

Daughterhood the Podcast

Episode #86

Dementia Daughter: Navigating the Medical, Legal, and Emotional Journey

Resources Mentioned:

[Daughterhood](#)

[POLST](#) Physician Order for Life-Saving Treatment

[MOLST](#) Medical Orders for Life-Sustaining Treatment

[Being Mortal by Atul Gawande](#)

To find your local [Area Agency on Aging](#)

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[Aging Life Care Managers](#) (Formerly Geriatric Care Managers)

[CSA](#) - Certified Senior Advisors

[Anosognosia](#)

• 45:54

Rosanne Corcoran 00:13

Hello and welcome to Daughterhood the Podcast. I'm your host, Rosanne Corcoran, Daughterhood Circle leader, and former primary caregiver to my mom, who lived with vascular dementia for 12 years. Through that journey, I experienced every phase of caregiving firsthand: the heartbreak, the joy, and the aftermath. That journey showed me how vital support and connection truly are, and that's why this podcast exists. No matter where you are in your caregiving journey, I'm so glad you found us, because caregiving is far too much to do alone. So welcome to Daughterhood, the podcast, part of the Daughterhood community, where we empower caregivers to navigate both the practical and emotional sides of caregiving together. Here, your efforts aren't just good enough; they're heroic, and here, you're never alone. Join me in daughterhood.

Disclaimer 01:05

Before we dive in, I just want to share a quick note. This podcast is part of the Whole Care Network. The conversations you'll hear are here to inform and inspire, but they're not a substitute for professional advice. The views you'll hear are those of the host and guests, and may not always reflect those of the Whole Care Network. If you have medical questions, please talk with your doctor, and for legal advice, check in with your attorney. I'm so glad you're here.

Rosanne Corcoran 01:28

Dementia is not just memory loss; it can start with small changes that are easy to dismiss: the mail piling up, repeated purchases, getting lost on familiar routes. Nicole Smith knows this firsthand. A mother of five, she became a dementia daughter and a long-distance caregiver when her mother, father, and stepmother all began experiencing cognitive decline just as the pandemic hit. She wrote the guide she desperately needed, "Diagnosis dementia: Your guide for elder care planning and crisis management. And today, she's a speaker and advocate for dementia awareness and proactive end-of-life planning. In this episode, Nicole shares how to document what's happening, prepare for medical and legal decisions, and find support before caregiving becomes overwhelming. We also talk about the emotional side of dementia care, including grief and resistance, and why flexibility and compassion matter so much. I hope this conversation resonates with you, Nicole. Your book, *Diagnosis Dementia*, really captures both the emotional and practical realities family face. From that first moment something feels off to navigating everything that comes next. What do you think people most underestimate about that early stage and what felt most overwhelming for you personally.

Nicole Smith 02:44

For me, it was just kind of a a slow roll into the unknown, and then it definitely got overwhelming. Like I think people, a lot of people underestimate the little signs. They miss the little signs. That's what we missed. I called them the "That's weird" moments, the "That's weird stuff" that mom was do would do, and I just was like, whatever. And you know, I initially probably thought, "Oh, it's old age, or she's, you know, I just haven't met her around her in a while because we lived on opposite coasts, and you know, I talked to her on the phone, and I would see her every, you know, a couple times a year maybe. But so some people, it's just you miss them because you don't. I didn't know anything about dementia. I didn't know what that meant, you know. And then other people, they know something's off if they live closer, but they're they're in denial. Like they don't want to go there. They don't want to admit it. They think it'll just go away, you know. For different people, it's it's different things. But I was just completely clueless.

Rosanne Corcoran 03:43

Well, when you say they miss the signs, what kind of signs are you talking about?

Nicole Smith 03:47

So initially, it might be, oh, the mail is piling up, or wow, they're getting a a lot of requests for donations. I wonder why that is, because they write one or two checks, and then and then the the email list gets passed around. The fridge has food, moldy food, too much food. Like my mom would go to the grocery store and just buy the exact same thing every time, regardless of whether she was out of it or not, because it was routine for her. So she had 15 boxes of Ritz crackers and five things of blueberries and six things of lettuce, and so they just don't register the the normal daily activities or cooking, planning, financial management, and these are the instrumental activities of daily living. Right, the the higher cognitive load stuff that starts to go first, and then then it kind of deteriorates from there. They get confused in normal places. They get lost. She was getting lost. Look, going to my nephew's soccer games, and my my sister was just like, whatever, you know. So, you know, they were supposed to meet for dinner, and she'd be two hours late. My mom was never late, but she totally got lost. But then she would try to fake it. Oh, I was just cruising the California hills.

Nicole Smith 05:03

Right? Right.

Nicole Smith 05:04

Okay. So there's a lot of signs, and but if you if you don't know anything about dementia and you're not around your parent, you're you don't you don't have a clue,

Rosanne Corcoran 05:13

right? Right. Why would you think that?

Nicole Smith 05:16

Yeah. Yeah.

Rosanne Corcoran 05:17

Especially when you know when we're still in that stage of it's a memory. Oh, I just forgot something, and it's so much more than I forgot something. And I think people get stuck in the well. I do that too, and it's like, yeah, you might, but these are a string of things that are bigger issues, and it's you know you you said cognitive load. Talk to me about cognitive load.

