

Daughterhood the Podcast

Episode #75

Know Your Person, Know Yourself: Better Dementia Care with Teepa Snow

• 53:19

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Rosanne Corcoran 00:00

Rosanne, 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 01:03

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.

Rosanne Corcoran 01:27

My guest today is world renowned dementia expert, Teepa Snow, occupational therapist and founder of the Positive Approach to Care, which offers training, services and resources to families and professionals worldwide. Teepa has spent decades helping people understand the brain changes behind dementia, and just as importantly, how to support both the person living with dementia and the caregiver. In our conversation, we discuss strategies for interacting with your care partner from mild cognitive impairment on what changes and what stays the same, accepting help from others, why knowing your person and knowing yourself are equally essential while providing care and so much more. I hope you enjoy our conversation.

Rosanne Corcoran 02:07

So much of caring for someone living with dementia focuses not on medical interventions but routines and interactions. Teepa, you often talk about the idea of know your person. What does that really look like in practice?

Teepa Snow 02:21

Really great question, and what it means is, there in dementia, there's always at least two people involved, if you're not the person living with dementia. So one of the people you really need to get to know in this new role is yourself, and the other person you really need to get to know in the place that they are now is the person that's living with dementia. Because if you're just always talking about what the person used to do and how they used to be, it tells me you're having a really hard time knowing them now, because you're comparing them to before, instead of saying, well, here's how they are now. You know, this is where we are now, and so this is what I'm noticing now. So it's not just the past person. I want you to know them, but I want you to know where are they, how are they doing now in these areas/

Rosanne Corcoran 03:09

Right and I think a lot of people get stuck in that when you start to say, well, you know, try and it's like, Oh, mom doesn't like that. She never liked that. And it's like, well...

Teepa Snow 03:18

Yeah, yeah, my mom would never do that. And it's like, I bet she's doing other things she would have never done too Right? Like, it's okay. And some are like, What is she doing? Because that's the dementia on top of where your mom is, and so it's changing her. I mean, I am who I was now. I'm different. I mean, I I can't be how I was, which is what it's all about. I mean, that's really the definition of dementia. I can't be how I was.

Rosanne Corcoran 03:45

Right. And I know one of the one of your things that you don't like is the phrase mild cognitive impairment.

Teepa Snow 03:53

Teepa really doesn't like that, because it's like, by the time people are saying it's mild cognitive impairment, it's like, more than one of us can't live our lives the way we used to live our lives. This doesn't feel mild. I mean, I'm having to answer questions over and over. I'm having to figure things out. I'm having to take over a checkbook, or I'm having to find somebody to take over the checkbook. I'm trying to figure out what happened to taxes last year. I can't find that. You know, where did all the pills go? They were here. Oh, my Lord, what has she done with the pills this time? I mean, that's not mild. I'm sorry. But when I'm living it, it doesn't feel mild. Maybe on some screen somewhere, in some image that you're looking at, it looks mild. And it's like, come spend a day and tell me this.

Rosanne Corcoran 04:36

Right. How do we get past that? Because, you know, they, the doctors say it and then kind of shoo you out.

Teepa Snow 04:41

Yeah, and I think, I mean, it's really interesting to me. I still feel like there's way too many medical support personnel who really are so uncomfortable with this thing that, you know, it's neurodegeneration, tell me how it's going for you. I mean, I wish we could get them into the idea of saying to the person. So if I were to ask. Ask you is, what's happening for you? And I'll ask your your sister, the same thing, your mother, the same thing, your husband, the same thing. How's it doing? How's it going for you? Does it feel like it's like, not a big deal. It's getting to start to interfere with living it's really hard. That would be a better measure for where are we? And I would ask the other person the same thing. And when there's a real mismatch, then I know I'm in trouble. Because, you know, that person is saying, Oh, I'm fine. I don't know why she's so worried. And

you're like, well, because she's, you know, like, had three accidents and she almost cut her hand. I mean, like, Look at this. Look at her hand. I mean, the reason we came in, she had to have 15 stitches because she messed with the knife. I mean, what do you want me to say? This is not how it was my mom. I didn't have to worry about my mom using a knife in the kitchen. Now I do. And so I think, you know, recognizing, for the people who are living the condition, what's their rating of severity? Because this whole thing is an opinion piece, because even if I looked at every scan, there was, it's not a one on one correspondence to how you're living life and how your brain is doing for you, the way you live, because it's really, how are you living, not how is your brain dying? I mean, that's a piece of it, but that's different,

Rosanne Corcoran 06:12

Right. And it's not about, you know, I don't mean to make it sound simple. It's not about, can you draw this clock?

Teepa Snow 06:18

No, no. I mean, yeah. I mean, it's good. I mean, like, if you used to be able to draw a clock, you can't draw a clock. Now I'm curious, what else are you going to have trouble with? But I mean that, in and of itself, unless you know you're drawing clocks as part of your daily routine, doesn't tell me how your daily routine is. And for many of us, our daily routine really matters, and my daily routine is now I'm skipping things that I used to do, like cleaning myself up, changing my clothes. Mean, that's not mild. I mean, if somebody tells me that's mild, it's like, I don't think so, you know. And it's like, well, they have to be prompted. I mean, they can do it, but you have to just say, Hey, Mom, why don't you try that other shirt? I got it out. I thought I laid it on the bed. Maybe not. Oh yeah, there it is, which is real different than mom. I laid this shirt out for you. What are you doing? Because then I say, well, she gets agitated. And it's like, well, I would say someone got agitated. I'm not sure who did it first, but it might have been, might have been you,

Rosanne Corcoran 07:14

Right, exactly, and that that's all part of this, and the interaction that we then have, because we have to see that things are different, we have to accept that those things are different, and then we have to look at it differently.

