Teepa Snow’s Practical Strategies to Support Loved Ones with Dementia Transcript

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Introduction to life after diagnosis

There is a treatment that is possible and it's not always drug-based and it does involve people and it does involve places and it does involve programming and it does involve props and other possibilities.

There is life. after the diagnosis. And it's lots of years of life. So let's talk about how we want to live them. This is Doctor Talks, real talk from real doctors on the issues that matter to you most.

Welcome back to the Think Well, Age Well podcast. I'm your host, Dr. Heather Sandison. And today's guest is someone whose compassion and wisdom have touched the lives of countless families and professionals, including us at Murama, caring for people living with dementia.

Deepa Snow is one of the world's leading educators on dementia and brain change, with over four decades of experience as an occupational therapist. She's the founder of the Positive Approach to Care, a practical, person-centered philosophy that empowers caregivers and their communities to better understand, support, and connect with people experiencing cognitive change.

Tipa is known not only for her deep clinical experience, but also for her extraordinary ability to bring empathy, humor, and humanity into the most challenging moments of caregiving.

So whether you're a professional, a family member or someone living with dementia, her tools and insights helped reduce distress and increase dignity.

In this conversation, we're going to dive into what it really means to age well with cognitive change and how we can better support both caregivers and those living with dementia and why small daily choices can make a big difference in the quality of life.

Tipa, I am delighted to have you here. Thank you. Oh, it's so great to be back with you. It's been a while, so it's good to be with you again. Thank you so much for joining us.

Now, you have been busy since I saw you last. You've worked in dementia care for decades. And I wanted to start with your origin story. What drew you to this initially?

Ooh, the idea that I was working in a long-term care facility, and all the other therapists would say, she's got dementia. I mean, there's not going to be anything we could do with her.

I wish people wouldn't put her on my caseload. And I said, well, give her to me and let me see what can happen. And like, what are you doing with her?

Why is she doing better? I don't understand. She has a plateaued. And it's like, well, because we do things together, it's a shared agenda, not I have, I'm gonna increase her strength or range of motion or I'm gonna get her to do X, Y, or Z.

I mean, we may not work on self-care right away. Of course, this was back in the era when you could work on what made sense, not what's regulated by Medicare.

Teepa Snowu2019s origin story in dementia care

So it's a little, in my world, the Medicare reimbursement system for dementia is so short-sighted and so limited that

it makes effectively working with people difficult.

And so, but that's how I started was working in both the UNC School of Medicines program and then Duke School of Nursing and then in long-term care and head injury, looking at, wow, this is really curious.

I wonder why that's happening. Let's figure it out. And let's figure out how people can live life with whatever impairments, but what they have left that we can use.

One of the most inspiring things about all of the videos and trainings that we've done with you is this sincere commitment to curiosity. Let's figure it out.

What's going on with this person? And I don't hear that often. This is really unique, I think, to you, and also with this sense of compassion and humor.

But really, it's that sincere interest in figuring out what's going on. Can you walk us through a scenario where you've put that into practice? Yeah. So let me give you one from this morning.

I did a home visit this morning and I was asked to come in. The husband and the wife are really struggling. The wife is living with a young onset primary progressive aphasia plus some frontal lobe concerns plus memory concerns.

Plus, she's saying that there are the girls in the garage and this man needs to get out of my house. He's not my husband. I don't know who he thinks he is.

He needs to get out of here. He needs to get out now. at certain times of day and then not. And so they asked if I could, we tried some things and so I went out to visit to see what the house and the environment and the situation really looked like in real time because sitting in an office and talking about it to me is not the same as being in the space where this occurs.

And it turned out that they have a lot of mirrors and They have a garage that when you go in the garage and the car's in the garage and the windows rolled up, when you look in, guess who you see?

Yourself, probably. Yourself and the spouse. However, if you think you're younger than that, you're talking to another person. And so we were like, okay, so what could we do with this?

We tried upping the light in the room. That didn't do it. I asked about cataracts, just in case. Could there be glare in making that be more of an issue?

And so what we said is, how about if we rolled the windows down in the car once you park it in the garage? So there's no reflection there. And I said, what if you put curtains in front of the mirrors in the bathroom so that there's not somebody in the bathroom when she goes in there?

What if when she says, you've got to get out of here, you actually go and go out of the house. Is there a place you can go for a little bit and then come and knock on the door and say, hey, I want to stop by and see how you're doing in that moment to see what happens.

And quit doing all the chores so that when she gets up, there's something for her to clean up because she likes to clean. Fascinating. Those are examples of like in that thing, I had to really get information in to figure out, okay, so I'm getting all this data.

Okay, all right. And I'm asking the person, I'm asking the woman, so tell me about the girls. And in that moment she goes, I don't know what you're talking about.

And then her husband says, Well, remember this morning? Uh-oh, we got a little work to do on remember this morning, which is not a helpful cue. And it's like, oh, so you're not remembering the girls.

