point in time, worked at home from his home office. And she, just on a normal day, I guess like their whole marriage.

Amanda

she would she would pop her head in and ask what he wanted for dinner which was totally normal but he started noticing that on a lot of days she would do that multiple times a day like she forgot that she already asked him what he wanted for dinner or would come in and say the same like oh so we're having we're gonna have pork chops for dinner and he's like you just

told me we're having steak or something like that so that was the first thing that he noticed and then he would tell me and my sister about it. I have an older sister. He would tell us about it.

Amanda

And then shortly after that, my mom started saying things to us like, oh, your dad thinks that I can't remember stuff or he thinks I'm going crazy. So that was really the beginning of it.

Scott

So that meant that they obviously talked about it between themselves. Yeah.

Amanda

Yeah. They would talk about it.

Amanda

My dad at some point wanted her to go to... don't know where it would start maybe a neurologist or he wanted to take her to a doctor and you know how a diagnosis if anything really happens it's just that you go see one person and then they send you to another person they send you to another person and then after a bunch of tests things are ruled out and whatnot but she was really adamant at the beginning that something that nothing was wrong with her actually she never admitted that anything was going on It just wasn't until she kind of like faded into herself enough that we were able to actually really start taking care of her because she was very, she was

Amanda

just really adamant that nothing was wrong with her.

Scott

When you started noticing things, did any of you immediately think, wow, this could be dementia or was that just nowhere on your radar?

Amanda

We were familiar with Alzheimer's because my dad's mom had it. So we witnessed it with my grandma and she was older. And. you know when you get to a certain age people's memories start to fade anyway so she was just a little bit older and she she declined with alzheimer's and we were all the whole family was used to it at that point like we understood like these things memory loss happens with alzheimer's and we knew more i think than somebody that had never experienced it before because we personality changes with my grandma and things like that, too. And she passed away when I was in high school. So I don't remember as much about that.

Amanda

But so we were familiar enough with Alzheimer's, but it happened so gradually in the beginning. And she was so young that I think we were more so thinking like something else is going on up here and we can just get her figure, diagnose what it is and just get her some medication and everything's going to be fine. Which I don't know what that would have been, but I know that's what I was thinking at first.

Scott

Looking back now, knowing what you know, do you recognize things even from her 40s that maybe you didn't recognize at the time?

Amanda

Yeah, there's one story in particular. And the only reason I know that this happened in her 40s is because I remember that I was in, I think it was like my freshman year of college. So she would have been in her late 40s. 40s. My grandparents, her parents lived out in Palm Springs. And we were out there visiting, you know, at least once a year. And she went out once at that point by herself. And she brought a carry-on suitcase with her. So it was in the overhead compartment. And when she got off the plane, she just forgot.

Amanda

it was there and she went to baggage claim and this is this is kind of funny just because she was notorious for having her luggage lost we went on vacations a lot and like i swear every single time she checked a bag something would happen or she would grab somebody else's or a lot of stories there but she familiar feeling for her being at the carousel not finding her baggage and then she went and told him it was missing and they figured out pretty quickly that she had just left it on the plane and so we all kind of just laughed about that and chalked it up to nothing, which still it could have been, but looking back on it, that could have

Amanda

been an early sign. Like we talk about that sometimes now and we're like, we think that's kind of when it actually started around that time.

Scott

But on the other hand, when you're flying, you're distracted with a lot of different things. You got a lot of different thoughts going through your head. So it's kind of easy to forget things sometimes, too. So it's fair to say that when that happened first, you wouldn't immediately think, oh, something's going wrong here. You know, it's, yeah.

Amanda

Yeah, exactly.

Scott

Do you think in the beginning, was she in denial that she had a problem or just not wanting to find out?

Amanda

I think it's kind of hard to say because she really kept those thoughts to herself. I would think that she she's. kind of a stubborn person. So I could see how she maybe just made her mind up that nothing's wrong with her and we're all crazy. And then she just stuck to that, but, and then didn't want to talk about it. So, and I feel bad for her. I get really sad for her when I think about that, because she, whatever she was going through, I think she internalized a lot of it. And like, we don't know, nobody knows what you're going through. unless you don't know what she's thinking or how she's feeling.

Amanda

And so I bet there were a lot of just scary moments for her where maybe she recognized something was wrong, but she just didn't want to talk about it. And she had already made up her mind that nothing was wrong.

Scott

And after a while, you don't keep trying to ask about it either, right? Because, you know, she doesn't want to talk about it. But yeah, man, struggling with all of that just within herself, that would be stressful. You were away from home during a lot of this. What was it like getting these updates from your dad instead of actually seeing it yourself?

Amanda

Well, at some point, my dad had me and my sister just making sure that we called her a lot. And during this time, too, he was traveling for work. And she was still, I mean, thinking about like right when I was out of college, like for the few years after college, my sister and I were calling her a lot when my dad was traveling just to make sure she was OK. And she could still.

Amanda

handle herself she could still feed herself she was just like more or less a forgetful person at this point so i could hear in phone calls with her like i think I think just on the phone, what I noticed from afar was that she would just say weird things. Like, I can't think of anything off the top of my head right now, but we would be talking on the phone and she would either respond to what I was saying with something that was bizarre and unrelated to what I was talking about, or she would say something like really weird and inappropriate.

Scott

Like she had a conversation going on in her head that was different from the one you were having with her, sort of.

Amanda

I think so. And then some, but sometimes it would be like, like she would respond as if she's talking to a different person. I think, I think I mentioned something to this effect to you last time we talked, but sometimes when I was around her and like my husband just hasn't. of this and my husband would be around and she knew or he was like my fiance at the time and she knew that that was like my guy she would i think she would like forget i'm her daughter and then she would say something like sexual about him to me and i'm just like dude what so something like that like it's it's relevant to the situation

Scott

but it's i was always taken aback because it's like this is you don't say this to your daughter right yeah she the way you described her initially as someone very presentable and put together and proper she probably would have been mortified had she seen herself as a third person say something

Amanda

Yeah, yeah, we've had a lot of moments like that, too. You feel sad because it's like, if she had any control over this right now, she would not do that. And if she knew that this happened, she would be, yeah, she would be absolutely mortified.

Scott

When you came home and saw the condition of the house and your mom and everything, was there a moment that you can remember where you said, oh, this is much worse than I understood?

Amanda

The house was actually very my parents were very clean, pristine people like the house was not messy. I mentioned, I think, that she hoarded things, but it was very weirdly hoarded in an organized fashion. So everything and it's not.