Teepa Snow 07:28

Yeah, then I've got to realize, wow, so me fussing at her about it is actually escalating it here and that, I mean, that doesn't serve either one of us. So it's like I got a new I have to have new skills. But nobody had told me I would need new skills. I mean, I wasn't on the agenda. No one said with it, with a diagnosis, quote, unquote, or a condition of MCI, I need new skills. I mean, that sounds like we're not there yet. And it's like, and that's where I, you know, run into like. So it feels like I can put it off for a while yet, because it's not that bad. And it's like, well, if you want to call it MCI, I guess, okay, but tell me that when it's MCI, we have some things we should be working on before we get to something more, right? I'd argue that it already is something more

Rosanne Corcoran 08:15

Absolutely that's why we're here. Yes, well, and it's, you know, it's, it's hard also to get a diagnosis to begin with. I mean, I don't know. I don't know how we fix this.

Teepa Snow 08:28

Yeah, I'm not sure either. Because right now, I mean, it can be nine months before you can be seen by someone, and then, if they're in a rush, they had a bad day or whatever. I mean, you're getting sort of an in and out, sort of, well, yeah, looks like this. I'm going to give your 30 questions. We'll see how this goes. I mean, you say I don't want to take this. I don't see why I should have to. I'm fine. And they say, well, we can't make her. And it's like, right, right. I waited nine months for this. Yeah, exactly, I mean, and it's super hard to then, because we needed help nine months ago,

Rosanne Corcoran 09:03

Right, exactly. And now we need more help. And now I'm getting a 10 minute appointment, and it's, it's really interesting, because I've seen you talk about the four truths of dementia, which I think it's so clear for those that have never seen the four truth of dementia, it is, it's a number one is, it's a progressive condition where at least two parts of the brain are dying, causing chemical and structural changes. Two is it's chronic and irreversible, with no current cure to stop or reverse the brain damage. Three, it is a terminal illness that will eventually be fatal. And four, it changes the person, their relationships and their world, it can't be any clearer. Teepa and I thank you for those how do we get people to understand that.

Teepa Snow 09:50

It's so hard because we have trouble with physicians understanding that, yes, they want to do things like stage it, and it's like, well, see her in the morning. See a certain person,

see her in the evening, see another person. I mean, because each day there's variability. But through a day, my brain, your brain, all brains change. And if you're counting an office visit as a scale of what she can do, it's called Showtime, because my brain is not stupid. I mean, it does its very best for me, and boy, can it do a great job for a short window of time. Sometimes, what's missing, however, is this idea that we're living a 24/7 existence, and we're going to need help 24/7 to figure out how to support someone whose brain is not just damaged, it's dying. And so no, people don't like death and dying, but I mean, sorry, I wish it were different. That's what it is. There is no magic elixir or pill that is going to reverse this right now. We have nothing that reverses anything despite what you hear. It can optimize some things, and I'm in favor of optimizing until it irritates you so much that it's not worth optimizing it because it doesn't optimize you. It's like, I'm not wearing my CPAP. It's like, you know, it's really important. I don't care it bothers me, or they just every night it comes off. Every night it comes off, it's like I could stay up, but I'm not getting any sleep, and that means by tomorrow I'm not doing very well, and it's like I gotta do well, because if I don't do well, we don't do well, right? So I wish I had the answer of how to get people to shift their thinking away from, oh, it's a memory problem, right? It's not about a memory problem. It's about brain failure and brain deterioration. And when you hear those words, you know it scares people. I got it, but we've got to quit being scared and start being proactive, or will will get ground under the overwhelming sense of it, right? It's like, well, it's brain change. So I've, I'm a probe, I'm a promoter of, well, you got brain change going on, and it means some things you used to do with ease, you're not doing, and you're doing different things. And some of those different things make sense, and some of them are real challenge. Gotta tell you, right?

Rosanne Corcoran 12:24

Yes, well, yeah. And that's, you know, you always get that question, does she know who you are? And like, okay, yeah, that's heartbreaking, but that's not the worst of all of this.

Teepa Snow 12:39

Yeah so I think, you know, I like to break that apart a little bit, because I think it is so heartbreaking, and people get overwhelmed by it. Yeah, it's like, Okay, let me ask you this, when she looks at you, Does she seem to recognize you as someone that has a positive she's positive about, all right? Well, then she does recognize there's something about your relationship that feels good to her, and that's a plus, yep, all right. Can she if you say, hey, it's Rosanne, can she go, Oh, hey, Rosanne. Okay, that's true. She's

when you give her a name, she doesn't say, Well, no, there's no way you could be Rosanne. She says, Oh, hey, Rosanne. Right. And then three would be if she goes, I have a daughter named Rosanne. And you go, Oh, well, do I look like her at all? Oh, no, she's young, exactly.