So that's frustrating because sometimes you do and sometimes you don't. Sometimes there's girls, sometimes there isn't.

Curiosity and environmental clues in caregiving

And she'll go, yeah, yeah, that's how it is. Interesting. Yeah. So this is really empathizing with her, really getting into her experience. What might she be thinking when she looks in the mirror, when she passes a mirror, when she sees her reflection in the windows?

And most people are not thinking that way. Right? We want to correct. Well, there's nobody there. And it's like, well, actually there is. And if in her mind, her perception of self is she's in another time in her life, and she's looking, and then we pulled out some books.

And it turned out she really notices and recognizes herself, the family had put together an album, in the younger pictures. She's less good at noticing herself in the more recent pictures.

And same with her husband. He's really good at picking him out in some of the older pictures. Which says, so now I'm curious, what if we use that information to guide our interactions?

and not demand of her a time awareness that she doesn't have, and instead acknowledge, huh, so she's operating in a timeframe that's different than mine.

Okay, well, do I have to push her out of that? Or can I say, so you're wanting to go with the girls. Tell you what, I don't think they're here yet, but we could go look in the garage and see.

I mean, I can stay curious. go look in the garage. Oh, yeah. Well, they're not here now that we have the window rolled down and we're not seeing them in the car.

Tell you what, why don't we go get something to eat? And if they come, they'll ring the bell, I'm sure. Or we can check again later. Because those things, are those true, Heather?

I mean, are those two things, would they ring a bell if they came? Or could we go check in the garage again? Right. It's a way to sort of reorient her towards reality without dragging her back into our reality by correcting her and making her defensive.

Because we know that when we do negative things to people, whether they're physical things or whether they're emotional things or whether they're social things, the brain picks up on that.

And when I belittle you or make you feel small or make you feel incompetent, your brain reaction to that is one of a couple things or a combo. I frankly don't like you as much as I did before.

I mean, I'm sorry, but I just don't really like feeling that way. And I also worry about, like, oh my gosh, I thought I knew what I was doing. So I might self-doubt and then be more hesitant or feel more incompetent or I might get angry or I might try less or I might get smaller and not want to engage.

No, those things are healthy. No, those are helpful. So why encourage it? Why foster that? Right. I think that there's the shift in how we think about it.

As caregivers, as care partners, we have so much influence on someone else's well-being in how we communicate. So this is one of the common mistakes that caregivers make.

I want to just double-click, are there other common mistakes that we can kind of think through and highlight here so that people can have some tools or at least be turned onto some shifts in their approach to make them more effective and compassionate and make everyone's experience of this more joyful?

So here's another one that happened at the same situation. So she had not taken her pill shift. Okay. And she had two large, one was a fish oil and one was a big calcium pill.

And now both of those had capsules. And then there were three tiny little pills. And so her husband said, you didn't take your pills yet, you need to take your pills.

And she says to him, guess what? What do you think she said? I already took him. I don't need to take you. And so then he goes, no, you didn't. Now he's standing and talking.

OK, so I said, oh, name. Let me say, oh, Heather. Oh, shoot. Looks like son of a gun. Some of your pills are still here. In fact, all of them are still there, but some of them are here.

Tell you what, before we, before we go to the other room, why don't you, you want to go ahead and take them now? And so she gathered them up and then she had all five in her palm and Is she spitting back out?

Oh, no. Some of it. Because when she chewed, guess what she did? Because she started chewing. I bet it wouldn't taste very good. Guess what happened? She broke apart some of the capsules.

When she broke the capsules apart, the ones that have the outside and you can bite down them and all the fluid comes out. And she was like, ooh, and she liked it.

So she spit it out. Unfortunately, the small pills were also still in there. And so they got spit out as well. Well, at least some of them did, but some of them got swallowed.

So then they're saying, don't spit them out.

Medication, cues, and body orientation

Don't spit them out. It's like, I think it's already over. I mean, I don't know. So again, it's this corrective action, but it's that idea of, Well, the setup was not a great setup from the outset.

She was willing to do what we asked. The problem is, so my brain went, okay, so these two that are bigger, they need to be separated out. I mean, whoa, we do not wanna try to do those at the same time.

And then I wanna sort of have her try it and see, can the little ones go down with fluid? Are we getting to a place in this that we should place them in something that's less fluid-like and more able to be taken in you a little bit and then swallow it and then add fluid, you know, fluid before fluid after, but don't put it in fluids, solids in fluids, sometimes iffy.

And then let's look at those, like, can we deliver calcium another way? Is there a way to do fish oil or something similar to fish oil that gives you that omega?

I mean, if that's what you're looking for, because I'm not correcting that, my goal was like, how can we make this work better? And whenever we find them, how can we have this be a first-time event versus a corrective sort of event.

So that's, for me, often family members and professionals can get into this mode of, no, no, no, no, no, what are you doing? And it's like, not a good plan.

And it's similar, but it's a little different because we didn't do the prep. In my world, not preparing for an event, knowing that you've had some episodes, he goes, yeah, she tends to do it.