Nicole Smith 05:43

Well, the the thing they use a lot in the dementia training is brushing your teeth, right? So we we automatically brush our teeth, but the in the dementia training they break it down. Think about how many decisions or actions that you have to go through to brush your teeth. You have to get your toothbrush, you have to get the toothpaste. You have to unscrew the cap. You have to put the toothpaste on the toothbrush. You have to bring it to. So, I mean, to to us, this is just automatic, right? I go to my mom several times a week, and I'm and they brush her teeth like most of the time, but I'm when I'm there, I'm doing the the dental hygiene stuff because they won't floss, so and she gets a lot of stuff stuck in her teeth. So I, I'm, I'm like, okay, let's. So even right now, she's like, she can't find the sink. I'm like, we're going to the sink. What, what's a sink, right? And then we do the toothbrush, and then we do the floss, and then we do the mouthwash and stuff. So I'm just doing those little extra daughterhood duties to try and help her keep her teeth.

Rosanne Corcoran 06:39

No, I get that, and it's it's funny because again we don't think of it as a neurological progressive fatal disease, and I think that's where people, you know, when it comes to well, oh, my mother would never wander away from the house. No, your mother without dementia would never wander away from the house, but you don't know that, and that's part of the the challenge in all of this is trying to learn. You're learning neurology. You're learning a different language to be in the system. You're learning all of these things, and it's very. It keeps you very off balance.

Nicole Smith 07:13

The analogy I always make is: I was like, when going through this, it's like learning four new languages simultaneously while under duress, I had to figure out the legal, the medical, the financial, and the caregiving has its own language. All you know, ADLs and CNAs, and you know all the the drugs and

the the conditions. And yeah, I mean, talking about the keys or memory, like it's not just memory loss. Or I tell people like I I have like 16 pairs of readers, and I still lose them 16 times a day. But I'm like, oh yeah, I was in the laundry room, I was in the bathroom, I was in the garage. I left them in the car. Like I, I can retrace where I left them, and and with keys you can retrace your steps or kind of figure out what you were doing. But a person with dementia can't retrace. They, you know, they're they're living in the moment. One of my favorite like weird moments that I mean we were fully in dementia and I took my mom to lunch and we were at this cafe, and you know she was eating and she was done so I kind of took it away and packed it up to to go and I was still kind of eating mine and she looks at me and she goes well am I gonna get something to eat and I had literally put the salad in the bag like 30 seconds ago, and I was like, "Oh no, yeah, sure, I'll get your salad. Here's your salad. So bizarre,

Rosanne Corcoran 08:32

Right

Nicole Smith 08:33

This is dementia. You know, she was mad. It's like, "Well, where's my food?"

Rosanne Corcoran 08:37

Right. Meanwhile, you're like, "Oh my goodness, you just ate. Like it's.

Nicole Smith 08:41

I mean, it's just typical. I mean, I knew I. It was just funny, but because I know all this stuff now, but it still presents itself. Itself. I was like, oh yeah, yeah. Here we are.

Rosanne Corcoran 08:50

Well, yeah, and that's. It's hard to deal with that as a caregiver, as a daughter, as a spouse. I mean, it's it's hard to deal with those things that come up because that's the reality of where you are.

Nicole Smith 09:03

Yeah, and my dad. So my stepmom has dementia, and my dad has normal pressure hydrocephalus, but he had the shunt put in his brain, so he's good to go. Like I tell people, that's really kind of the only curable dementia is the normal pressure hydro. If the shunt works for you, and it did for him, and you know, so he's my stepmom's been in memory care a year now, and you know he experiences all the same frustrations. And she's got really bad incontinence issues, and he tries to take her to church and try, but he can't go in the women's bathroom. And you know it's just all the things, and we talk all the time. And I try to help where I can and go visit, and but it's it's different if you're a spouse versus a daughter, but it's all hard. It's all

Rosanne Corcoran 09:43

Absolutely, absolutely. Well, you know, there's also that really long gap between, geez, I think something's wrong, and getting them to their primary and then getting them to their neurologist. So, what can caregivers, daughters, sons, what can. Do in the meantime?

Nicole Smith 10:01

Yeah, well, just realize like not all primary care physicians have a clue about dementia. So you know, you it depends because some of them, some of them just say, "Oh no, you've got depression. Oh, it's midlife crisis. Oh, let's just you know let's just give you some meds. So just make sure that your primary care physician knows about dementia. Like here in Arizona, I think we're pretty good. Like Arizona, Florida, you've got we've got a lot of elders, so hopefully they kind of you know know what's going on because it's everywhere. And then I would just say start documenting stuff, document all those that weird that's weird moments, document what you saw, what happened, what you did. So we, my mom finally got to the neurologist. It's hard to get an appointment, and she was in a good healthcare system in LA. And my aunt, the nurse, was like micromanaging that process. But even with the the follow up, we had the baseline appointment, and then with the follow up, I had to like surreptitiously give this list to the receptionist to give to the doctor before we went in, so that she would know what we had been dealing with. She fell down the stairs twice. She was fine. She, we think she had shingles, but we, you know, I this was during COVID, so we didn't have eyes on. And and but she, you know, the weird things she did. We had to document the grocery store list and the falls and the, you know, just like to start a journal, a document, a Word document, a Google Doc to capture the dates and everything going on because the doctors like history. They like you know kind of something to a reference point. So just start documenting everything because you forget. I still have a running log for every single thing that happens to my mom, my dad, and my stepmom all the time. Anything comes up, I document. So you know, just notepad on your phone, however you like to to keep track of things. Just start keeping track because it gives you perspective. Because you forget, and then you can kind of trace the progression. Yep, and it's because when you go in and say, "I don't know, doctor, something's just off. That doesn't. That's not going to work. Doctors need data. They need data. Exactly. We all need

Rosanne Corcoran 12:03

Data. Yes. Yes. Then once they, you know, once you finally make it to the mecca of the neurologist and you get a diagnosis, what are the questions to ask the neurologist?