Amanda

anything meaningful it's like her impulses when she's out at a restaurant is to take a bunch of napkins and stuff them in her purse or take a bunch of paper towels from the bathroom or toothpicks or mints like stuff that you would just gather when you're out and about bottles of empty bottles of water things like that and in the main place where all of this she was storing all this stuff because i didn't even know about this there was for a while my dad figured it out at some point was like you got to check this out she was stuffing things in their

walk-in closet like behind her like under her clothes and in drawers and behind things so like you

Amanda

didn't actually see it until you started around for it and was the same like the laundry room had a bunch of stuff stuffed into drawers and and things like that and so i don't know how i first came out came to find out about this i'm sure it's my dad figured it out and just told me so the house looked fine it was just you would open a certain drawer and it would be stuffed with paper towels and toothpicks and tampons and sinus medication she had some weird thing about this specific sinus medication we found like 20 boxes of them or something wow

Scott

And did she have any kind of sinus condition that she would use that for?

Amanda

Nah, our whole family has horrible allergies, so we were always taking allergy and sinus pills.

Scott

Did it become kind of like a scavenger hunt to find things that mom hid away?

Amanda

Yeah. At one point we did, when my dad was out of town with my mom, if she knew that we were touching her stuff, it would be. insane. But he was out of town with her and one of our family friends came over and we just cleaned out all of the garbage. I think we had like nine giant garbage bags of just all of this trash that she had collected and hidden away. And you didn't see it in plain sight. So we're like looking in drawers and in between her clothes and things like that.

Amanda

So we did that just to clean up and she was far enough gone at that point that I don't know if in her head when she got home, she realized that all of her stuff was gone because she never said anything to us about it. And we had done this a few more times after that. So just to get the house clean and stuff out. So there was that side of it. But then thinking about the question scavenger hunt, I definitely this happened on more than one occasion. But the first time that I noticed she was taking my stuff, I came home and I still had my childhood bedroom at that point with some stuff that I just hadn't taken with me.

Amanda

and she apparently I figured out was going into my room and she would just like take all of my stuff I had like a I don't know like some coin collection from

when I was a kid I had some at the time meaningless pieces of jewelry in there I had a few little like makeup things just things like that But I figured out at one point she had taken all this stuff out of my room. So I would say at the same time as this friend and I were cleaning up the house, I was also finding some of my things. And then at that point, I started to figure out what her usual hiding spots were.

Amanda

So for a while, when I moved back home before my husband and I bought a house there. We I was living in my childhood room and she would go in there when I wasn't around and take my stuff. And then I would go back to like where her usual hiding spots were and find my stuff and bring it back to my room. And then eventually I wasn't there living in that room for very long. But eventually my dad just went ahead and put a lock on the outside of my door so that when I wasn't in there, I could lock it so she couldn't go in and take stuff.

Scott

Wow. Yeah, you know, obviously it's clear that she's taking your stuff when you go and find it hidden in some of her spots, right?

Amanda

Yeah, and she only had a few different spots, but I will say there are a few things.

Amanda

that we never found and we looked into like my dad had it she had so much stuff think about like the clothes lady with all the shoes and shoes and shoes for days but we went through like all of her clothes as when we were selling things and my sister and i were taking some stuff too we went through every pocket of every single item of clothing she had and we kept finding stuff but we i'm still missing a couple things but whatever wow but nine big garbage bags full that's a lot of stuff especially when everything is kind of little trinkety kind of stuff you know yeah it was all meaningless stuff but i i would say most of it was like

Amanda

there was a lot of paper towel rolls and water, empty water bottles and a lot of paper towels. So that stuff kind of takes up a lot of room. Bubble wrap.

Scott

Why do you think your dad started keeping the journal?

Amanda

Yeah, I'm not, I actually would have to ask him why he started. I think it started to be a therapeutic thing. But I would bet, I think at this point, we had

gotten my mom to a neurologist and had not an official diagnosis, but at least the official confirmed, like, this, this isn't going to get better. It's just going to keep getting worse and worse and until she died.

Amanda
some of her behavior was bizarre and you can't really do anything about it but i'm i'm wondering if maybe one of the doctors told him like maybe if you start logging this then and picking up on patterns you might be more equipped to be able to handle some of the situations i'm not really sure at least that's how i was using it he was sharing with me the journal notes that he was taking it Oh, my gosh, I can't remember. I would have to pull some up. It's, you know, like 10 a.m. Linda refuses to take a shower. 1130 a.m.

Amanda
Linda, I don't know, went and put on a pair of mismatched shoes and walked out into the backyard and just like documenting some of this weird behavior. So then when I was around, if I saw that she was doing something weird, I'm like, oh, this isn't new to me. My dad already documented that she does this.

Scott
So you've gone back and read those journals.

Amanda
Yeah, I kept my dad sent them all to me. I had it in my head that I was going to write a book about this someday. I'm incredibly unclear on what the intentions or why.

Amanda
want to write it so I haven't started but I just remember at the time getting these journal entries and he just documented like in the notes app on his phone and he would send me screenshots every once in a while and I saved them all because I was just like I wonder if you know 10 years down the line If I look back at these, there's something else in here that could be helpful for someone else or it's just because it's such an isolating thing that even just if I had heard somebody else going through this or read what somebody else's journal looked like going through this, I would at least know I'm not the only person that's witnessing this, I guess, is

Amanda
kind of the reason I saved them all.

Scott
How is it reading those journals that something that your dad wrote in real time now that you know how the story ended?

Ama

I think when he was doing this, I also lived close to them. So I like outside of my dad, I was the person that was spending like the second most amount of time with my mom. And then my husband, Patrick, probably the third spending the most time with my mom. So when he was kind of writing this stuff down, we were witnessing this stuff in real time, too. I just wasn't documenting it.

Scott

Was that when you had moved back to Ohio to help take care of your mom?

Amanda

Yeah, Patrick and I were living in Seattle, and the only thing tying us there was his job. my dad, it was just becoming too much for my dad to handle. And we were just so far away. My parents were in Ohio. So he got his boss to agree to let him work remotely, which we all know more about that now in the post COVID world. But that was the only thing tying us there. So we just moved back.

Amanda

And he's also from the same town in the toledo area that i'm from so like his family is there like it wasn't i wasn't moving him to my hometown i was moving him to our hometown well that worked out well then yeah when you Finally made this decision to come back and live in Ohio.

Scott

Did you have any kind of thoughts or what did you imagine helping take care of my mom would actually mean or what would that look like?

Amanda

I didn't. I don't know. I try. I'm very much like an ignorance is bliss type person. So I think I tried not to think about it too hard before I got there. But it was mostly like I just wanted to help my dad. Like we already knew at this point that my mom wasn't going to get any better. So we. collectively we're trying to just make sure that she had some quality of life or we kept up some

Amanda

normalcies with her as best as we could while she was declining but my my thought was just like my dad can't do this anymore by himself and because she was so young and this is a whole different thing but because she's so young navigating getting her into some sort of medical facility or getting any type of care, even if we did something at home, was going to be really difficult. And in the beginning, my dad really wanted to keep her home the whole time. So

I was like, well, I mean, if he wants her to stay here, he's definitely going to need help. And then eventually we got to the point where we're like, we can't do this.

Amanda
It's not fair to us and it's not fair to her.

Scott
How do you handle it emotionally when she looks at you and doesn't know who you are?