Okay. Well, let's change something then. So we're not there again, because once we notice a pattern and we're not liking the pattern, not blaming the person and recognizing, wow, we need to change the pattern.

All right. Well, where she's doing it, when she's doing it, who's around when she's doing it. what the properties of the stuff are. I mean, there are lots of variables we could change that don't require her to not have dementia.

Because if she still has it, I've got to work with what we've got. I mean, and she's like seven years in. I mean, I, you know, and she's got a habit now that's chewing things.

And I've got to account for that, frankly. You also have a lot of practical tools that you talk people through. You mentioned that when he said, hey, it's time to take your pills, you haven't taken your pills yet, he was standing.

So how you describe strategies for how to approach someone and the hand-under-hand technique. There are lots of techniques that you teach that can help us interact with our loved ones suffering with dementia so that we elicit sort of the response that everybody is hoping for.

Oh, Heather. Go on. Water. This is mine. This is your water bottle. What have you got? Have you got cheers? Cheers. I've got tea. Tasty? Yum. Yeah. Oh, yeah.

So that's an example of a visual cue, verbal. But I started off with verbal. I said, oh, Heather. Getting my attention. I put that little question mark at the end of Heather, which meant interjection.

I have something to ask you. And you paused. And you, yeah, I mean you're doing that. What? And then I gave a visual. Didn't say anything, I did the visual.

Now I didn't put the visual here. Oh, so just for our listeners who aren't watching, you've got a water bottle and you stood so that I see your left shoulder, your face is turned towards me, and I see your water bottle in front of you, but you're oriented towards the left.

So instead of having the water bottle right directly in front of you, underneath your face, say, with your shoulders square. So tell us about that, how this orientation of the body changes our response.

Yeah, so when I'm in your center field and I have an object in your center field, most human beings are more interested in the person that's right in front of them blocking them and there's no way out.

I've got you trapped and I'm saying things to you. You're going to have a hard time listening and then figuring out what I want. Here, I want you to take it.

And then if I bring it toward you, it's like, whoa, what are you doing? Even right now, and we're doing this remotely through the screen, but you just put that bottle and you made it closer to the camera.

It came towards me, and all I want to do is back up. All I want to do is put further away. That's a primitive brain reaction. I mean, the reality is that's a very primitive brain.

That's an amygdala. Whoa, what are you doing? Surprise. And so when I go, ooh. And notice I'm doing a gesture to it. It's actually what's in the center of the field.

I'm here, but this is what I want you to pay attention to. And then I'm actually going to demo. Taking a drink of the water. And then I go, cheers. I love it.

Make it fun. And there's a pause. And if you're still hesitating, go. Point at the water bottle. Have you got something there? There you go. You got it.

Cheers. Yeah. And then I, again, it's an idea, can I invite you? It's invitation, not, Heather, you haven't had anything to drink this morning. Heather, Heather, look at me.

You don't want to end up in the ER again, do you? You know when you get dehydrated and you get impacted? You know what I'm saying? You don't want, look at me.

I want everyone to go on YouTube and watch this video if you're listening right now, because you will have the experience and understand, just be more empathetic.

You'll be in the position of someone who is being cared for, and it's visceral. It feels so icky to have that going on. And if you have a partner you can role play this with, and I mean, you saying my name and doing it, I'm sure just ratchets up the intensity of the experience even more.

Well, and if we think about it, think of how many historic references to hearing your name in that manner you have from teachers, from parents, from somebody who's not liking something.

And it gives you that feeling of, you don't like me. I'm in trouble. You don't think I'm skilled. You think, and that setup is a failure setup. And instead, you know, like, oh, Heather, I have a huge favor to ask of you.

Let me show you something. What is that? How can I help? Oh, yeah. Look, come here.

Caregiver support, respite, and community

I want to come with me. Now, what I'm doing now is a come along motion. What did I do with my body as well? Yeah, you're oriented away, so you're not in that center field.

And so I'm amazed how many times a caregiver says, I tried to get her to come with me, but when I watch them, they stand right in front. They're still talking.

So we're going to go in the kitchen. I want you to help fix lunch. Okay. And the person goes, yeah, okay. He said, well, come on. And they say, okay. And so if I say, Heather, I could use your help.

Come on. And then you start to shift away. What's the message about the conversation at that point? I don't know if it's intuitive, or again, it's this reflex, but you're just wanting to follow.

Yeah, because we're not going to stay here. Look, we're going. And so there's a visual plus a verbal plus a physicality to it. And I just truly believe that carers so underestimate the power that they have to shift a brain's operation into a higher order of ability.

And we assume the worst because we get in people's spaces and faces in our effort to help, and we don't lift, we push. And that's not a good thing for most people.

Thank you, because I just experienced it myself, the contrast between these two approaches. So what is the potential here? What does a good day look like for someone who's living with dementia, with moderate or advanced dementia, who have care partners who can help implement this sort of approach to care?