Nicole Smith 12:15

Yeah. Well, there's this saying that circulates as you get the old diagnosis and adios. Like, yep. And then, and that's what my stepmom got. Yep, yep, she has aphasia. We'll see you in a year. Okay, great, thanks a lot.

Rosanne Corcoran 12:27

Here's your hat what's your hurry? Yeah, yep.

Nicole Smith 12:29

So yeah, so we as caregivers, we have to be proactive and figure it out. The things are getting better. There's you get more than the random pamphlet, but I mean you know there's places like daughterhood, but you just you need to say okay, you know what? What are the resources? What resources do you have? Are you connected with any local caregiving groups, memory cafes? Like I went to a presentation the other day. He he works at the Alzheimer's Institute. He's a doc. He's a psychiatrist. So sometimes you know you get into that psychiatry, the neuropsychiatry. They're more helpful in how do we deal with this with our family members talking about it, preparing for it. But there are more resources. But ask them first. Like, is there a caregiver center? Do you have your own

support group? Do you coordinate with them? A lot of times they'll bring elder law attorneys. Just say what you know. What resources do you have? And if they're like crickets, then you just gotta start figuring it out on your own. But there are resources everywhere: the area agencies on aging, the library, the Y, the senior center. So I mean, you just have to go digging a little bit. But there, there are resources there. But you might not get them from your doctor. Just just don't, you know? Don't expect it.

Rosanne Corcoran 13:41

You were flying back and forth from coast to coast trying to help your mom. How were you able to try to balance or find some semblance of balance in that?

Nicole Smith 13:51

Yes. So, well, first of all, don't shit on yourself. Never should on yourself, right?

Rosanne Corcoran 13:55

Yes.

Nicole Smith 13:56

I yes, and I am so grateful. Like I was super lucky in that my mom's older sister, my aunt Nancy, who has been a nurse for half a century, and was very much embedded, engrossed, invested in caring for her sister as I was in caring for my mother. So we were a team working this thing from the get go, and basically still are. So she was my rock, is my rock, and and vice versa. Like we talk all the time, we were talking all the time, we were crying, we were collaborating, we were sharing notes, and I mean, we I I had a 24/7 you know helpline in this person on call, so I I was lucky. So you I feel like you you had to join a support group, find a support group for caregiving. There's a million of them out there, but also find one you like. But also find see if you can find just one person that can be your you know your three a.m. person, your vent person, your support person. So whether it's your spouse or maybe a sibling or maybe. A neighbor or a coworker, someone that gets it right. Either you know, she and I were kind of going through it, kind of at the same time. Our their older sister had vascular dementia for about a decade, so she was in on that one too. But if you can, if you know, just find somebody, and and maybe it's not even someone you're super close to. It might be in that outer circle, but if if you can at least find someone you can rely on, because you you just need somebody to rely on. Just when you're having that moment and you're just like, I am so done.

Rosanne Corcoran 15:30

It's it's too many things at one time. It's like you're juggling knives all the time. When it comes to legal, financial, housing, all of that, they're all overwhelming separately, and then when you put them all together, where does a caregiver even start when it comes to legal issues? We'll we'll go one at a time. Legal issues.

Nicole Smith 15:49

Well, legal. I that's what I always start with because I say you know have your your power of attorney for medical and financial done for yourself, your parents, and your kids over 18, so that because those are they're very state specific, but those are kind of like the the starting points that that get you access that are allowed because you know you've got HIPAA, you've got bank accounts, you've got I mean

you've got it gets it gets exponentially confusing from there, and not everybody needs to have a trust and the will like everyone's like oh do your will will is just like your stuff who gets the dining room table? Like who cares? I need into the bank accounts. I need into the portal. And I always just say, if you you know, please try and use an elder law attorney in your state because they know there's these document preparers and yeah, and you can download a form online and fill it out. But you don't. You really you know is that going to hold up in court? I I don't know. I'm not a lawyer, so I would say start with the powers of attorney, and and that's not. It took us two years to get that from my dad because he was under the impression it's a very valid superstition. If I do my will and my documents, I will die. Right, and I mean that was real for him, and so we were. You know, luckily we had a good relationship. I flew in. I'm like, I hired an attorney. I'm going to go talk to him. You can come if you want to, but I, you know, I need to get prepared because that's why I keep trying to get ahead of the game when there's a little bit of calm. I'm like, okay, what do I need to be reading next, looking at next, doing next? It's you know, it's caregiver whack a mole is what I call it.

Rosanne Corcoran 17:15

Yeah, yeah. And it's very interesting that you say that. Everybody thinks about a will, and they do, but they don't think about, and if you're unconscious, and I have to make a decision for you, what decision am I making?