Rosanne Corcoran 13:29

She's a lot thinner than you. Yes, yeah,

Teepa Snow 13:32

No I mean, yeah, of course not. No, my daughter is like, she's a cheerleader. Oh, plus, is that she remembered some of your life, you know. So again, how can you take this pain and start to tease it apart a little bit so it isn't this block that sits on your chest and crushes you? How can you start to explore what it's a change and it's there's loss, but there's change too. What's still available? I mean, what's can you create a relationship where she likes you right now, even if she looks at you and she doesn't know who you are? If it's not starting off with, what are you doing here? Get out of here. To me, that's a huge plus. I mean, that's a huge plus, if I could get something positive in a relationship to start with, which means, what did I do the last time I was here? Or what happened before with someone else? Right? Because if she's having trouble identifying you, then I've got to be super thoughtful about who's else around who else is around her, and what, what mood do they put her in or him in? Because now I've not only got to think of myself, I've got to think of other care people that might be in the mix or family.

Rosanne Corcoran 14:46

Yes, and it's because we bring them our moods and they can't change their mood, which is, when you think about it, it's really hard to process that.

Teepa Snow 14:57

It is because if they don't know my name. Name, then, you know, they don't know me. And it's like there's a lot to life other than a name. I mean, there's, you know, there's my face, there's my touch, there's my smell, there's my voice. And so it often turns out, when I in my experience, after you've spent like, about 10 or 15 minutes with someone, they suddenly turn you say, well, when did you get here?

Rosanne Corcoran 15:22

Yeah, I've had that happen, yes,

Teepa Snow 15:25

Well, yeah, a little bit ago. Well, why didn't you come on in? And it's like, good question, I guess it should have, you know, yeah, it's just like brains are fascinating in their own sort of interesting way, and brain failure is fascinating so they can change like that. And so that's only going to happen if you stay, if you're scared, and you run, you never get that experience. And you think she doesn't know me, and it's like, but she can get to know you.

Rosanne Corcoran 15:52

Right that's it's such an important piece of this, because, you know, you also hear, well, what's the point? She doesn't know who I am.

Teepa Snow 15:58

I mean, she may not know you're her daughter. Does she like you as a human being? Can you have something of value, or is it for you? It is all about the she's my mom, and I want her to be my mom. And it's like, it's not uncommon with certain dementias, at least that at some point you got to go, hey Rosanne, rather than Hey mom. And can you do that and be okay with it? Or is it breaking you? And if it's breaking you, you need a break, right? I mean, it may be a big break, I'm not sure, but if it hurts you that much and it pains you that deeply, that's not a good match right now. I mean, it's too hard on you, we'll just have somebody else who's struggling. I mean..

Rosanne Corcoran 16:36

Yep, yep. Because it is, you know, we talk about care partners. It is a partnership. You are in this with them, and you are just as important, if not more important in this relationship.

Teepa Snow 16:49

Because you're the arbitrator of where, where the ship's going to go here. So we got to take care of you, I mean, truly and and sometimes just getting you to pause and take and take stock of yourself and go, I'm not doing great right now. And sometimes having somebody to say, it really hurt when she couldn't say my name, didn't know who I was, and wanted me to come and I'm here, and it's like, yeah, that's, that's hard. Tell me a little bit about what she was wanting from you. And we now, we move, yes, that's really hard. Let's let's get curious about it and figure out what might have gotten us here this time. And that means you need someone you can call and someone you can talk to, and someone you can bounce ideas off. And again, doing this solo, alone, without

anyone in your world, it can eat you up as a human being, because unless you're an introvert, well, even if you are an introvert, you're your own worst critic when you're an introvert, I could have I should have done that better. What did I do? I did something wrong. What should I have done and have somebody else go I'm not sure you do anything wrong. I think her dementia is different today, right? Let's talk about it and taking it and allowing it to be can make a huge difference for folks, right? In my experience.

Rosanne Corcoran 18:06

I fully agree with you, isolation and is no one's friend, no one's no and it's, you know, it's interesting because it's, and I don't know if you have examples of what caregivers can do, to notice, to reveal, like, what is actually happening in this moment. That might not be obvious. It might be those undertones. What? What can they look for?

Teepa Snow 18:30

So some of the things to do is stop, back up and breathe. Um, because sometimes we don't realize how often when something like that happens, we it catches our breath, and we we stop really breathing deeply, and we stop when that happens, our brains are oxygen deprived, and with oxygen deprivation, our primitive brain gets more prominent, and it's thinking, oh no, how awful. And I go into a fright state or light. I want to just get out of this. I want it to stop. I can't do this anymore or fight. She knows better than that. If I just push this, she'll get it or hide. I want to hide from this. I just can't, I can't, I won't. I'm gonna pretend like it didn't happen. It's like, I don't necessarily recommend that, right? Or I seek, I poke and I prod and I like, here, no, don't you remember here? Let me show you the pictures. Now, this is us, and it's like, whoa, whoa, whoa, right? So that whole idea of pausing and thinking, huh, wow. And the hardest part is breathing out, letting go and break the eye contact and just go, wow. Huh? Wow. Okay, hmm, different. So what's one thing she's doing that's okay right now? Yes, we have to get to a slightly different place, you know, like she greeted you. I mean, she didn't slam the door on you. She said, You know, like, come on in, you know. And who are you? And it's not. Opportunity, you know, it's like, wow, okay, you're wanting to know who I am. And so then we go back to our, you know, we teach reflexively, when you don't know what else to say, use the words they give you. You know, they got those words because they had them. Yeah, you're wondering who I am, yeah, well, I'm Teepa. And then if it's, if it's a mom, my grandma, was like, tipa, I have a granddaughter named Teepa, and it's like, Huh? Well, she a good girl or troublesome both,

Rosanne Corcoran 20:30

Right.