How does it change things? Um, it's dramatic. I mean, and it's so fun to watch when people goes, it worked. She did it. And it's like, I mean, well, at first she wasn't interested.

And so I let it go. And then we went in that living room and we were, and she helped me vacuum. And it's like, she hasn't done that in years. And it's like, wow.

tell me what happened because having them reinforce it for themselves, what did they do that made a difference is huge. And then they're like energized.

And when they're energized, the energy between both of us gets better. And I said, wow, yeah, that's huge. But it didn't last. And it's like, Understood.

Well, the chemistry can only last so long, but boy, look what you did for chemistry and ability and firing. I mean, how many synapse fired today that didn't have a chance to fire for the last week.

And it's like, wow, talk about brain sustenance and talk about brain change. You did it for yourself and for the person. Yeah. So sounds like after about an hour though, you might need a break.

Hmm. Right, how much of this is about caring for the caregiver and making sure that they are getting their needs met so that they're not tired and irritable and at their wits end all the time?

And helping them recognize before they need help, they need help. I mean, they do need some support for themselves because I want to actually get the person I'm supporting used to somebody else in that role.

So I can step out, someone else is in that space and I get a chance to observe it, listen to it, watch it. But I also get a chance to go take care of me a little bit so that when I come back, my brain is in a healthy, sustainable mode.

So I got my exercise. You know, they can't exercise like we used to. We used to run together. That hurts because now I can walk. She can walk. She can't do it.

All right. Well, let's go to a new mode then. I can be present for her walking if I get my running because I need my running for me, for my brain fitness and my brain health.

If we don't start respecting ourselves, we'll just have the next generation. I mean, we just perpetuate this phenomena of dysfunction if we can't get ourselves to form community in new ways.

And it's new community. increase our own risk of disease later on. This is a fear-based tactic, and you can correct me if you don't think it's appropriate to use.

But I also tell caregivers for people suffering with dementia, I want you to have help because who knows what might happen. you might be called away to take care of your parent or your daughter, or I've had caregivers who end up in the hospital with a broken leg.

And then there's no one. Or a heart attack. Right. Right. All of these things that happen that are unpredictable. And then there's no one who's comfortable with that person or who your loved one is comfortable with that knows their picadillos and the nuances of caring for them.

And so having that person before you realize you absolutely need them, that gets you that step ahead. Yeah. And it is a force. You have to force yourself into a space of discomfort.

And I'd rather do it as discomfort than pain. And so earlier in most people's experience of dementia, I find that discomfort, it's uncomfortable and it's like, understood, it's uncomfortable.

So let's figure out who you would be the least uncomfortable asking. And let's make an ask and let's bring them in and let's see what happens. And let me be the third party rather than you trying to do it.

And let's just see what happens. I mean, if it doesn't work, it doesn't work, but you know, I'm willing to do a shuffle around and give it a try. because recognizing, yeah, this is so important.

And you might not find that perfect person on the first try. So you need time. You need a runway to find a person who's going to fit. Her sister said she would help.

And it's like, let's get her in. Let's see how it goes. Oh, well, it turns out she's babysitting the grandkids. So she's not. But if I ever need her, I could call her.

And it's like, OK, I want to pause. So Heather, tell me what you just did. I thought you just did call her and said you needed her. What happened? She had another commitment to the grin.

So let's throw the net a little wider because just in case, let's just try it while we can. And it's that idea of the first time it may not work doesn't mean it's a wrong idea.

It means, wow, did you get what you just learned or are you still ignoring what you just learned? And so helping people, I think we underestimate the impact of dementia on the care partner.

and how it impacts their brain and their brain keeps thinking it's either all going to work out or it'll never work out. It's like both of those are false.

It's like, how do we hit the middle ground? Where do you recommend people look for support? Churches, through family, where is a good place to look for someone who can help them?

It's a really super great question, and I wish I had a super fantastic answer. I was hoping you would give it to me. Yeah, I know. Yeah. So I look in all those places, and then if those don't turn out to be good places, because, you know, in that church, they think, well, you just, I have someone who could come and stay with her, and the person who comes to stay is somebody who says, sit down.

Now remember, John's going to be back in three hours. What did I tell you? I said, John's going to be back. There's no training. There's no prep. It's just I'm willing to do it.

And I get, you know, I'm doing a home visitor thing, but it's not a good match.

Brain change language and early screening

I don't like to burn bridges. So I say, tell me a little bit about what you know about and how you work with people living with dementia a lot. I took care of my mom.

Tell me more, you know, kind of thing. So one of the things we're trying to do is get people in community, whether you're younger or older, if you're interested in brain change, Come, let's learn about healthy brains and brain change and then see if you want to do some volunteering or some service or, you know, come and be part of our community in a safe space and see what happens for you.

See if it draws you in and got you curious or not. And we often are finding sometimes when I get three couples together, they can start to figure out how to coalesce themselves.

So two people get a break and one person is taking three people to go bowling or doing something of interest, going to a lecture that they like to listen to, go to the art museum, participate in a course or a class, go out for a walk, hike.