Nicole Smith 17:27

Also, it's like okay, the advance directives and everything. Well, you know, if if I'm in a coma, just pull the plug like that. That is just like there's so much more to it than that. Yes, that is again, it's not like the movies, like Barbara says, right? Barbara Carne says,

Rosanne Corcoran 17:41

"We do not die like we do in the movies. Yes, yes,

Nicole Smith 17:44

Exactly. So, yeah, just stop watching movies or stop believing. So that's why I read books. I that's the real deal. Getting the books, like Atul Gawande and his book, like that's that's where you get the good

Rosanne Corcoran 17:54

Being mortal. Yes. Well, and and the other thing is like the pulsed. Look, in Pennsylvania, it's called the POLST. They're called you know MOLST, but it specifically asks you these questions, and they they are gut checks. But it's better to have this information than go through the rest of your life with the trauma, thinking you did the wrong thing. Th

Nicole Smith 18:15

The guilt, the

Rosanne Corcoran 18:16

The guilt.

Nicole Smith 18:17

Yes, yeah. So physicians' orders for life-sustaining treatment or medical orders for life, and these are physician documents. So that's the other clarification I like to make. So some of these documents are legal, and some of them are medical. So you've got your lawyer, and then you've got your doctor, and the polst and the bolst is more, you know, the detail: DNI, DNR, DNH, like all that stuff. But it's more end of life. And then my mom has one, so I follow Dr. Brittany Lamb. She's a ER doc. She's amazing, and so she she likes the Maryland version, which is a most I think. But it's got all it's like very detailed in the categories because, like you said, state by state, the legal documents are different. State by state, your physician documents are different, so you you have to figure out, you know, who get those professionals in place to create these documents. Yeah, it's yeah, and then financials a whole other.

Rosanne Corcoran 19:15

Well, right, you don't know what you don't know when it comes to finances. How do you have these conversations, Nicole? Because at this point, you know, if the time has passed, what do you do, and how do you bring it up if the time hasn't passed?

Nicole Smith 19:29

Well, that was one thing I didn't understand initially. Was um, okay, well, if because my stepmom was getting diagnosed with dementia, and I was like, oh my gosh, we we got to do these legal docs stat. So it's a gray area, right? So if you have a legitimate elder law attorney, they're going to be able to determine if the person has capacity to sign these documents, and usually at the beginning they do because it's it's a slow going. So you know, get get those documents done, and and I also say it's like it's a relationship, it's many conversations, and. It's two steps forward, one step back. So, and it's it's empathetic, and so you don't just want to like show up and be like, okay, I need access, I need legal documents, I need you know, because my mom, my gosh, like she had all your documents, but that was a another nightmare in a different way. But she thought she could stay in her house forever. She was staying. She wasn't leaving. I have all the money in the world. I'm like, no, mom, you're you're running out of money. Well, you know what are you doing? Looking at my checkbook. How do you know you're not? You know, you're not in charge of me. You're not the boss of me,

Rosanne Corcoran 20:27

Right.

Nicole Smith 20:27

Because the a had set in the paranoia. You're stealing things. You're you know. And then because I got really good at therapeutic fibbing, I was stealing passwords and documents and hiding things under the mattress because I'm like, you know what? This is untenable, so I'm going to use this memory loss to my advantage to figure this out. And so, the other thing that I didn't understand is that the the elder attorney in LA kept saying, "Well, if she's not going to leave her house, we're going to have to go for guardianship, guardianship, guardianship. And I was like, I didn't think I wanted to do that, but I wasn't sure. But we were we were getting desperate, and so when I finally said, "Okay, let's pursue guardianship, and he and I said, "Okay, so then we can move her out of the house in like you know a couple weeks, and he goes, "Well, I'll get the court date expedited, but it's like six months. And then what he didn't say is \$10,000, and I'm like, "What? Right. So luckily, she ran out in the middle of the night, and all this other chaos ensued, so we didn't have to do guardianship. So yeah, can you when

can you say, thank goodness, mom ran out in the middle of the night and we lost her, and you know that was good for us, right?

Rosanne Corcoran 21:32

Right.

Nicole Smith 21:32

So yeah, so that sometimes they'll say, oh, guardianship and conservatorship, and you don't you don't really want to go there. I proceed cautiously with that. So again, going back to the finances, right? You can use an elder law attorney to spend down to Medicaid, or you can private pay like we do, which is astronomically high, and they they have you, they've got you. You don't want to move your parent again, so they can just jack things up, jack up the prices. Private equity is getting involved, and you know it's it's a runaway money train. So unfortunately, yeah. But there, I mean, there are things you can do. There's provost bronson services. But again, I mean, again, this is a lot, right? How are you supposed to understand all this stuff? That's why I'm saying, you know, listen to the podcasts, read the books. Well, who has time to read books if you're caregiving and not sleeping? But I know, right? Yeah. So, but I, what I would say, just find you know, find again, find a person, a way in, somebody in the system. Like I mentioned, that my friend worked in senior living. She was in sales for one of these, you know, continuing communities, life plan communities, and so I was like, "Oh! So I just started firing her with questions, and she had the answers. She's like, "Oh, well, talk to a geriatric care manager. Talk to this. Talk, you know. And then I became a certified senior advisor, which is kind of like a geriatric care manager. Manager very light, but I I know the resources. I know who to talk to. And anyway, so she pointed me. She was my entree into the language and the and the resource pool, and then now you know I try to be that for others because

Disclaimer 23:08

Yes, yeah.