Teepa Snow 20:31

Yep So it's that moment where you get to choose, but you don't know you're choosing, and then afterward, a time of reflection. I think sometimes we just go on rather than pausing and go, Well, that was a big event for me, yeah, and for some people, it's journaling. For some people, it may be talking. For some people, it may be out walking and thinking. But I think giving ourselves permission to recover so we can build resilience, rather than taking it in and having this wound that now seeps we need to, like, let it heal. Let it heal over a little bit, so that we can come back and and work again and be again and whatever that, whatever that is for you, you know, and humans are unique in how they want to cope, but I would encourage coping rather than hiding.

Rosanne Corcoran 21:28

Yeah, wow. That's just Yeah, because I don't think number one. I don't think caregivers breathe at all. I think I wore my shoulders as earrings for 10 years.

Teepa Snow 21:39

I love that one. Yeah. I mean, it's just like, you live, like, the other shoes gonna drop. I can be ready for the other shoe. It's like, yeah, you know? Well, she hadn't got in her hand yet. Let's just right, see what we can do to keep it from flinging, you know.

Rosanne Corcoran 21:52

Yeah. And I think also we, we're afraid of looking at that and being in that emotion, because it's like, I can't deal with that right now.

Teepa Snow 22:01

When are you gonna deal with it?

Rosanne Corcoran 22:03

Yeah, we never come back to it. That's the thing.

Teepa Snow 22:04

When will that happen? Because something else is coming down the road, right? If you put it off, it being it's not like it's gonna get easier, no, because you got the rest of the day, and then you're trying to get to sleep. And if it hits you when you go to sleep, forget

it. You're not asleep. You're ruminating. And ruminating, is that thing many carers find themselves doing. I could have, would have, should have, here's what I could have done, here's what I should have done, here's what I should do. This is who I you know, this whole litany, and then your brain revs back up, and it's really hard to get rest, which you desperately need. And so taking that pause after an event to go, wow, that was a rock there that hurt. And just even saying out loud, wow, that was a rock and that hurt, yeah, huh? I that was a surprise, yeah. And I'll tell you, as a carer, surprises aren't fun anymore. No, some people like, I wanted to surprise you, it's like, don't do that anymore. Just tell me. Like you could say, You know what we were thinking of bringing you something to eat. We'd rather have this or this. Don't surprise me coming to the Dory, just fix lunch. Now, what am I supposed to do? And so I'm viewed as being it's like I took time to fix lunch, and now you show up. I wish you had known you were going to do that right. And now I sound ungrateful when what I am is overwhelmed, and it's like, I can't let go of Well, I just spent all this time on this, because now what you pick, she don't even like I mean, she used to like it, she didn't like it now. And now I have to pretend like I'm excited about something I know isn't right. And this is tricky, because then you get rid of your helpers and your supports, and here you go again. And it's like, okay, how do we do this better?

Rosanne Corcoran 23:45

And that's you hit all of it right on the head, as always, cheapa, yes? Because then it becomes, well, I tried to help you and you didn't want it.

Teepa Snow 23:52

Yeah. And it's like, I'm not going to go and get my head bit off, right? And it's like, well, you know, like, so let's look at how that came to be. And when you want to help, reflect Again, pause and reflect. Because those of you who are on the periphery, who are trying to help someone, you know, we get the questions in sometimes like, well, I try to help, she just refuses help. And it's like, and I'm talking about the care support person, not the person living with and it's like, Well, talk to me a little bit about how you did that, because often it's what I think she needs, or she won't take help. Or I, I came and I told her I would take care of her mom for a couple hours, and it's like, well, have you ever done that with her mom before? No, well, I'm wondering what would happen if you came in and said, Hey, I'm going to ask you for a big favor. I'd like to spend some time with your mom while you're here, because I'd like to, I'd like to get to know her as she is right now. Because, I mean, it's been a couple years since I've spent time with her. Is that possible? I brought some flowers, and I thought she used to like arranging flowers

and vases. Is that anything she might still enjoy watching or doing or talking? About, do you think much different? Yeah, or I want to get you something to eat for dinner tonight, and I'm hoping I caught you before you started prep. Is that true? Or have you already started tonight? And again, it's that same idea of establishing permission relationship and not assuming that I come lady bountiful to support you and you'll be great. You know, great. I mean, yeah, I get it, but it'd be not nicer if we it was sort of an equal footing kind of thing. You have something you want to offer, and let's just see whether it's something that would be helpful to you or not.

Rosanne Corcoran 25:36

Exactly I love that. I wish everybody had that in them to be more inquisitive.

Teepa Snow 25:43

Yeah, and I, Rosanne, you make me think of this. It's like one of the things we never talk about, I don't think, even when I get people to think about, you know, there's two of you, right, and you want to learn the art of asking for help, is we need to educate helpers, family, friends. How do we get them started on this journey in a better foot, rather than saying, Well, how's your mom today? I mean, please, yeah. Is she doing any better? How are you doing? You know, I worry about you. Yeah. And instead, Rosanne, would you rather have me bring something sweet or something crunchy? Yes. Are you looking for comfort food or you're looking for health food, because I could stop by and get either one, and I'm open to either,

Rosanne Corcoran 26:25

Yeah, and, but it's one of those things Teepa, where we are then responsible for figuring out where our person is, figuring out what stage they're in, figuring out what works for them, figuring out what works for us. And then we have to tell our people around us. Oh, this, by the way, this is how I want you to care for me. And what happens is, it's like, whatever. Forget my Never mind.