And so all of a sudden they've got a new family and the new families are people who are also experiencing some brain change. And it helps I don't have to explain everything to you.

Your person is different than my person. We have different dimensions. But boy, the guys get along really well, or the women get along really well. And it gives us a safe way to take some time and to feel comfortable.

We're not imposing. We're lifting each other's load a little bit. And you can relate. I mean, it acts as a support group, more or less. You can share resources.

You relate to each other. You don't feel so alone. You can go out to dinner and decide we're going to eat outside, away from the crowds. We're going to eat something that's good.

We're not going to order the junk that's on the menu. We'll pick a place that has decent food and it's finger food for people who are having trouble with utensils.

We'll pick things that you can pick up and eat. But I don't have to explain that. Yeah, I don't have to constantly explain myself. You use the word brain change, and I know that you do that intentionally instead of brain disease or neurodegenerative disease or even saying Alzheimer's out loud.

Tell me about the intentionality around that language. The number of times I have people that can hear and talk about, it sounds like your brain is changing some.

It sounds like sometimes getting words in is really challenging, or getting words out. And people go, yeah, I know the, yeah, so you know the thing you want to say, but it won't come out.

Yeah, that's frustrating, huh? Yeah. Oh, so let's try something. And then we try something and they go, well, that was better. And it was like, hmm. So brain change is what I experience when I learn something, but it's also what I could experience when I lose something.

But it's like, I'm not just losing, I'm changing. And finding another synaptic pathway is a human being's way of adapting to brains that are dying. I mean, my brain is dying, but I'm still trying to find pathways that work.

which is why when you tick me off, you're gonna hear me swear at you, shut up, you're an idiot. They hired the stupidest people to work here. And it's like, wow, I would probably not have said that that way before.

I said, I told you no, leave me alone. I might have done that before, but I wouldn't say they hired the stupidest people, you're an idiot, leave me alone or I'll break your damn arm.

It's like, whoa, that's a little intense. It's like, well, it means I felt captured, trapped, and my brain still has capacity to try to protect me. And what you did made me feel trapped and endangered.

So I'm reacting to that. So I'm learning I don't like you. That's a new pathway. Because I did not like you before, but now I don't like you. And it's like now I see you and I start anticipating that I'm not going to like you, which is not a good place to be.

Man, this is very preserved. We see this over and over again that if you get off on the wrong foot, the people who have these brain changes going on don't always remember exactly what happened, but they remember the feeling.

They remember they don't like you. So it is important to approach conversations with care and intention and that neutral language of brain change versus brain disease or degeneration or loss.

Mom, you have dementia. What did I tell you? I mean, the reason you're having so much trouble is you can't hold on to anything. I think she's holding on to something.

Probably not what you think she's holding on to, but she is. And so that's a change. And you don't want that. So let's talk about your brain change. How can your brain change?

talk about change, let's talk about the healthcare system. And you mentioned Medicare, and we don't have to dwell on this for too long, but there's a lot of changes happening right now.

And supporting people with dementia and their caregivers, I'm curious, if you could wave a magic wand and say we're starting from scratch, what would caregiving support through the healthcare system, through Medicare, look like if you could design it?

Well, first it would be if we have a good health care system and life care support system in place, I mean, because it has to be the courts as well. It has to be financial institutions as well.

We've got to sort of really start in the social institutions. We've got to start realizing, yikes, we have a lot of missing fabric here. And health care is one of the pieces, but there's lots of other pieces too that are not present.

If that were the case, I would advocate we need to screen our brains a lot sooner than we screen our brains for function. We need to quit avoiding things that, I mean, it should never be this sort of like, yeah, I don't know what my baseline is, actually, because I haven't had it done.

I don't know what it is. I mean, why would I know what it is? Nobody asked me. And it's like asking me who the president is and what today's month is.

You know, like those kind of three questions, those many cognates. I personally could be pretty impaired and still would be able to do that because that's the kind of data I hang on to.

I mean, I'm not a hard piece of data typically.

Non-drug approaches and purpose-driven care

When I can't do that, we're way past the beginning of the cycle of being helpful to me. And to me, my frustration comes when I have somebody who used to be a university professor and had to give up their job.

and can't work in the work they did before. And when they go to their provider, their provider says, well, you're MCI. And it's like, really? I can't live my life and my purpose is I've lived it and I'm just mildly impaired?

I don't think so. And this mismatch between, well, they can do their self-care and it's like, That's really late for most people. I mean, unless you've had a stroke, I mean, or something, a head injury, being able to dress yourself, toilet yourself, unless something acute is going on, you know, that's a later phenomena.

For most people, there's nothing mild about mild cognitive impairment, right? Yeah, it's just a disservice to call it that. That's not helpful. That does not serve me.

I mean, labeling it as mild makes me feel like, okay, well, why am I feeling so impaired if it's just mild? And my family is like, well, no, she's just MCI.