Nicole Smith 23:09

But you just it's a lot,

Rosanne Corcoran 23:11

yeah. Well, it is a lot, and you know I can't stress enough the importance of elder law attorneys because I see it. I'm sure you see it when people are posting online. Like I live in Missouri, and I'm trying to decide if I should do. And it's like, no, no, no, no. I'm you. You have to talk to an attorney. Please don't just throw it out there, and then you have 14 different responses of, well, I did this. Okay, like it's it's a big deal, and it's overwhelming. And I know everything costs something. I know that it does, and I know that it's really hard. But who am I spending it on? Elder law attorneys, because they know they know the they know the rules,

Nicole Smith 23:49

Right. And you, I mean, you get what you pay for, right? I mean, if someone says, you know, oh yeah, I'll do your trust, will, and estate for \$0, guess what? You're going to get zero efficiency.

Rosanne Corcoran 23:58

Yeah, yeah.

Nicole Smith 24:00

Well I mean, I often say too. Well, if you don't talk about this stuff and get the professional on the front end, guess what? You're going to probate, and that's expensive, and that's delay, and you don't know the terms. Like I see on Facebook and stuff. Oh well, you know, my mom's in memory care, and I'm the executor. I'm like, no, the executor is when they pass away. Like you know, they don't know the terms. They're using them incorrectly, and I mean that's just the the beginning of it. So just don't believe what you read on Facebook, right? Right. I want a person. I don't want to like click a million ways down a rabbit hole on a website. I I just again to get the the lay of the land. See if you can find a person that will talk to you because you've just you've got to start somewhere, and for everybody, that that may be somewhere different,

Rosanne Corcoran 24:44

Right. This is all what adds to the frustration and the overwhelm and the isolation and everything that goes with caregiving. What can, how can caregivers work with their person when they're putting up the roadblock? Like I, I'm not, I don't need your help. I don't want any help. How do how do you navigate that without damaging your relationship?

Nicole Smith 25:05

Well, in in the case of dementia, you have to understand that you know their their reality is the only reality. So you can't argue with them. You can't correct them. You just have to figure out, just agree, and and segue. Or again, like I did, I I got yeah, I got devious, and I just I was like, okay, she's not giving me this information. I'm gonna go digging. So when she would take a nap, I would sneak into her office and start. So I, I mean, I just was. It was in her best interest, and I just did what I had to do. So every situation is different, but also everybody's gonna be reluctant, right? It's the it's that phase of life where it's you're beginning to rack up the losses. You're losing friends. You're losing independence. You're losing your facilities. You're losing memories. You're you're losing everything. Right. You're. I mean, so to have empathy about that and not be scolding and well, no, you're not driving and you're not cooking and you're not. So figure out a way to how how can we help you maintain independence by bringing in someone to you know I hate cleaning the toilets I hate do why don't we bring someone in to someone to clean the house or someone to hang out with you or you know just some interaction and and a little bit of help because mom I'm you know I'm struggling here I'm working. I got my kids. I I can't be here all the time. And how can we work this out together? Because give them agency and ownership and ability to make decisions for themselves with your conversational encouragement.

Rosanne Corcoran 26:36

Yes, I love that. I love that and dignity because it plays a big part in this, and what goes along with it-that it's that simmering underneath the surface of of dementia and dementia diagnosis-and it's grief, and grief runs with it, because you're you're grieving the relationship you had with them, you're grieving for them, even though they're they're with you. How do we deal with that? How do we deal with the anticipatory grief of "I'm going to lose them" I'm watching this and witnessing it. How can you try to cope with that?

Nicole Smith 27:10

Yeah. Well, again, a support group, right? Talking about it, not not burying it inside because then it's going to come out as frustration and yelling at people and your health suffering. So I in my own way, so I feel like I'm, I'm more. I mean, I'm emotional, but I'm more practical, and I'm still literally on the caregiving whack-a-mole. Just what do I got to do today? What's popping up? What's coming up next? What do I need to do? And and I, yeah, I say that the caregiver, the undercurrent of caregiver stress is constant, so right. I get I get a letter in the mail from Medicare or Social Security, and like my heart stops. Yeah. Or I get a text from memory care, and my heart stops. You know, and they are the they're so good about it when they're like, "Your mom is fine. I'm calling about. You know, and they're so good. Like at the school too. Like you know, you get a kid called right the nurse. Yeah. Yeah. Okay. Okay. You know. So um. So that is great that they're they're good with that, but I um, but I will say, oh my gosh, before all the dementia stuff, um, well, my dad had he he fell out of the attic and wrenched his shoulder and had to have like you know throat shoulder surgery, so I was not there. My stepmom was there, and I called him just you know like a couple days post op, and he was home, and oh my gosh, his he sounded like he had aged a decade, and it it hit me. I'm like, oh, I'm gonna lose my dad. I'm gonna lose my dad, and I was like, oh, it just hit me right because I didn't, and so I've talked to him every day or every other day since that day six years ago, five years ago, whatever. And so, but because then we were closer because of me constantly checking in, then I was able to get the legal document. It's okay. Then I that well, even he said to me the other day because he just had another like he had an MRI and he had you know he's fine but I said well I'll be in touch and he said I appreciate your touch so um but so I had a wake up call for with him and mom again like mom's good like I called she's like trapped and drugged and fat and happy so I'm like, well, because it's been a long haul, and she is so she's good, but she would be horrified to know the state she's in and the stuff she's doing. She would be horrified, mortified, and you know, I'm like, well, there's nothing I could do about it. Just thank God, you know, you had the asset that we sold to pay for this care, because I don't know if I'd be shelling out 10 grand a month of my own money for this. I don't know if I. I don't have it.