Teepa Snow 26:51

If you can't figure it out I can't tell you. And so we might have a good friend or two, or we might not. We might find and, and I'm number of people that say, you know, I don't have friends anymore. Honestly, I don't have time for him, right? It's like, Tell me about that, because it's like, if you lose the old ones, get some new ones, because you need somebody. Humans are really meant to be in community at some of some level. And I get that, you know? I really do understand that there are introverts who really like to do

things on their own. Even introverts need a space and a place to share, because otherwise it just builds up. And this is where male carers sometimes find themselves struggling to find a space and a place because they're not so chatty as a rule, but they are curious about information that they need. So I have established educational support groups, because I find that they're much more interested in an educational support group, and when we get there, we practice some skills. So I'll say, so I'm asking you, I'm going to ask you, and I'm going to actually ask you four times in a row, just so you know it's coming. Okay. Almost universally, if people are at that place, they go, Oh, my God, this is my day. It's like, yeah, yeah. So let's play with it a little bit, because you know that, frankly, as far as we know, I don't actually have dementia, but I I'm a good imitator. So let's see what happens without you thinking about it. And then let's work on a response that you can build a skill so it moves out of this place. Because from what you've said, where we are is not working for you very well. It's wearing out. So let's see what we can do to get out of this place quicker, because it doesn't seem like it's a good place for you to answer the same question over and over for have the person come and ask you same thing, right? It really is irritating, and I find that once I'm irritated by something, it's really hard not to be irritated by something. So let's try something different, because it's going to be hard for you not when you hear that same question. There's going to be a spontaneous trigger that just goes, right? So one of our habits be waiting on a break, is don't share information so soon, like, like an appointment. So people say, now we're going to go to the doctors this afternoon, after lunch. Yeah, don't do that in the morning. Yeah, and then all morning. So when is the doctor's appointment? It's after lunch. Oh, okay. What time? 1230 Oh, okay, so what time we're going to need to leave? Probably need to leave around 12. So that means we're going to eat at 1130 Oh, okay, all right. Well, thanks, Hey, sweetheart. Do we have a doctor's appointment today? I seem to remember that we have, yeah, well, what time? It is very predictable, because I'm a detailed person, right? I mean, if I'm a detailed person, and you're not, and I get dementia, I guarantee I will wear you out, definitely. Because it's like, well, we're going to go later, mom, it's later. Don't worry about it. Well, what time? And it's like, after lunch. Well, what time after lunch? 1230 it's like, well, what are you mad about I just asked you a question. I want to put it on the couch. Calendar, right? Without thinking it's already on the calendar. I have told you, you put it on the we did this. It's like, Huh? Okay, let's take a deep breath here, because what I can tell you is, did it work? No, all right, so do we need the calendar anymore the way we're using it? No, no, because that's not it. Do we need to share it so early so it comes up as a topic? No, oh, here's a suggestion. Let's try this. Oh, really, you got an opening? Okay, well, let me just, I think we have enough time. Yeah, I'm going to make some lunch, and then

we'll head out. Thank you for letting me know about the opening. I did not know. I didn't even know you wanted to see her. Okay, hey, mom, doctor's office just let me know that they have an opening this afternoon and he wants to see you. So we're going to grab lunch and we're going to go, let's get your jacket, because we're going to eat out, because it's too much work to try to do it here. And I timed it so we're going to have food and then we're going to drive, because I don't want to hear the question, well, why does the doctor want to see me? I'm not sure it's a good question. So we'll want to ask him, when we get there, why he wants to see you. That's a really good question. I'm not sure you know what. Let's get Wendy's or whatever. You know it doesn't I don't care. It's just like all I have to do is cope with this.

Rosanne Corcoran 31:16

Exactly. That's brilliant. And that goes back to the you have to know where they are, and you have to know what your triggers are. And it's a it's a dance.

Teepa Snow 31:26

It is. It's this dance and when you see someone doing something that you know is risky or annoying or dangerous, even you've got to really learn that's a trigger. Oh, my heavens. When I observe somebody doing something and I know it's like, what are you doing? What a stupid statement. You can see what they're freaking doing. I mean, like, right? It's like, Wait, why are you saying it that way? That's not helpful. It's like, oh, Rosanne, because to get that pause, if I sound like you're doing something wrong, I'm going to trigger in you that desire to fight, flight, fight hide or seek. But if I go, Oh, hey, Rosanne, it's like, yeah, it's an interjection that gets your brain to pause and go, oh, somebody wants me, which is really different than somebody thinks I've done something horrible, right? Boy, did that take practice?

Rosanne Corcoran 32:17

Boy, does it ever?

Teepa Snow 32:18

Boy does it ever and I don't care how good you get there'll be a moment where somebody scares the bejerseys out of you, and you sort of go, oooooooo.

Rosanne Corcoran 32:24

Yes,

Teepa Snow 32:26

And you the voice changes. And you know, the voice Rosanne no, it's like, Oops. What did I sound like my mom in a bad day? Exactly? Boy, am I going to have to eat some crow now. Now it's going to be, I am so sorry. I yelled Oh, I had no right to do that to you. I am sorry. I probably scared you with that. Oh, man, that was, that was a bit much. Yeah, I am so sorry. I'm thinking is, my heart is thumping through my chest wall. I thought you were going to fall off that stool. What were you doing? Oh my heavens, you were trying to reach what's up there? Oh my heavens, it's it's nothing. What did you see up there? Oh my heavens, you're having hallucinations, right? There wasn't anything up there. I have no idea what you're reaching for. Neither do you, right? Neither do you. And it's not there. Can't fix it. I mean, I can recognize Wow, Lewy Body and I keep forgetting how hard that is to live with,

Rosanne Corcoran 33:26

Right, Right. Well, and that's the thing, no, you know, you're lucky if you get a diagnosis, and if you do, you still don't get the actual diagnosis. I mean, nobody told me, my mother had vascular dementia and Alzheimer's probably mixed until she was on hospice. Thanks for telling me.