Amanda
Yeah, she when it got to the point where she probably didn't know who I was, she was also not able to communicate enough to really tell me that she didn't know who I was. If that makes sense, like the more she declined. the and like the less she was able to do the less she was also able to vocalize that to us or communicate to us in any way what she was thinking or what she needed what does that mean does she become just non-verbal or just couldn't form the right words in her head Eventually, she became nonverbal. By the time we got her situated into a memory care facility, she couldn't talk anymore.

Amanda
We would know based on, for example, I would know that she knows who I am because I would walk in to visit her and her face would light up and she would smile. But if I walked in and she just kind of gave me a blank stare, I'm like, yeah, she doesn't know who I am today.

Scott
Can you talk about when she believed there were two men in the house?

Amanda
Yeah. This was a whole phase in time, too. This wasn't even just like one incident. She got to the point where, so my dad's name is Jay. And she liked Jay, but she didn't like her husband, but they were the same person. So depending on the moment in time, whatever she had in her head at that time. And like I could be sitting there with her and my dad would walk in the room and she would be like super sweet and nice to him. And she would say something to me about how it's Jay. And I think she's even told my dad before when he was Jay, like that she doesn't like her husband or something like that.

Amanda
And then if it was her husband, she was not nice to him.

Scott

That is so interesting because obviously he looks the same every time. Yeah. Well,

Amanda

I think there was something else going on with that. Well, in the same realm of whatever was happening in her mind that it's kind of like goes along with the hallucinations, for example. If I came over or something and I came through the garage and closed the garage door, because she heard the garage door close, she would go look in the garage and say, like, there's a guy in there. Because she knew the garage door was closed, so she would have the impulse to go see, like, forget that I just walked in. She heard the garage, so she needs to go see what's going on.

Amanda

And then she has it in her head that somebody is coming into her house, and now she's imagining that there's a guy standing in her garage.

Scott

Can you talk about the incident that happened in the car with your dad?

Amanda

I will give the caveat here, the type of dementia that my mom had was, she was eventually diagnosed, we didn't know this yet at the time, but she had frontotemporal lobe dementia, which is, I call it FTD, well, people call it FTD. It takes away your impulse control and it also kind of makes you angry. And so a lot of people with FTD are incredibly aggressive, which is, I guess, a theme and issues that we had to deal with with her throughout her decline. But one day we were all out somewhere. It was my parents and then Patrick, my then fiance, and one of our friends. One of his best friends was with us. And my parents left to go home.

Amanda

And I think, you know, we tried to get my mom out and about. And this was at the very end of being able to take her out places. But, you know, we were trying to give her some quality of life. get her out doing things. And on their way home, she just started violently attacking my dad and he's driving. So he has to hold her away from him. And then this, and you know, he gets, they get home and they go inside and she was, this was also a phase that she was going through where she was dialing 911 all the time, which that's a whole separate story in and of itself. But

Amanda

I think it's just the last thing that stuck out in her head. Like, you know, little kids know they can dial 911. She's forgetting a lot of things, but now she still

remembers 911. So they get home and she's still trying to fight him. I think I wasn't there for any of this, but. My dad eventually calls me and said, hey, your mom's, she just called 911. We're in a fight. The police are on their way over. Can you come home? And so we head home. I'm with Patrick and our friend. And we get there. And I've never experienced anything involving domestic violence. But it does make sense. They separated my mom and my dad.

Amanda

And there was one police officer talking to my dad and my dad's trying to explain calmly what's going on. And then there's one talking to my mom and I can overhear her a little bit. And it's just kind of gibberish like she couldn't form. real thoughts but she could form sentences so she was probably saying stuff like she would hear on like a episode of law and order or something like well he hit me and then he hit me and and then we walked over there and just like I don't know, just some level of sentences that made sense, but the story didn't make sense. And they wouldn't, there were probably like six police officers there.

Amanda

They wouldn't let me talk to either of my parents. They put a third officer on me. And so I was trying to calmly explain to him what was going on. And in these types of like. crisis situations somebody you know somebody with dementia it's just crisis after crisis i'm very calm and cool-headed and it's almost like i completely shut off emotion and i just try and handle the situation which i only found out because of all of this it's good to know though right yeah for sure So this police officer is talking to me and he's not understanding what I'm saying. I'm just like letting him know, hey, my mom has dementia. I know. And I know at this point.

Amanda

to explain this to people, I know she doesn't look like it because she looks very young and she looks pretty put together, but she has dementia. She was diagnosed. I don't know. I probably spouted off like whatever amount of years ago. And even at this point, I'm starting to get a little mad because number one, he's not believing me. Because they're really leaning into this as a domestic violence situation. And so like he's treating me as like an abusive daughter at this point. Like I'm involved in the domestic abuse. But at this point, she had dialed 911 enough that we informed our local police station that was just down the street.

Amanda

several times in several different different ways like just so you know what's going on this person lives at this address she keeps calling you guys like one time i was home with her and i didn't even know that she did it but she for no reason at all like she just dialed and then must have been from the landline because then

they showed up at her house and i let the police officer know i was just like hey she has dementia and we're doing our best to take care of her maybe we should disconnect our landline whatever but we're fine just like if you could note that somewhere so that if you're dispatched here again like i don't know if you have a

Amanda

system for that i just kind of had that conversation with him i know my dad at least called the station probably more than once just to like let them know because this kept happening and i'm pretty sure patrick I actually just drove over there and walked into the station at one point to let them know like all of this before this incident happened. So we're already frustrated because we've told you so many times that like we just thought something like this was going to happen. I don't know what else you'd do about it. I mean, even right now, if you ask me for advice on how to handle the situation, I have no idea. There's no guidebook for this.

Amanda

But so then what happened from there, they didn't believe me, really. The officer that was talking to my mom came over to the one that was talking to me. basically just said yeah she's not really making a lot of sense but she's saying that he hit her and i was just like trying to explain to him and he's not even looking at me either and then at this point the ambulance shows up so there they do end up taking her to the hospital i don't know what for so yeah but did she you said she had some kind of an injury right Oh, yeah. So she had, well, I guess, yeah, people won't see this, but she wore glasses. There's a couple things.

Amanda

One, her face had a scar on it from her glasses from when my, I think when my dad was having to hold her down while he was driving. But it might not even have been from that because she also just like, this is a weird thing with dementia too. I've seen this with other people with dementia. She picked her face a lot. So she had this one spot on her face, like on her cheek, that was raw for years and years because she would just pick at her face. So I don't know if it was from her glasses or if it was from her picking.

Amanda

But yeah, she had like a little open wound on her face and it wasn't really bleeding if I remember at the time.

Scott

But then the cops, she's saying, he hit me and the cops see this open wound on her face.

Amanda

exactly have a lot of discretion there they have to do something right yeah no and i don't i don't blame them for that like i know there's i understand their side of it we were just so frustrated because we had tried to talk to them about this so many just alert them so many times and like my husband was so mad at the moment i'm glad that our other friend was there because he was very cool calm and collected and kind of calmed him down So I totally understand their protocol there. But I remember they were loading my mom into the ambulance. I asked the EMT if I could go with her.