Rosanne Corcoran 29:48

No, I. I. I mean, who does? Right. Thank you for sharing that, Nicole.

Nicole Smith 29:53

Well, I. It like the tears just come. Like so, I feel like I get my emotions out in little bursts. Like I don't. I don't hide it. I don't. Don't know when to expect it, but yeah, you you don't know. And when they all pass, I don't I don't know what how I'm going to feel. I I have no idea because it's very individual, right?

Rosanne Corcoran 30:11

Absolutely, it absolutely is. And you know, you're I'm going to take a minute here because you're you're caring for you have five children, and you have three parents that you're caring for, and it's a lot, and a lot is an understatement, like the biggest understatement there is. What do you? What do you? The in in flying back and forth across the country, or or grasping for the conversation over the phone, and dealing with that, and your children interacting with both sides of this. How in the world do you do this?

Nicole Smith 30:47

Well, I think I'm just I'm lucky that I always tell people I'm not a doctor, I'm not a lawyer, I'm not a financial advisor, I'm not a social worker, but I am a communicator and a delegator. So I I mean I'm I could talk till the cows come home obviously, and I'm lucky that, like I said, I have my aunt, have my husband, and I'm not afraid to ask for help, talk about it. Like a lot of people, you know, the shame and the blame and the guilt. I'm not going to talk about what's going on with my parents. It's not, you know, it's not kosher conversation. But I, you know, I'm, I'm letting it out to the world, you know. I'm I'm not afraid to talk about it. I bring it up. Like my husband's like, oh God, here she goes, dementia. Like I, I find someone in the grocery line to talk about. Oh, dude, dementia. Well, because I just I I feel like we need to talk about it and aging and and all that stuff. So I'm lucky that too that I you know I had the the resources to fly back and forth because you know air air tickets aren't cheap. No, and um and it also to me like I don't mind flying. I fly all the time, and so you know that six hour flight was a kind of a time to read and listen to things and kind of and write and and process. So that was kind of like my alone time when you're in this little seat and you're just kind of like, okay, what's going on here? What can I do? Where am I? Who can I collaborate with? And so, so that was that was very helpful for me to process. But at the beginning, I didn't know if we were allowed to share my mom's diagnosis or what's going on. But her her neighbors knew two years before we did because they saw the signs. But they, you know, they're not going to pick up the phone. They didn't they didn't know me or anything about me. And like, what if you think, oh yeah, I'm your mom's neighbor. She's got dementia. Better get over here, stat. Like what? Like

Rosanne Corcoran 32:34

Right.

Nicole Smith 32:34

We've talked about this. You can't compare. Like, well, my situation's worse than your situation.

Rosanne Corcoran 32:39

No

Nicole Smith 32:39

But my mom is not living with me. I, you know, I get to sleep, right? I, I get to be home and sleep. But that's not saying I'm not worried. But I sleep, and my my aunt had vascular dementia, and she lived with her daughter for the last five years, and and her daughter is a saint, like literally a saint. So, this this is like this is no small undertaking, right?

Rosanne Corcoran 33:03

Well, it gets very personal. It gets very personal, yeah, and just

Nicole Smith 33:07

Emotional, physical, personal. Like yesterday, I was there, and they're like, "Okay, well, you know, we're gonna. It's time for her shower. And I'm like, "All right, I'm out, you know, because whenever I like, she loves her caregivers, but whenever I show up, they're chopped liver. Like,

Rosanne Corcoran 33:20

Well, exactly.

Nicole Smith 33:20

Get away, get away, get away.

Rosanne Corcoran 33:22

Right, right.

Nicole Smith 33:22

So if I exit the scene, then they could do what they needed. Yeah,

Rosanne Corcoran 33:25

Yeah, yeah. Well, and and you have listen. You have you've done your research. You've done your your your certified senior advisor now. Like this has put you on a on a completely different path than what where you were before your mother had had dementia.

Nicole Smith 33:40

Yeah, I mean, yeah, yeah. Well, I um, so when my kids were growing up, I was able to stay home with them, and I enjoyed it. But I also had my own stuff, like I I did my own stuff, volunteering, whatever, engaging, and so when all this kind of started, I just like shifted my focus, right? And um, you know, just decide, well, I'm going to learn about this, and what about this? And you know, the curiosity-that's what they're saying. Be curious. Be curious. Instead of like, I mean, I know we all have our moments of depression, and why me, and why now, and why this, and and those are totally legit. But just be curious. Like, how can I figure this out? Be creative. Be curious. Get help. Get help. Get help. Right.

Rosanne Corcoran 34:21

Well, and yeah, I mean, we talk about you know we talk about that all the time with daughterhood, and you know it's hard if you don't have an aunt Nancy, if you don't have your friend that works at the at the assisted living that you can talk to. That is where these groups come in. What have you found when it comes to support groups or finding other people. How does it help you in the long run?