And it's like, she. can't put a meal together anymore. I mean, she's eating junk food. She's eating crap. She's going and buying these ho-hos. She's never eaten ho-hos.

I don't know what she's, you know, like, what is going on here? And it's like, well, I'm compensating for my distress by doing comfort foods. I mean, yeah.

And it goes on and on. And then by the time we're parachuting us, the room is like, oh my God, have you seen the house? And it's like, well, yeah, she has early dementia.

And it's like, so that's part one. Yeah, changing the nomenclature. And doing screening. I mean, really screening for ability and say, I mean, I just got a message that someone had been a psychologist that was treating people and starting to develop their own dementia.

And when the individual who noticed that it was doing harm because they were treating people with PTSD and bipolar conditions and when the person said, well, no, I didn't set up an appointment with you.

And the client was like, well, yeah, you did. No, it was never set up. I mean, that's causing harm to somebody who has conditions. And when they took that to the board of psychology in that state, they said that was not their purview.

Yeah, that's a rock and a hard place, right? But if there's no criteria for, I mean, it's self-report, it's self-test, I mean, there's no system. And I'm not for taking people's abilities, you know, capacity to treat away, but we don't have anything in place that protects one another.

That's, to me, not okay. and finances and I mean lots of bad stuff happens to people because we don't have systems to in place to be supportive. I ask every patient I see about their financial health how do they feel about it not the number in their bank account but how do you feel about your finances and when someone has and I ask if they are managing their own finances And at least once a week, I have someone who says, I'm OK, but my neighbor had everything taken.

Because people in this over 65 who might start to have cognitive impairment, who struggle with technology, become easy targets for fraud. And it is, I mean, how heartbreaking to have your entire retirement disappear, to become a victim of this.

Sign over your house. I mean, yes. Oh my gosh. It's just absolutely. And they can't catch them. And by the time, I mean, there's no amount of that that's going.

That's the fastest area of white collar crime we know about. And I would say the bad guys are figuring this out a lot more than the health care system is.

And so getting ahead of this, doing the screening so that that isn't your first clue that mom or dad or somebody in your family, someone you love, is going down this brain change path.

It's challenging. So I wanted to dive into a little bit of controversy. There's debate about reversal of Alzheimer's disease. And I feel compelled to tell everyone who will listen, because it's something that I see in my clinical practice routinely.

But I know that not everybody sees that. And it's a new idea. Many of us are exploring how lifestyle choices can impact brain health. I'm curious from your experience and what you've seen, the role that you see for prevention or slowing through non-pharmacological approaches kind of in combination with this positive approach to care.

Okay. So let me start off by saying I think the latest treatments, quote unquote, for people living with Alzheimer's, Look on me, whatever the meds are, you can take the trade names or whatever.

I think what they're promising and what they're delivering are two different things. And I'm really concerned about people getting signed up to do things in that sphere.

And I don't think they're getting straight messages about how many points on a paper test, what's that going to do for you in daily life? I'm really curious, but let's move on.

But I'm super curious about whether or not that's delivering at the price tag what is promised. I'm particularly concerned about this idea of Alzheimer's early signs and applying a medication to that.

The medications that they say will keep it from progressing as fast. And it's like, and we're talking about points on a written scale, and it's like, you know, the value of that for the people who are currently in those situations, added to which they are, I'm sorry, they're enrolling people who are not in early state.

They are much more involved. They're in mid-state. If you were to watch them in daily life, this is, I mean, because I work with people who are in the program, and I'm going, so they're identified as being in early state.

That's, I mean, they're needing guidance to go from activity to activity in a day. They're needing support to be able to put together a routine that they can follow.

They have trouble going to an unfamiliar environment. It's really stressful. They can't function. I mean, that to me is not early state. That's something different.

and it all focused on Alzheimer's and I just really have challenges with it. When we're investing that much money into that little change, when we can show with some decent evidence that there are other ways that people can preserve or improve their abilities and their function and their life.

And my experience is we can see some really significant improvements in abilities When we help people live into their purpose, they find a new purpose, they live into that purpose, they find pleasure and joy in that purpose, and they get up and they go to work because what they have to share or do or how they're living matters to them.

Many of my folks can say, this isn't how I was. This isn't what I used to do. This means something. I'm doing well,

I'm keeping myself going. And you ask their partners and it's like, yeah, I mean, we have some hard times.

Nobody's lying about that. But the quality of how they're doing is so remarkable. We've had people with Lewy body dropped almost everything that they were on and they were like became new people.

Of what they are doing and how they're finding purpose. Yeah, so I have a former physician who actually helps me do podcasts and recordings.

Hope, balance, and individualized negotiation

He actually serves on a number of boards and serves at medical schools teaching and educating about what does it look like to be a former physician and to live with Well, initially what I was diagnosed with was early onset Alzheimer's, young onset Alzheimer's, and now it switched and then it switched to a frontal temporal dementia.

And now they think I have Lewy body plus some vascular. I don't know, they keep changing every time I go in because my symptom profile is different. And they do the scans and they say, well, you have some changes, but it's not changing like we thought it would be changing.