Amanda

And whatever their protocol is, again, I've never been in a domestic violence situation other than this. So their protocol must be, like, get her out of here and leave everyone else behind. And I just kept trying to plead with her, too. The EMT, I was just like, she can't advocate for herself. She has dementia. She can't answer questions. She won't be able to, like, call me later. Like, I don't know where you're going. And they wouldn't let me in the ambulance. And then we didn't know where they were taking her. And, like, and by the way, in the end of this, the police officers did understand. They were like, okay, now we understand what's going on. Like, they did apologize to us.

Amanda

They didn't, you know, they're not going to take my dad to jail or anything like that. But they did have to take my mom to the hospital. But then they also couldn't tell us where she was going. Or at least the EMTs couldn't. I think at some point I learned where she was. At some point that night, I learned where she was from the police officers. But because it was a domestic.

Amanda

violence situation i had to have like a special password for them to let me in to go see her and whatnot and then then everything that happened at the hospital is a whole different story because they didn't understand her condition either and they didn't treat her for anything because nothing was wrong with her Yeah.

Scott

I mean, that kind of makes sense in a domestic violence. The injured person gets taken and you don't necessarily want the abuser to know where they're going. It all makes sense from a protocol standpoint. But in your specific situation, it was a big inconvenience.

Amanda

Yeah. And that's that's part of it. It's like the systems aren't set up to handle someone like her, even in the hospitals like we were there. occasionally in the

emergency room for one thing or another with her. Because, you know, once your mind starts to go and you're not personally taking care of yourself as well and you're not eating as well, like you get sick. So we were in the emergency room with her on a few separate occasions and like nobody ever knew how to handle her or ever listened to us when we're trying to explain what's going on. They would just try and ask her questions and she couldn't answer them.

Amanda

And then but or she'd say something bizarre and they'd be confused and they wouldn't listen to us.

Scott

When did you finally realize that keeping her at home was no longer possible?

Amanda

I think I'm guessing if my dad and I probably had conversations over maybe a year or two span of time as she was declining, like when I still live there, because I only lived there for two or three years, I think, to help him. I think we just started talking about it. And I was like, are you sure you want to keep her at home? Like, are you going to be able to do this? And I know we had those conversations over time. But I think what finally did it for him is when she when he realized that he couldn't take care of her on his own is when she became incontinent and she was peeing all the time. accidents everywhere.

Amanda

So he's just like, I don't know. Because it gets to that point and you need somebody that knows what they're doing, a professional to take care of her. That's what I meant earlier when I said it's not fair to us and not fair to her for us to be caring for her because we don't know what we're doing.

Scott

Family has love, but not the skills, not the training. Yeah. Yeah. Yeah. Was there guilt associated with that decision at all?

Amanda

A little bit. I think in the moment, I think looking back on it, I don't feel guilty because she ended up getting, in the end, she ended up getting care that was, you could see that she was being cared for much better than what we were able to do for her. And the place that she ended up was great. Like the people that work there were great. They did activities and things with all of the residents there. It's just stuff that we couldn't, we didn't have the capacity to do.

Amanda

So we're just seeing how her quality of life living in this facility is probably much better than it would be with us because we don't have the knowledge or the capacity to be able to give her that lifestyle.

Scott

You said she kept asking to go home and your dad would drive her around. What did that look like?

Amanda

Yeah, this was very shortly before we put her in a home. I think this probably factored into our decision, too, because she got to the point where she didn't know that she was at home. And I think that's what we thought in the beginning was like, well, maybe as long as we keep her at home, she'll be comfortable because she knows her home. But she started to say, ask to go home. And I think it started to become more and more frequent as well. And I heard it from her, too. But, you know, it was mostly she was saying it to my dad.

Amanda

So I think on more than one occasion, he would then just put her in the car, just sort of as something just to do. but also to see if he knew which house she was talking about, because she grew up in the Toledo area as well. And she lived in a few different houses. And then my parents lived in a few different houses. And then they had kids and moved to a few different houses then too. So she had houses all over town that she lived in. So my dad would just put her in the car and I think maybe go in order of where.

Amanda

which house she lived in first to the most recent and just drive by and see if it struck any memories with her or if any of them she's talking about a specific house because we were also curious to know if she was at least I was if she was thinking of a specific memory in time like she would she would talk about some sort of childhood memory that was true on occasion but I think that she thought she was back there So he did it just kind of just something to do to get her out of the house.

Amanda

Maybe it would be a little comforting, but then also just the curiosity, like, are you talking about a specific house or do you just not know?

Scott

I know you mentioned that when she went to the first facility, you dropped her off there instead of your dad doing it. Was that a decision that you made between the two of you deliberately?

Amanda
I just offered to do it because my whole point of being there that I was, my dad had been going through this every single day with her much longer than I had. He would get the brunt of everything else. And I think I probably just offered to do it so that he didn't have to. And he said, okay.

Scott
That would have been very difficult for him. I imagine. I'm sure it was difficult for you too.

Amanda
Yeah.

Scott
Did she understand at that point that you were leaving her there?

Amanda
No, she didn't. And they, she didn't really understand much of anything at that point, which is, and my dad and I always talked about this, that like, she was, when she was with it enough, she was in feisty and still in denial. She, we wouldn't have been able to take her anywhere. It took getting her to the point where she really didn't know.

Amanda
what was going on to be able to take her somewhere so i think one of our indications was that she didn't know her house anymore too but the way that they have you do it is that you drive you you bring her in and you bring her into like where her room is we had to move in a bunch of furniture and stuff to her room like you provide your own furniture so we dropped that off days before and then you bring her in drop her off i sat with her for a minute just chatting and then as soon as she turned her back and was kind of chatting with somebody else the nurses told me to leave and then you're not supposed

Amanda
to come back and visit for a week because they need them to adjust i can't imagine how difficult that must have been for you Yeah, I think it was also one of those moments, like I said earlier, where in times of crisis like that, I just kind of shut off. So that's kind of what I did. I was okay until I got back out to my car and then I just kind of burst into tears.

SPEAKER_6
Yeah.

Scott

That place you researched and they said, yes, we can do this. We can take care of her. But that one didn't work out, right? What happened?

Amanda

I think we started looking for a memory care facility before we were ready. Like once we realized that we're going to do this, let's start looking around now. So we were probably doing that for probably more than a year. again i don't remember the exact journey but i know for a fact we went to a couple of places where they just straight up told us she's too young like she was 59 at the time and a lot i remember one place telling us that they had an age limit of 65 and then i don't i don't remember We got her into this place, but part of the reason that we went here is just because we could get her in.

Amanda

So it wasn't like we chose the place that we wanted to go, although it was a good location. And actually, my husband's grandmother was in the same facility, so that was convenient for a moment there. But yeah, we just got her into where the, a place that would take her and we didn't, I don't think we asked the right questions up front because we learned later from the facility that she ended up in that we should have asked like, how do you deal with aggression? What happens if she's aggressive what what would she have to do to get kicked out of here?