Nicole Smith 34:44

Well, the thing that I tell people all the time about daughterhood, because you know, people show up and they're like, "Oh, well, I heard about this a year ago, and I'm finally logging in. Yeah, caregiving's hard, and you just don't want to add one more thing to your list. So, again

Rosanne Corcoran 34:56

Absolutely.

Nicole Smith 34:56

But I always say the best thing that happens. And literally every single group that we have, every call that we have, is that you know we we're kind of facilitating it or moderating it. But it's when one daughter sees another daughter or son or whoever that's going and like oh oh I I went through that and this is what I did and this worked and they're like oh my gosh all of a sudden they're empowered they're

engaged they they're useful, you know. It wasn't all for naught. Now you know you're passing passing the torch and sharing your heart or knowledge with someone else who needs it right now.

Rosanne Corcoran 35:31

Exactly.

Nicole Smith 35:32

That is golden.

Rosanne Corcoran 35:33

It is. It's reaching back. It's shining a light. It's saying, "Yep, watch that. Watch that pitfall there, because that'll take you down. Yeah.

Nicole Smith 35:40

Yes. Yeah. Yes, and I feel like that is great. But I'll, you know, also again, you just gotta find your people. So maybe it's a neighbor, maybe it's through your faith community. There's all kinds of stuff out there. If you kind of just open the door a little bit and and just kind of get curious, pretty soon you'll find something that resonates with you, and you'll probably find a person in that journey too,

Rosanne Corcoran 36:02

Yeah.

Nicole Smith 36:02

No guarantees, but I I have faith.

Rosanne Corcoran 36:04

Well, yeah, no guarantees, and sometimes it takes a couple of tries, and it's that thing where it's like I'm too tired to try this. I don't. It's like I don't. I don't want to. I'm not taking applications for new friends. I don't. I don't have the energy to put out, but that's where a group comes in because you're not that. That's not what you're doing. You're there to to share, to receive, and to go.

Nicole Smith 36:29

Yeah, or just to listen, right?

Nicole Smith 36:30

Or just to listen. Yes.

Nicole Smith 36:32

ecause just knowing that you're not floating alone in space here. That you you have a an army of 50 million in your cohort, that you can so just even well, I well the other thing too is like you know I'm Catholic and I'm not you know not a super practicing Catholic, but every time I would give up something for Lent or try and do something for Lent, it seemed easier because I knew this entire community was like in this same realm at the same time, like you know, it's not like you were talking about you know what you're doing or what, but you just kind of knew that like it's like an energy,

Rosanne Corcoran 37:07

Right.

Nicole Smith 37:07

Right. I mean, I don't know that makes sense, but

Rosanne Corcoran 37:09

No, it makes perfect sense. And and you hit it on the head. You know that you're not alone. You're not alone.

Nicole Smith 37:15

There's so many, but I mean, still we hear it every time. I I feel like I'm the only one, and because again, they're afraid to talk about it. Because, but I also say, you know what? You know, I was in sales. Like I was just always going, going for the no, so you can move on. But people don't want to give you the no. You've got people that give you lip service. Oh, anything you need, anything you need. What do you need? I can help you. And then you ask for one thing, and they're like, oh, gotta go. Sorry, gotta go. But then you have other people who are legitimate helpers. They're authentic. They know what they know what they're saying. They mean what they're saying. They they come out to help you. So you just gotta kind of know the difference. And if someone you know don't beat a dead horse, if someone has offered to help, but it's clear that they're they're doing it so that they look good on Facebook or whatever, then just move on. Just move on.

Rosanne Corcoran 38:04

Yep, yep. Agreed.

Nicole Smith 38:06

Next. It's true. People, some people just want to appear helpful, and you know they're saying it, you know, out loud, but they there's no substance there.

Rosanne Corcoran 38:13

It's performative, yeah, yeah. I get you. So this is, you know, dementia is a long journey. What would you want to say to a caregiver right now who's just not sure what all of this looks like and where this is going to go? And I don't know if it's something that you wish you knew from the start. It could be something you've picked up in the middle. But what would you what would you say to them?

Nicole Smith 38:35

Well, I just go back to you know find find your people or find a person. You know, because it's again, we're social creatures. If you just bury all this, you're going to implode. It's it's going to affect your health. It'll it'll come out. Like um, I the other quote I always share is, "If you don't make time for your wellness, you'll be forced to make time for your illness because it's going to come. I mean, the stress alone just eats away out our bodies, right? Yes. So you've got to find an outlet. A like I use exercise. Like exercise helps me, brain and body. But I've always exercised, so that wasn't a new habit that I had to add to my schedule. It was already ingrained in everything that I've ever done. So nothing, you know,

I'm not running marathons. I'm just moving my body, just moving my body every day in a way that I like, so you know, if whether it's a walk, but yeah, I I just I feel like people are so important because I just if you can find a group or a person or someone that you can rely on, which isn't always easy because my other saying is everyone is a flake until proven otherwise, because I mean, I you know I don't fault people for it, but they're busy and we all have our own lives. But you know, it's just you know it's just you got to find those reliable folks, and sometimes it is your family because they kind of have to be, but not necessarily. Family can create its own issues too, right? So