So, I mean, you can't. I had somebody who had posterior cortical atrophy and they actually were told, you're not degrading as quick as we thought you would, so you can't have post cortical atrophy.

How bizarre. And this is a major university medical center. I was like, wow. odd way to look at somebody's ability to hold on to life. She's someone who, and she still is, is active as a leader in her faith community, support within her faith community.

She's changed some of her roles. She's still doing things that matter. She's had to change a lot of her life because of the impairment that's coming from visual disturbance and now motor disturbance, but she hasn't given up herself.

She still knows self and how to promote self. I have somebody else who does programs with me on post cortical atrophy talking about it. And whenever he comes in, his wife will say, he is able to do things here that he can't do except when he's here.

And it's like, yeah, because what he's doing here really matters to him. It makes a difference for him. And so we have people who help us clean the building.

And when they're done cleaning, they go, well, I need to go do X, Y, and Z. And their partner's like, she wanted to go do that for a while. And it's like, yeah, she just got energized by getting the right support at the right time.

And when that happens, the chemistry of brain changes. And it's such a dynamic phenomena. This idea of this downward progression of craft is like, it's a myth that we support by promoting loss of abilities by just allowing things to happen and moving into a acceptance of deterioration mode versus a, well, you know, You know what, Heather, would you help me cut up these apples?

I know you were looking for apple pie, but I'm wondering, I'm just wondering, what if we made homemade applesauce? Have you ever done that? Okay, tell you what, here's the ricer.

Let me have you do this. And I'd rather have you eat apples without a lot of sugar than I would have you stock up on three cookies because you're stressed.

Do you see that diet plays a role in people's experience? Yeah, what have you noticed? What typically happens is people who are entering in and they think they're in early state, but if I explore it I'll say, so have you seen an uptake in desire for sugar?

Oh my God, like she is like eating sugar, like nobody's business. She never used to be that much of a dessert

person, but if she gets whole, I mean, and salt, she will, like chips, she's just into the, she eats a whole bag if I, and so the disbelief in somebody's voice, and I've tried to get her to stop, and it's like, tell me about that.

Why tell her it's not good for her? It's like, how's that working for you? I mean, but sometimes it's a mount eating, sometimes it's nighttime eating, sometimes it's, but I see a lot of not drinking fluids, particularly water.

I mean, just like water's off the radar. And people are like, I try to make her drink, I tell her, and it's like, okay, so Heather, cheers. Makes me wanna take a sip every time.

And so it's the learning the art of supporting somebody's habits and say if they say I'm not eating that then going all right I hear you that one's off the table tell you what would you at least taste this for me and see what you think because I tried something different and I just want your opinion and you'll be amazed how many times people will eat it and like well it wasn't my favorite and it's like I hear you not your favorite here's the good news it is good for you So here's the part that you get to have now.

And so it's a small portion of something they do like at the end. I mean, I'm not the Gestapo or the police. I just want to provide opportunities for best life if we can.

And I see a big difference when we do that. People will acknowledge, you know, I'm controlling my diabetes with activity and exercise, and I'm not on anything really anymore for that.

My hypertension is better now that we're participating in this program that we're doing. It's like, cool. And there are other people who are like, yeah, no, I just want to eat sugar.

And it's like, all right, well, that's a different care plan. I mean, we're just going to have a different care plan for them. I'm curious how you and your work balance hope with realism when you're supporting families through this journey, because what you're describing, just like what we do with patients, it requires work.

And so you have to have hope that things are going to get better. And yet the harsh reality is that for a lot of people, it doesn't. So what is the balance when you're communicating with families and navigating that?

Yeah. So when someone says, and this will be a common statement, she can't do anything anymore. I mean, she can hardly do anything anymore. That's a very common statement.

I'll go, wow. Okay. So you've seen huge changes and you've seen huge losses. Okay. So I'm going to work with her and I want you to watch and I want you to tell me if this is what you're experiencing every day or if what we're doing is a little different.

And they'll watch and they'll go, how did you get her to do? She never does that. And it's like, ah, So you're wanting to know what some of the skills are I'm using.

Because this is skill, this is not magic, it's skill. So here's where I want you to try something. You be her and I'll be you. And let's role play it and let's see what happens.

And we start there. And then they start, and that's usually when the next time, oh my God, you're not gonna believe this. Because like in one, it was like, we get into arguments and I say, okay, are you standing like this when you Do the argument.

Are you using your hands? Are you saying, now take your hands and put them around your eyes like this. And now let me do that. And it's like, Oh, that's really awful.

And it's like, yeah. So if you're really focused in on you, you're much more intense. So if you instead say, you don't like this, you want to go and I'm saying we should stay.

Is that right? Yep. The argument's not gonna happen as much because I just, I shared with you, I got your

message. We're on different pages, aren't we?

Which is a very different framing. And it's like, oh, so are you actually saying what I do matters? And it's like, yeah. And I think carers really have in their head, everything is about the dementia.