Amanda

And do you kick people out and a lot of other questions along those lines that we just didn't know what to ask They just they let her in and it was a memory care facility.

Scott

So we took her there It's interesting that you phrase it that you guys didn't ask the right questions This place should have asked the right questions of you you know? Yeah. Is she aggressive? What do you, what's going to happen if she can't, we can't keep her here? It sounds like they were just wanting to bring in more residents because obviously that means revenue for them, but then they regretted it not too long. How long was she

Amanda

Just the timeline that I remember, it was January, so it was after the new year. But when she got kicked out, it was on her birthday, which is January 25th, so no more than a few weeks.

Scott

Not even a month, and they decided, okay, this is a mistake.

Amanda
Yeah.

Scott
But you finally, you did find a place that was a good fit for her.

Amanda
Yeah, we did with with I mean, and this was all a journey and also with help. So she got kicked out of there due to them not being able to handle aggression, which, again, that comes a lot of that comes from the fact that she had specifically FTD and they sent her to.

Amanda
they wanted us to come pick her up that day and we couldn't like i was like we don't know what to do we can't bring her home so i don't know what my dad did he pulled some strings on the on his side and got her into a geriatric memory care inpatient program at the hospital so we had to pick her up that day but they would take her over there Because we needed to figure out what it was really coming down to is that, like, throughout all of these different doctor's appointments and different types of doctors and different trying to find a diagnosis, everyone was just giving some medication and trying different experimental medications and things like that. And so.

Amanda
At some point, and we don't know what's working, but at some point she had her, whatever her lineup of medication was, and we got her to this geriatric inpatient facility and their strategy was to take her off of everything and have her stay there as long as she needs for them to figure out what the best course of medication is for her. And I think at that point, she was able to do it.

Amanda
that point it was just whatever she you can't treat what she has so they're trying to treat like how do we just get her to be calmer because she was just facing so much aggression at that point so i think that that's what they did was just level out her medication so that they were treating her for what she actually needed to be treated for and not just have a bunch of meds going into her body constantly. And then they pointed us to, I think, to the place where she ended up, which is not a nursing home, but it's a facility specifically catered to people with dementia. and memory, basically memory care.

Amanda
And they were the ones when we went to go interview with their lady to try and get her in there. She's the one that was telling us all the right questions. She

was like, even if you guys don't come here, here's a list of the correct questions that you should be asking for whoever takes her in next.

Scott

and then just talking to that lady we were sold we're like i think of course i think they know you're thinking okay these people they really have her best interest at heart that's what they wanted Instead of just, we needed more residence and more revenue. Yeah. There was a time when your dad was going to take her to a baseball game and he couldn't go for some reason. And you ended up taking her. How did that work out?

Amanda

Yeah, this is, and this I think just goes into how much we liked this facility for her because they did all types of activities and stuff and they would even do field trips like that. So they were going to the baseball game. We have the Toledo Mudhens, I don't know, leagues. They were going to go to the Toledo Mudhens game and they were going to bus everybody out there from the facility that wants to go, but you have to have a caregiver with you. Like you can either pick them up yourself or just meet them at the stadium. So my dad signed up, signed her up to go to that.

Amanda

Something happened at the last minute and he wasn't able to go, but he was just heartbroken because she hadn't been on an outing like that in a while and he really wanted her to be able to go. So he asked me if I could go and this was still when I was living in, yeah, I was living in town still at this point. So yeah, I went, I drove to the facility. And just chatted with the nurse ladies there. And I was too nervous to handle her on my own in my car. So I had her go on their bus. And then I met up with them at the front gate. And it was a whole group of us. It was funny.

Amanda

I mean, it felt like a kid's field trip, but it was adults with memory. memory and all the all the caregivers are kind of like the parents going in to take care of the kids right yeah that's a little and that's literally what it looked like you know everyone's getting off this bus and then people I'm standing around with a bunch of other adults and we're walking up and just grabbing our person by the arm and and then we had a whole section I think that the tickets came along with like hot dogs and ice cream like we had a few snacks and then her she loves popcorn so I went and I got her A bowl of popcorn.

Amanda

It was one of those bowls that looks like a baseball helmet. And I can't remember if we finished it all or if she dumped it on the ground or what. But

at some point, the bowl was empty and I was just watching the game sitting next to her and I look over and she just has the bowl on her head and she's just having like the best time ever.

Scott
Well, it was a hat, right?

Amanda
Yeah. Yeah. She knew it was a hat. Wow.

Scott
Did you get a picture of that by any chance?

Amanda
I did get a picture of that. Yeah. It's that's, it's in terms of memories of my mom having a good time as she's declining with dementia. That's probably my favorite memory of her because she just, it was, it was nice to see her having fun. Like she wasn't all there. She might not have even known who I was or why she was here doing this, but she was laughing and having a great time.

Scott
That's awesome. Yeah. at one point you decided to have an estate sale and so all of your mother's belongings are just kind of laid out for strangers to buy is there any one particular thing that was especially difficult for you to see go

Amanda
She just she had so much stuff like back to how like her fancy wardrobe like she had 10 times as much clothes and shoes and stuff as people needed. So it wasn't there wasn't one specific item and me and my sister both. were able to take things that we wanted like we went through my dad didn't you know he he took his time with it and he let both of us go through and see what we wanted to keep and grab anything that's really sentimental or something that that meant something to us so a lot of it was just stuff to me but it was just weird because it was just like her whole life and we were just selling

Scott
Yeah. Well, they are just things. I mean, they represent something, obviously.

Amanda
Yeah.

Scott
Tell us about the last Christmas you had with your mom.

Amanda

Yeah, it turned out to be a really special Christmas because my sister and her husband, they live in L.A. and they don't come to Toledo for Christmas very often. And my Patrick and my son and I, we always now go up there for Christmas still because we're not too far away. And his family's there, too. But it was nice because my sister and her husband were there. We were there. I happened to be pregnant at the time.

Amanda

with my son and my dad for all holidays at this point when my mom was in her memory care facility my dad would always still cook the whole holiday meal and then go pick her up and bring her over and we would spend time with her. So for her last Christmas she at least got to eat Christmas dinner with both of her kids and their husbands and unknowingly to her the little baby that was in

Scott

So she didn't know you were pregnant?

Amanda

She wouldn't have been able to register that. She was very nonverbal, very closed off and into herself at this point. The most we would get out of her interactions was just get a smile or a tiny little laugh out of her. But I mean, I told her like I pointed to my belly and I and she touched my belly. And that wasn't the first time I had been to visit her.

Amanda

a couple times in her home while i was pregnant and like kind of tried to explain it to her and i don't know if anything registered but she did touch at that point i had a had a little bit of a pregnant belly at christmas time and so she touched it and was just kind of staring at it but i don't know if she really understood there was a you took a picture at that christmas right yeah

Scott

Is the picture of the whole family?