Rosanne Corcoran 39:57

Yes

Nicole Smith 39:57

Sometimes it's the opposite with family, but um. Hopefully, you have in your your wheelhouse or your network, or you know, again, it could be a stranger that you meet on a support group or that you connect with. Like I, I just definitely feel like we've got you can you can kind of you can feel a mutual connection when it happens, and it it may come out of the blue, but that's what I would say. Just find find a a group or people or a person that you can rely on, but I'm a super communicator, so it's easier for me. Yes, you are, Nicole. You are. I know to a fault, Nicole. I just want to circle back. You mentioned anosognosia. Tell me what that is. It is the condition where the person has some kind of impairment, but they are not self-aware. They are not aware that this is what they have, and so what it looks like to us in reality is denial, paranoia, accusation, anger, anxiety. So yeah, they're like, "Well, no, I'm fine. I'm fine. No, you know, no, you, you're the one with the problem, not me. Like I've got my finances in check. I've got my house in order. You're the one that's crazy. You have to understand that that is where their reality is. That is where their mind is. So it's not going to do any good to remind them, or I mean, or bring them back to realities. It's it's very common, very common. Yeah, because again, the brain is changing. The brain is changing. Well, the other thing I will say is what people don't understand is the brain. It's not like you get dementia and your brain shuts down. It's it's gradual. So on certain days, my mom was, you know, firing firing on all cylinders and doing her stuff, and then she would be crazy town the next day, and then because you know it just it's short circuiting it's changing, and so when she was on, man, she was undoing everything that we were doing. She was like, "Oh, I got this. You guys are in the fault. What are you doing to me? And I mean, that's that was the maddening part. Like, okay, who who are we going to get today? Which mom are we going to get today? And what is she gonna what what wrench is she going to throw into our progress? So that's what I'm saying. Two steps forward, one step back. Do the dance.

Rosanne Corcoran 42:06

Yeah,

Nicole Smith 42:07

It's

Rosanne Corcoran 42:08

Yeah,

Nicole Smith 42:08

It's a challenge.

Rosanne Corcoran 42:09

It's it's an awful cha cha. Yes,

Nicole Smith 42:11

I like that. It's an awful challenge. Dementia cha cha. That's it.

Rosanne Corcoran 42:17

Because and then you're like, wait, what am I doing? And then and then the flip side is you work something out with them where they agree to it, and then you go the next day, and it's like you never spoke about it.

Nicole Smith 42:29

All bets are off.

Rosanne Corcoran 42:31

All bets are off. Oh yeah, yeah.

Nicole Smith 42:34

That's why you have. I'm sorry. You have to be devious behind the scenes. You have to find people to help you. You have to work a framework. I mean, every situation's different. Like, case in point, my stepmom left the gas flap open on her car one time, and so she's like, "Oh my God, I have to stop driving. Drop the keys that minute. Done, like done. So rare, yeah, so rare. But you know, my mom like months and multiple DMV trips and cars and keys and police and oh, just astronomically difficult,

Rosanne Corcoran 43:05

Right.

Nicole Smith 43:06

Well, I mean, we got to the point where it's we were just so desperate that whatever we're doing whatever it takes at this point because we've tried the conversations, we've tried the help, we've tried the reasoning. Of course, wasn't working, and we tried, you know, we tried all the tricks, and we're like, okay, you know, DefCon one, we're going in.

Rosanne Corcoran 43:24

Yep, yep, because you have to, because their brain is changing, and that's what it always circles back to.

Nicole Smith 43:29

And it's a constant game, right? It changes, and then you do, and then it changes, and it changes, and then you change, and then so

Rosanne Corcoran 43:36

Yes, yes, you put that very well. Yes,

Nicole Smith 43:40

Yeah, yeah. Well, and the other thing I will just say is that everyone's like, "Oh, you know, you gotta have balance. You gotta have balance. I'm like, "Well, balance is by definition, you know, you're balanced for like one second, and then something shifts, and you're out of balance. Yes. So the best explanation I heard from a very wise man a while ago was, "Let's. I like to focus on alignment. Are we aligned in our goals and our actions to to get to this outcome that we desire? Because we know there's going to be weaves and turns and segways and unexpected minds popping up, but we you know we have the the end goal in mind, and we just have to be flexible and we have to be curious and we have to just work through it and understand that it's going to be setbacks, but just it it takes the pressure off. I think you know you're you're in alignment. You're you know you're on track. You just might be standing on what one foot every once in a while.

Rosanne Corcoran 44:31

A big thank you to Nicole Smith for being my guest today. For more information about Nicole, including her book *Diagnosis Dementia*, you can find her at njsmithbooks.com and at various daughterhood circles throughout the month. I hope you enjoyed today's episode and found something helpful, whether it was information, inspiration, or even just a little company. You'll find the full transcript and links to resources mentioned today at daughterhood.org in the podcast section. While you're there, explore more. What Daughterhood offers. We're more than a podcast. We're a nonprofit community providing free services and support for caregivers, including nationwide virtual support groups we call circles. On our website, you can register for a circle, sign up for our newsletter, and read our founders' blog. Don't forget to subscribe and review us on Apple Podcasts or wherever you listen, your reviews help other caregivers discover the support they need. Follow us on Facebook and Instagram at Daughterhood to stay connected. And if you know someone else who may benefit from Daughterhood, share it with them. Also, a very special thank you to Susan Rowe for our theme music, *Mama's Eyes*. This is Rosanne Corcoran. I'm so grateful you spent your time with me, and I look forward to being with you again next time, here in Daughterhood.