Rosanne Corcoran 33:44

How many years did you do this?

Rosanne Corcoran 33:46

12 Exactly. Like, are you kidding me? So how do we know where, what type they have? By their behaviors?

Teepa Snow 33:56

Yeah and so, like, we actually put together an umbrella card with info on the back. Because, frankly, people couldn't get that anywhere. I mean, they were like, I just need what kind of what could it be? And it's like they read through and they go, Oh, my heavens, I think she has, like, I mean, the symptoms are really consistent for Lewy Body, and it's like, well, if the symptoms are consistent, I'd sort of look at it like, sort of a road map. I mean, it could be wrong. May turn out it's something else, but let's go with that anyway. Let's see what happens. Because I can tell you right now, if it's Lewy Body, Oh, that explains a lot of things. That's why she has these episodes where her blood pressure drops and her heart rate drops, and I think, you know, I'm calling EMS, and by the time EMS gets here, she's fine. She's fine. And they're like, Why did you

call? And it's like, she wasn't, she wasn't hard at breathing, and her heart rate was almost nothing. It's like, well, I mean, she's fine. Now, do you want to take her in? Oh, I can't. I mean, again, I don't know. Does she worked up? It's like, you tell me you're the one who called.

Rosanne Corcoran 34:57

I know and but that's the problem. And. And again, no one's handing us this, except for you. You're handing us this.

Teepa Snow 35:05

I'm handing it out because I've just watched people struggle, and I don't know they said, you know, she has dementia. I don't know. I mean, I assume, like it's Alzheimer's, and it's like, huh? Is our main challenge holding on to new data. I mean, that's the main thing you're experiencing. It's like, well, no, not really. I mean, she's got other issues. I mean, like she can't find words like crazy, like she's trying to say something and she says, you know, the one, you know, thinking the it's not when you put the thing in it, you know, when you drink it, you drink it and you put the thing in the hot, hot thing, not the other one, because that's I don't I do regular, but I don't do real, real cold. And it's like, are you talking about coffee, mom or something else? It's like, I don't know. And it's like, wow, not only does she have trouble getting the words out, she has trouble taking the words in. So then I know, Hey, Mom, is this the thing you're talking about in here? Oh, yeah, yeah, yeah, that's the one I couldn't find it. It's like, right over here, which means we also have visual regard issues, right? And so until someone helps you, truly explore what parts of the brain are working, what parts have changed and what are they doing? I think people just assume you will know this, and it's like, how would you know that? I mean, we don't do classes like that in elementary school or junior high or even senior high unless you're going into a health field, and even then, not much, unless you get into undergrad or graduate work that you choose that, like, how do we expect people to do this. It's a mystery.

Rosanne Corcoran 36:46

It's beyond me.

Teepa Snow 36:49

And so, you know, you have a provider that says, Well, you know, she's showing some extra pyramidal symptoms. So you know, I'm gonna put her on well, but I hesitate to put her on that because, you know, then it might make her blood pressure changed a little

too much. Here's what I think we're gonna do. It's like, okay, what are we doing? Why are we with us? It's like, well, you know, our blood sugar's up a little bit. Well, that's because we had ice cream before we came. Because, frankly, you know, if I don't get her ice cream, she won't come see you. They'll really like you that much. She's not that fond of spending time with you, right?

Rosanne Corcoran 37:21

That's the thing we're left with, trying to find our own education and trying to train ourselves.

Teepa Snow 37:27

Yeah and how unfair is that? I mean, about 70 to 80% of dementia care is done by family members, and it's like, we take huge advantage. We make expectations of family members. I mean, it is just like, really, this is what we do to people, and we think it's okay. We call it like they're just supposed to be the care people. And it's like women, men, children giving up life to do this without guidance, understanding, if I make a choice I want to do this, give me guidance so I can do a good job of it. I mean, there's nothing worse than doing a job and not doing and, no, you're not really doing it very well, and you're getting no good feedback from sometimes the person you really are caring for because they they're doing the best they can. And then some provider comes in and says, Oh, well, you just should place her. And it's like, Tell me about that. Well, I mean, it's almost like, Well, clearly you're incompetent, right?

Rosanne Corcoran 38:22

Clearly, you can't do this. Yeah, she'd be better off anywhere but with you. Yes, yeah.

Teepa Snow 38:29

And I doubt, you know, rarely do I see that be the case. Might I say? I mean, there are some times when I look at you and I go, Wow, you need a break. And if we don't pull the plug on this, I'm going to find you gone before she's gone, because you're not you're not actually looking in the mirror at all, and I'm watching you fade. I mean, you've lost weight, you're not sleeping, you have pain, you can't think you're telling me, and it's like, we need to do something different. Let's work on something different.

Rosanne Corcoran 39:02

Yeah, and it's so hard. And I, you know, I was fortunate to see you in back when I was caregiving in 2019, and and the thing that you said that hit me was, we have to look at

how we're surviving this. And you said it, you know, it was a lot like the frog in the pot. You don't realize it until you're and when I left there, I was like, Oh, my goodness, I have to make some changes, or I'm not going to survive this.