Amanda

Yeah, it's my mom and dad, my sister, her husband, and me and Patrick, yep.

Scott

And in what you sent me, you said that photo makes you really happy and really sad at the same time. What are those components?

Amanda

I don't know. It just, it makes me happy because we were able to... Just the fact that all of us were there with her for her last Christmas makes me happy. But we didn't know that at the time that it was going to be her last Christmas. So I don't know if... That gives me some sadness just because I don't know what I would have done differently or if we would have spent a little extra time with her or gotten her some other special Christmas gift. I don't know. I just think I think I wish I had known.

Scott

Right. You were doing what you could to make her happy. And it's the holidays. That's what family does. But yeah, sometimes I do the same thing. If I look, I can look at a picture of family or even anyone. The picture was taken before something major happened. And I just think, oh, you people in that picture, you don't know what's about to happen, you know? Can you describe the final goodbye that you had with your mom?

Amanda

Yeah. So my mom died on April 3rd of 2020. And we would all be familiar with this date because this is, you know, only, what, a couple weeks after the world pretty much shut down for COVID. And I was living in Chicago at the time. Patrick and I were just at home in our apartment, probably working from home. I'm sure we were. It was a weekday, I think. And my dad called and let me know. And I don't remember the conversation, but he basically let me know, like, hey, mom's about to pass away today.

Amanda

But the tricky part of the situation was that the world just shut down for COVID and they weren't letting anybody into nursing homes or anywhere where there were elderly patients and things. So my dad had been going for those few weeks when things were shut down just to pick up her laundry and drop it off and like wave to her through the window. Luckily, when they called him to tell him that this was happening, they agreed to let him come in. I'm sure they were basically just like, hey, you know, nobody's supposed to be in here, but we're just going to let you in and not tell anyone, I guess, so he could go sit with her.

Scott

Nice people.

Amanda

Yeah, I know. I didn't. Yeah, that was very lucky. And so he went in and sat with her all day. I think he I'm sure he was just listening to music and like painting her nails and just sitting with her. And he wanted me and my sister to be able to say goodbye. My first instinct when he called me was that I was going to

jump in the car and drive there. He and Patrick were both kind of just like, you're pregnant. And you're like, you're pretty super pregnant. And there's this crazy disease happening in the world right now.

Amanda

And my dad was like, you know, they're already bending the rules, big time letting me in here, like, you're gonna drive all the way here, and they might not even let you in, just like, just stay where you are. So We kind of just sat around all day waiting for word from my dad. And at one point he called so I could say goodbye. And he did the same for my sister and just held the speakerphone up to her face. And he said that all day she was really just laying there totally unresponsive until she heard our voices. He said that her eyes shot over to the phone like she recognized it was us.

Amanda

And that was the last time I got to talk to my mom. I don't remember what I said, but I like to think that she knew it was me.

Scott

It seems clear that she knew that.

Amanda

Yeah, I hope so.

Scott

You went from losing your mother to becoming a mother yourself just in a matter of weeks. Did that feel like emotional whiplash in some way, or how did you handle that?

Amanda

Oh, I think I would say the overstimulation of. That happening with also everything else that was going on in the world was it was so overstimulating that I was almost emotionless because what happened was my my son was actually due the first week in June and he ended up being born on.

Amanda

april 27th which is just a few weeks after my mom passed away and i think what happened was that i was just in so much emotional i had so much emotional trauma at the time that my and i had a not a good pregnancy in the first place i was sick the whole time so i didn't really gain enough weight my body just couldn't handle it and I just naturally woke up that morning and just went into labor on my own and we went to the hospital and he was born that night at 10 10 31 I think but what was so weird about that was that April 27th is six weeks earlier than he was

Amanda

And I just went into labor naturally and everything was all good. And that happens to also be my grandpa's birthday. And that's my mom's dad. And at that time, he was still alive. My grandparents lived out in Palm Springs still. They were very old and not in good shape themselves at that point. But it was just so interesting. Like, not only did this kid come out six weeks early, but it happened all on its own without complications for me. And it was on my grandpa's birthday. And then something else that was weird to me is that I have, I had a really close relationship with my grandpa.

Amanda

So this, this was something that was really special for me, but my grandpa and I share a middle name and we also gave my son my middle name. So all three of us, three of us have the same middle name and then they share a birthday. And my grandpa was still alive for me to call him and FaceTime him to show him the baby. Just from the NICU, he was in the NICU for a month because he was so tiny and premature. But I got to FaceTime my grandparents from the NICU and show him to them. And I sent them some photos and things like that.

Amanda

And he, I think it's when I called my grandpa to tell him, I think I was still just sitting. in the hospital. He was so excited. It was like the most exciting day of his life.

Scott

That must have put a big smile on his face. Yeah.

Amanda

Yeah. Wow. Yeah. He was so excited.

Scott

That's six weeks is way early. That must have been a little scary when you realized, okay, this is actually going to happen.

Amanda

Yeah, it was very interesting because also we had just a strange experience because, you know, the hospitals were pretty empty and all the COVID protocols were in place and whatnot. But at the same time, they knew because of how small he was and how early he was that they were going to take him to the NICU immediately. So when like the moment he was born, we had. I don't know, maybe 10 to 12 people in the room with us because there was an entire NICU team that had to take him away pretty much immediately and then handle me

because, you know, there was nothing wrong with me.

Amanda

Nobody could explain why this was happening so early and why my body was just doing it. Because normally, if your kid's born that early, there's some sort of pregnancy Just checking to make sure there was nothing else wrong with me, but I was fine. It just happened.

Scott

Well, that's sometimes it just happens, right? Yeah. Were you, I mean, giving birth is just such a joyous time. Were you able to really enjoy becoming a mom or was there that grief still from your mom alongside that?

Amanda

It was really weird. I didn't have time to go from being the girl without a mom to then being comfortable also being the mom. I had three weeks of being the girl that didn't have a mom before I was a mom. So I would say... I feel guilty saying this, but I didn't really feel the joy that I think most new moms feel. And it wasn't him. I was very happy for the baby, but I felt like I was missing out on what that experience was supposed to be, if that makes sense. And then it's taken now. I mean, this was six years ago.

Amanda

I'm still kind of unpacking some of the grief about my mom, but a lot of it comes from the other things that I experienced with a person with declining dementia, more so than like the last moments. But it was really hard to. Like, I just look back on that period of time, and I feel like I was robbed of what having a new baby is supposed to be like.

Scott

Right, because part of the joy is sharing the new baby with your parents.

Amanda

Yeah. Well, and the weird thing about it, too, is just the timing with everything. The world was shut down. There were silver linings.