Teepa Snow 39:27

And you're essential. I mean, in the worst, I mean, I will say Rosanne, the worst situation I come across is we get, like, three quarters through the dementia, and you're fried, you're done. Your health is deteriorated point your mental health is deteriorated. You're thinking, you can't. You just can't. You're actually you yourself are having issues that are so severe, cancer. I mean all. I mean, I see all kinds of things, sure, mental health, and now your person has to get used to a whole new person set up. Their routine, and you're not there at all. And it's like talk about devastating everything's ripped away from me. So I mean, the idea of coming in early, setting up routines, early, finding support, early. Can choose. I mean, we can choose to change both our lives that way, and it can be super hard at first, because I don't want anybody. I'm fine. I don't need anything. And it's like I hear you, and yet I know that over time you will so let's get used to it before you have to, because I get it. Let's go, at least out of the house and go do something somewhere, at least once a week. Let's make a pact. We're going to do it at least we're going to do something neither of us likes that much. I'll pick something. You pick something. We're each going to commit to doing something we don't like very much, at least once a week. So we can get used to this idea. There are going to be things we don't like, we have to do. Let's do it now. Let's get it on the books. Let's figure out how that works for each other. And you're going to complain. I'm going to complain. We'll get it over. We'll complain to each other, put it in the complaint jar, and we'll still do it. And if you hate it, I won't make you, but if we don't like it, we got to get used to I don't like and it's like, it's uncomfortable. It's like, it sure is. See if we can get it to be more comfortable by repeating it and modifying it to where we can live with it. Didn't say you're ever going to love it. Never said that, but I got to get us to where you can take your clothes off. And I'm here because at some point you won't be able to take your clothes off, and I'm going to be here, and I need to know what to do, because we've got to figure this out, while we can.

Rosanne Corcoran 41:29

Fully agree, and I applaud all of the resources that you provide, tipa, because I know, and I know you've said, you know, if you're not a reader, you can listen. If you're not a listener, you can read, you can watch. The little things that you do daily on the on your Facebook is it's fantastic, because they're quick, you're in and you're out.

Teepa Snow 41:49

And if you just listen for a couple minutes, I mean, at least you heard something that maybe later on, you go, Oh, I need to go back and find that. And now we've created these YouTube channels. You can go back and find things and so, oh, that's what I need. And dig in a little deeper. Because, I mean, you don't know you need it till you need it, but if you've heard something at least, then when you need it, you go, wait. I think I'm going to go look for this, because I think I remember something. Or you always give us a call and say, I need some help. I think you did something. It's like, let's look.

Rosanne Corcoran 42:21

Right, right. Well, and it's because I think a lot of times people are like, No, I don't want to look at that. I don't want to know what's coming. I don't want to and it's like, I get that me too. But you have to have something, then file it away. Don't listen to the whole thing. File it away. And then when you need it, go back to it. But you have to be informed in this. And I think that's the piece people miss sometimes.

Teepa Snow 42:43

Yeah, well, that again, I would say, is your amygdala acting up. That's your primitive brain saying, I just want to keep me me, and if I don't know stuff, then I'll be me. And it's like not in this world. In this world, you know, if you don't know something, that's called hiding. If you don't know something, seeking out that information. When you're exhausted, when you have too much on your plate, it's super hard. But starting with baby bites can make a big difference. Just like get curious about something and allow yourself to be curious and start exploring some things, even if you choose not to do anything, at least you've looked and you've listened, and you've got some niggly back there of an option,

Rosanne Corcoran 43:25

Right I love that. What advice would you give to a caregiver who's just starting out, and somebody in the middle and somebody towards the end?

Teepa Snow 43:34

In the beginning, I would say, be very careful about rabbit holes you can fall down. And be very careful about seeking out magic, because I don't truly believe there is magic in the world. And I mean, yeah, I do. There's a lot of magical things in the world, but it's not a cure. It's not like if you spend all your money doing this, or you, you know, do X,

you do Y. I mean, the greatest thing that I see that hurts is keep looking for some resolution where they won't have dementia anymore, for way too long, and you spend way too much of your energy and their energy seeking to disprove the reality of where you're at, not giving up hope, but wow, we're living with dementia. Okay, some brain changes happening, all right. Well, let's move forward. So I think first is just an acknowledgement of, wow, we're in a different place than we were. I was sort of afraid we might be or, wow, this is a real surprise. I didn't know we were here because I was out of town, and I was like, Oh, wow, something's going on here, and that surprise. But once we get over that, then give yourself a chance to breathe and then start being curious. Super gets curious early. Okay, in the middle, I think, Wow. Now you need to build some new skills. You handled the first part. Now it's going to get physical at some point, doing some things, things you used to be able to use a voice and say, Mom, go ahead. And drink that. It's it's your, you know, you need to stay hydrated. Oh, okay, now you say, go ahead and drink that. And she goes, drink what the stuff in the glass? Well, that's not mine. Yeah, it is. Well, I don't like it. Mom, what do you want? Then? What do you mean? It's like? So at some point, language and the ability to guide and direct is not going to be helpful in the way that it was. And so noticing when what you're doing is starting to hit roadblocks. Notice it before it crashes, and notice it before you crash. And keep looking at yourself every night like scheduling that am I? How far off my baseline? Am I how far off my baseline? Am I? So you start to really recognize, wow, I'm getting pretty far away from my baseline.

Rosanne Corcoran 45:47

Is that like a weekly thing? Do you think?

Teepa Snow 45:51

Uh huh, I think it is yeah, I think weekly. Because when you're in the middle of this, you can really lose yourself, and you hear your voice, and even if it's you notice, wow, this I don't like the way I sound, I don't like the way I'm acting, or while I'm not getting sleep, I'm, you know, like, if you check your sleep every week, like you could when you have a Fitbit or whatever your system is, like, take a look at it and go, Wow. It's dropping. It's like, boy, her Lewy body's really active this week, and it was really active last week, and week before, it's like, wow, this is no longer old rhythm. It's a new one. I think I'm going to need some night help, because I got to get some sleep, right? And then late state is, don't be scared of palliative care. And I'm going to say everybody's scared of hospice because it means the end is coming. But don't be scared of comfort care. Don't be care scared to transition, for both of yourselves into some place that offers a little more

comfort and a little less faith. Really get to that place where it's like, okay, so we're moving forward, and let's let's start changing gears here. Let's downshift. Let's shift this through to a different place. All right, so, how many times a week do you actually have to clean a body? How many times a day do you actually have to do this? I mean, and you you start to ask yourself, What's what's okay, what's vital, what do they tolerate? Like moving somebody every two hours, going to the bathroom every two hours is, like, really great. If I put you on that skill, she could be so ticked off at me. I would be, yeah, like, I'll go when I need to it. It's like, Yeah, I know, but you don't know when to go. So let's look at how I can say, oh, Rosanne, come with me. I want to show you something. Check this out. You know what? This goes in the library. Tell you what? Carry it for me. I've got two other things to pick up. We go down the hall and it's like, oh, you know, while we're here, tell you what I gotta go. Why don't you try you may or may not need to go. You know, in the shuffle down the hall and giving yourself permission falls can happen as much as I hate it can happen. So I don't need you to, like, if only I had. It's like, if only they had. It's like, yeah, if only Yes, the woulda, coulda, shoulda again.

Rosanne Corcoran 48:08

It's a lot to try to manage in the how much information, how much like, how do you balance that with life?

Teepa Snow 48:18

My general rule is five to 10 minutes and it's a pause, break and see how you're doing. If you're starting to feel like, oh, wow, I don't know if I can handle all this. Then say, maybe I can't, and I need to pause. What did I get out of that first bit? You know? And if that's enough, pause, if you still want to go back for more, because it feels like, wow, this is feeling really good. I'm starting to feel really the rhythm. Then go back for a little more, because, I mean, that's where learning, what's your rhythm of learning? You know? Because some folks are kinesthetic, some folks are linguistic, verbal, linguistics. Some are more, you know, visual, motor. So depending on what you are and who the teacher is. Some teachers will speak to you more than others, and some content areas will speak to you more than others. When you find something that's good for you, watch for binging. Because binging gets a little risky in and of itself.

Rosanne Corcoran 49:17

Yes, with anything.

Teepa Snow 49:19

With anything.

Rosanne Corcoran 49:20

Yeah.

Teepa Snow 49:21

It's like, get up and move every now and then, because it's sort of like when you get a novel you love, or a TV show you love, or anything you love, you're really enjoying it. You're amygdala says, yeah. It's like, yeah, like any drug or any alcohol, anything you can overdo, and then you get sort of a hangover kind of thing. So it's like, give yourself permission for a little and then say, I need a break. I need to go do some other things. Plug in balance into your day, if you can, at all points along this journey, little bit of balance.

Rosanne Corcoran 49:51

And it doesn't have to be big, like you don't need to say, I need 72 hours off today, like, for the next three days, I'm just off like it. Can be little chunks, because it has to be.

Teepa Snow 50:02

It can be five minutes. I mean, when I'm in the airport, I'll often do a five minute, absolute stretch break where I put everything down, I don't I put the phone away, and I'm just doing some stretching. I'm doing breathing and stretching. I don't care who's watching. Mean, hi, if you want to program here, watch. This is what I do, right? Because I know I'm going to be sitting on a plane for five hours. I know I'm going to be working on projects for the next I know I'm going to be talking to somebody. I know I'm going to be in front of a group, and it's like, well, how do I take care of me in a small way? So I can do this other thing in a bigger way.

Rosanne Corcoran 50:35

That's great. And we have to realize that we we matter in this, and we're part of this, and we're

Teepa Snow 50:41

We're so critical in this. I mean, we are so critical someone is trusting us with their life, whether they know it or not. When we sign on for this, like their life is now in our hands. It's like, wow, that's a lot. And so get some support for yourself, because we shouldn't go into this like, thinking, yeah, yeah, I should be able to do all this. It's like, nation,

nation. The good thing about kids is they grow up. Yeah, they may come back but, but they've learned a lot of skills while they're out there, and so you're not having to watch for every little thing, unless you have a child with special needs. And people who do that, your lives are really complicated, and you can lose a lot of years and and I think that's similar to what we do is we discount how complicated this is and how much it would serve us to recognize, you know, I would never enter into this relationship thinking I'm the Only I need to really, from the outset, realize, Wow, I'm going to need something more. Because you're an introvert, I'm an extrovert. One of the things I'm going to need is connection, and you don't want it, so I'm going to need somebody to be with you so you can do your thing while I go do my thing for a bit. So when I come back to you, I'll be whole, and I can spend time with you. I've got my needs met, and I'm not going to push that on you. I won't chatter. I'll be quiet.

Rosanne Corcoran 52:03

A big thank you to Teepa Snow for being my guest today. For more information about Teepa and access to all of her incredible resources, visit TeepaSnow.com. 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@daughterhood.org in the podcast section. While you're there, explore more of 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.