Amanda

to that because the roads we lived in the city and so the roads weren't crowded nothing was open like we were going back and forth to the NICU like it was a breeze and there was nobody else there which was was nice and quiet and we got to spend that time with him but we didn't get to have all of our other parents come and meet him for a while because they couldn't they weren't allowed to go into the NICU to see him so they had to wait until he we brought him home and we didn't bring him home for another month so all of the other

grandparents didn't get to meet him until he was a month old how's your dad doing

Amanda

now oh he's actually doing really well honestly getting through all of that and and where he is now he's probably the happiest i've seen him in almost my whole life because i think you also have to find this really puts perspective going through something like this gives you a lot of perspective on life and you can find joy in more parts of your life than before He actually has a new partner and she moved into his house with him. She's awesome. I love her. She's a part of the grandparent team now, too. So I think my son is lucky. I talk to him about Grandma Linda all the time.

Amanda

But he also has on my side of the family, he has two grandparents that are really involved and love him very much. And then on my husband's side of the family, he has another grandfather and then two grandmas because my husband has a stepmom, too. So it's just like he has five.

Scott

living grandparents and then we talk about grandma linda all the time so this kid just has grandparents oh he doesn't get spoiled at all i'm sure oh my gosh yeah your mom's symptoms you've acknowledged they may have started in her 40s and you're about to turn 40. Are you, do you have concerns that you might go that same path?

Amanda

I do. And I have kind of come to terms with that and I feel comfortable. You know, we all we all have our issues, you know, everybody's going to have something health wise happen to them at some point. And I was kind of obsessing over it for a while, thinking, like, if I really get ahead of it, then I can fix this. but you can't fix it if that's what's going to happen you know until they cure it someday you know if that's what's going to happen that's what's going to happen but i did go to a couple appointments with a genetic counselor

Amanda

And she started to map what they really do is like map your family tree and who has had what type of, you know, you can do cancer, you can do dementia, anything. They map your family tree and then they start to do blood tests that are just testing for certain like certain genetic things. Right.

Scott

Is that what they call them? They call them markers, I think.

Amanda

Yeah. Yeah, I think so. So I was going to go do that, do those tests after she mapped out my family tree. And then when it came time for that appointment, I was just like, you know, I don't want to know. I just don't want to know.

Scott

If there's nothing you can do about it.

Amanda

Yeah, there's really, my mom was on some medication at one point that's supposed to slow things down. And I think if you get ahead of it enough, you can, you can slow things down. I don't know. I don't know that I would want to do that. I don't know. There's so many side effects to the medication and you don't actually know if it's working. And a lot of the different types of dementia, I think you can't even really get a diagnosis. It's just like, unless you can really cut your brain open, you don't know what's happening in there.

Scott

Yeah. Why add to the stress of, because now you can, you can rationalize in your head, I'll probably never get it. So you use the word isolation when you talk about your mom, how does that word fit for her story?

Amanda

I think anyone who is taking care of a family member with dementia at any age as a one-on-one caregiver is going to feel isolated because you, I mean, this person isn't really partnering with you in any way. You're taking care of this person that can't help themselves. But especially with my mom's situation, she was so young when it started, and honestly, we were just so confused for so long that it just felt, in our state of confusion, that felt very isolating, but people just didn't understand.

Amanda

I mean, just in daily interactions, like, you know, I talked about the police officers that, for a moment, didn't believe us, but then... than they did because she looked so young or you'll be I would be out in public with her like maybe I take her to the mall to go shopping and we're in the bathroom and she's in the bathroom just stuffing paper towels into her purse and the other people that are in the bathroom are looking at us like we're stupid or something or like looking at me like aren't you gonna what are you gonna fix this what do you why why is she crazy and so like you know there's physical looks of disgrace when you're out in public and

Amanda

people don't understand it and then even just being able to tell other friends

and family what's going on like we had close family my dad's siblings were great they understood and they were kind of a safe space for us but I didn't I didn't know how to tell my friends what was going on partly because I didn't really understand what was going on there was no way to no way to put it into words. It's just an intangible thing that's happening to us and you can't explain it to anybody. And then when they're around it, if they haven't been around it before, they just think it's weird.

Scott

Right. And especially for a stranger, someone that you're not going to interact with more than 30 seconds, you don't feel any obligation to tell them the whole story, obviously. It's just they think what they think and not much you can do. Yeah. You've carried this story for a long time. What made you decide to talk about it now?

Amanda

I don't know. I mean, it's been six years and I feel like I was finally ready to tell it. It's hard to talk about. And I've never actually like spoken the whole story out loud. I talked to my husband about it because he was around and he knew he understands it. I talked to my dad and A phase after my mom died where I was very specifically trying to not remember the last 10, what would it be now, 15 years, 16, you know, from whenever it started to whenever it ended. I tried to put those memories aside and just think about who she actually was.

Amanda

And I think at this point I was, I'm just ready to, I have enough good memories of her that I've washed away. the dementia memories to an extent that I can talk about it now without those being the dominant memories.

Scott

Good. You've, you've handled it well. Yeah.

Amanda

And I've, I've seen a lot of therapists and like grievance counselors and things. So I think that helped to kind of unpack things over the years. I recommend therapy for anyone who's dealing with anything, honestly.

Scott

Even if you're not dealing with any, anything. Sure.

Amanda

go for it one thing you mentioned the local chapter of the alzheimer's association was a big help for you how did they help what do they do i think well when i was pointing to them because i think it's a really helpful resource for anybody that's

looking for help i know that they fund they fund research i don't i'm not up on everything that they're doing in terms of research But I know within our local chapter in Toledo, I went to and I think my dad, my dad also did with me, at least for one, went to a support group on a few occasions, which is helpful because you're sitting down with people that live locally that are going through what you're going

Amanda

through. And even even aside from like the therapeutic. aspect of that. You can find resources from people or ask, you know, how did you handle the situation? Because we're going through this now. So I think it was just a connector for us to find some support. And then I think it was probably somebody from the Alzheimer's Association that I chatted with in the first place, or maybe my dad, actually, probably my dad, I'm giving myself too much credit to start us on the journey of finding a good memory care facility for her, because it's like anything else where you have to network and do a lot of research and figure things out.

Amanda

And The people that you'll find at your local chapter of the Alzheimer's Association are in your town. You can see them in person and they will just know if you're trying to figure things out and you know nothing, they'll just know more than you about what your local resources are.

Scott

I was thinking the support groups, that must have been a big help in terms of the isolation that you were talking about, because there you are with people going through the same thing.

Amanda

Yeah. Well, I went and we went to I know that I went to at least one or two on my own. And then my dad and I went to one. And he might have gone to a couple. But after I went to one with my dad, that thing that we were talking about is like, it was still helpful to talk to people that are caregivers for somebody that has dementia. But it was in that particular group. It was I think Like the two other people that had dementia, you know, the people with dementia weren't at the support group. They were somewhere else, but they were just much older. It was like somebody's 80-year-old grandson.

Amanda

father and, you know, some lady that was like in her 90s. And then we're sitting here talking about my mom, who was, I don't know, probably 57 at the time. So even that, even within the community of people that are caregivers for people with dementia, it's still kind of isolating.

Scott
What's your favorite memory of your mom?

Amanda
My favorite memory of my mom. And I like to tell this one about childhood. And this is good because I don't think we talked about this aspect of her personality. So to set it up a little bit, I just want to say at my mom's memorial service, my best friend, who I've known since I was two years old, gave an impromptu speech. And one of the things that she said is that Linda didn't take shit from anybody. And she didn't like she was you did not want to be on her bad side and you didn't want to fight a battle with her because she's going to she's going to win. And she did it.

Amanda
I don't know how she always did it, but she also did it in kind of a classy way. Like she wasn't she wasn't. rude she just she was relentless and fierce and just kind of always got her way and she didn't take shit from anybody and so a memory that I always come back to and I was just talking to my sister about it so I think that's why it's fresh in my mind was when I was in kindergarten I was put in a class where I didn't know anybody And I grew up in a neighborhood where I had like all these neighborhood friends. We would all ride our bikes around together and stuff.

Amanda
So I had a bunch of friends in the neighborhood. They were all put in the same class. And I was put in a class where I didn't know anybody. And not even that, looking back on it now, I wonder if it was just like, I don't know why this happened, but the class that I wanted to be in had way more kids in it than my class. So it just felt like kind of the spillover, like reject class. I don't know. But I would come home from kindergarten every day crying. And I don't know the time span of this. I assume it was only a few weeks into school. But I was coming home every day crying.

Amanda
I saw all my friends just in passing. I didn't have any friends in my class. And so my mom told me that she was going to try and get me put into the other class. And then at first, something I don't remember, you know, I was only five, so I wouldn't remember, but it didn't work out at first. And so she kind of told me, like, you know, I don't think they're going to I don't think they're going to let us do this. That class is full. There's a lot of kids in that class. And then probably the next day, I usually took the school bus home.

Amanda
I'm walking out of my little kindergarten classroom and my mom is standing in the

hallway with, I don't even know, just a bunch of probably the principal and both teachers. I don't know, just a group of other adults. And I'm like, what's going on? She had this fierce tone in her voice, like, because I think she was probably just battling with all of these people. And she just said, Hey, Mandy, go in and get everything from your cubby. You're switching to the other class. And I grabbed all my stuff from my cubby. And we walked down the hallway with all these other school people who probably hated my mom because you're not allowed to do this.

Amanda

And I don't know how they got how she got them to agree to do it. But I switched to the other class. It must have been early enough in the school year that that's why I think it's only a couple weeks because I'm in that year, that class in the yearbook pictures. And I don't know how she did it. But I was thinking about that recently, too, because I tried to do something similar with my son and his baseball team. And I am not as fierce as her because they said no.

Scott

Well, it's, it's, that's a great story. And it's funny because at, at the, in the last part of her life, you were advocating for her, but she started off really early advocating for you way back then.

Amanda

Yeah, she did. She, and she did all this stuff for my sister too. She, my sister gave me a few stories the other day and she just, she fought every battle for us and she never lost.

Scott

Currently, more than 5 million Americans have Alzheimer's, and that number is expected to grow to as many as 16 million over the next 25 years. But ongoing research means progress is being made. Every year, Amanda's dad, Jay, helps to raise funds to honor Linda by participating in the Alzheimer's Association Walk to End Alzheimer's. So even if you don't have a friend or loved one with this disease, you can help. Even a small contribution is appreciated, and it's money that goes toward an important cause. I kicked in a few dollars and I hope you will too. The walk is on Saturday, October 17, which happens to be the day after this episode goes live.

Scott

But the fundraiser is open till the end of the year. Check the episode notes for the link. And at that same link, you can see pictures of Amanda and her family and the picture of her mom at the baseball game. All of this is at whatwasthatlike.com slash 272. Have you ever been surprised because you won some money? We want to hear about it. This week, the question in the Facebook group is, how much money did you win unexpectedly and how did you

spend it? You can answer that along with the other listeners who commented at whatwasthatlike.com slash Facebook. Graphics for this episode were created by Bob Bretz.

Scott

And now, it's time for the listener story. We end all the main episodes this way. It's just a short story sent in by a listener. And it's really easy to do. Just record it on your phone, like 5 to 10 minutes, and email it to me at scott at whatwasthatlike.com. This listener talks about a vacation that didn't go perfectly. Stay safe, and we'll see you next time.

Listener story

I was headed to Colorado, just me and my three daughters, ages of about 5, 9, and 11, and our five-month-old puppy. We were going to meet my mom and stepdad there for vacation. I didn't realize that the gas gauge on our truck wasn't working properly. And I thought I had plenty of gas to get to the next town. The gas light wasn't even on, and the next town, I could see it about three miles ahead of us. And all of a sudden, the truck sputtered and quit running. I called AAA, and they figured it was just out of gas. But when they put gas in it, it still wouldn't start.

I had no idea what to do besides just have it towed to the nearest dealership. At the dealership, they figured out what happened was it did run out of gas, and when it did, it burned up the fuel pump that was located in the gas tank. And when that happened, it somehow fried something in the electrical system, and it was going to take three to four days to fix it. We were nine hours from home and about eight hours from my mom and stepdad in Colorado. My husband was either working overseas or across the country at the time. And me and my three daughters and our puppy were stranded in Dumas, Texas.

I decided the best thing to do would be to rent an SUV. and go on about our vacation, then pick up the truck on the way back. I called a rental company and was able to find an SUV, but it was 45 minutes back in Amarillo. They were not interested at all in delivering the car to me. At this point, I'm feeling trapped and pretty hopeless, and I'm barely keeping it together. I asked the person running the dealership if they had someone that could give me a ride to Amarillo to pick up the rental, and they just flat out told me I was shit out of luck on that one. I finally reached the end of my composure, and I started crying hysterically.

Suddenly, the dealership guy felt sorry for me and said, oh, they have somebody that can give me a ride. We got our rental, we went back to Dumas to load everything from our truck, and finally got headed to Colorado. We had a great vacation while we were in Colorado. But a week later, when we got

back to Dumas to pick up our truck, it still wasn't fixed. We had to spend another two nights in a hotel waiting on them to get it fixed. So $4,200 later for the cost of fixing the car and renting a car. Then add the cost for another two nights at a hotel.

And the cost of having to pay a fine in Colorado at the hotel because I tried to sneak the puppy in without paying the pet fee. I mean, I thought maybe I'd get some good luck in there somewhere, but no, of course not. Then the cost of the vacation itself, I really have no idea what that vacation ended up costing me. To this day, I still hate driving through Dumas, Texas.

i always want to flip that dealership off as i go by i can't believe i had to lose it like that before they had any compassion for me the gas gauge on the truck did malfunction on the way back but i wasn't taking any chances i'd fill up every two to three hours and just a little note i remember back in the day if you ran out of gas The car would just die, and you'd just get more gas, be on your way. But most vehicles today have a fuel pump in the gas tank, and the gas is what keeps the fuel pump cool and keeps it from burning up. So, don't run out of gas.