And it's like, yeah, no. It was about who the person was before who you are. Yeah, they're dementia, but what other brain changes may be happening? But then, what other health things have you got going for you?

the environment and how you're going to use your time. I mean, put the puzzle together because it's a puzzle. It's all about dementia. Right. What do you wish every family, maybe you just said it, every family knew when they received a dementia diagnosis or an MCI diagnosis?

There is a treatment that is possible and it's not always drug-based and it does involve people and it does involve places and it does involve programming and it does involve props and other possibilities.

There is life after the diagnosis and it's lots of years of life. So let's talk about how we want to live them. Because there is life. This is like what you didn't know yesterday.

Well, you know One Piece, but you don't know what the future holds. What's going to happen today? I don't know what's my future. So I can live in today, plan some for tomorrow, and how much energy I want to put in tomorrow versus today.

What I do know is there's not a whole lot of value in keeping on what to have yesterday. This is not going to happen. Yesterday doesn't come back. There's tomorrow, there's today.

Yesterday's done. Let's move forward. And you know, sometimes people have to sit with that for a little bit. And if you need to sit with it for a little bit, let's do that.

But then let's come back and let's have a conversation. So I'll keep checking back on you. to see when you're done grieving that loss. Now it's chunked to what's left.

Yeah, you talk about the gems. How do we create an environment? How do we create a world where this person shines? All of their abilities that are remaining are really accentuated by what we do, how we do it, where we are.

You've trained thousands of people to help support loved ones, but also to help professionally support those suffering with dementia. What do you hope that your legacy will be?

I'm working hard to find enough evidence to share out so that it becomes an accepted practice rather than an exceptional practice. We want it to become the culture that we look at dementia and this is the cultural support for people living with brain change.

Dementia-friendly environments and safety

I personally am very doubtful that we'll find a cure to all the different reasons that brains change, deteriorate, struggle, for a long time. I think it's going to be really tricky to find all the bits and pieces that are going to make a difference.

I mean, the Lewy body is really very different than, you know, than FTD, than Alzheimer's. I mean, and sometimes, you know, if I get MS, my risk of developing a dementia associated with my multiple sclerosis, you know, it is there.

So how do I live well with my MS to reduce my risk? But I've got to acknowledge, wow, the potential for brain change is really there. In chronic conditions, we just have this attitude about what can we use to treat it, and we don't look at how can we learn life with it.

It's a little tricky because now with the latest treatments of diabetes, it's sort of like, oh, look, a new med. And this

one is going to take away all responsibility, except it paralyzes some people's guts sort of like significantly and causes risks in other areas.

So let's pause a second and let's get a little curious before we all jump on away. I mean, that's just like… Let's look for an external, rather than let's look in the mirror and go, okay, Teepa, what could you choose to do that might make a difference for you in the long run?

Because it isn't just about one condition. Right. No, no, absolutely without a doubt. Now, if you could design an environment for people with dementia, What would it look like?

If we were creating dementia-friendly communities that foster inclusion and dignity and the support from people who've probably been trained by you, what would it look like?

Could you describe it? Yeah, I don't want anyone to feel trapped on the other side of a door. We can't have spaces that feel like prison cells or feel like I can't leave.

Because as soon as you do that, my whole thought process is, how can I get out of here? So, it's got to have a combination of familiar and comfortable and known and functional, but it also has to have elements of possibility and transition and risk taking.

And so, I don't believe we should wrap people up in cotton wool. I think we have to know me a little bit and get to know about me. Am I a risk taker? Okay, well then Teepa needs some places and spaces and people that will allow her to risk take.

But we also need those people to know how to go, oh, hey Teepa, as I'm trying to climb a ladder, you know, to get stuff out of the gutter. And I go, yeah.

And they go, I know you're trying to do that. I could really use your help over here for a few minutes. And if I say, no, I've got to get this first. Okay, well, let me hold the ladder for you while you go, I've got it.

I know, it's for me, not for you. Fine. But that idea of, I still get to live my life. You support me and you encourage me and you try to transition me, but you're not the boss of me.

And in an inclusive environment, there's room for all of us. Yeah, and there's a rub there with safety, right? How do we keep you safe but make sure that we're not controlling you?

Yeah, it's a little bit of both. And if I've always been a risk taker, my idea of what's safe and my degree of being willing to take risks, you're going to change me at my age?

It's like, good luck with that. You know, I'm going to be the one that will stand on that edge and tie onto a zip line and zip right down and not hesitate at all.

And if I start changing, okay, well then modify based on what I'm showing you. But the reality is there are other people who would never climb up to the zip line to start with.

They'll go, that doesn't seem safe. And it's like, okay, well, I mean, you know, you can't fall far because they always hook you in. But me saying that doesn't make you feel safe.

It's really about the individualization and knowing the person. And so people talk about client-centered, but I truly, truly believe, and I know that's part of your life story as well, is we have to individualize support and care and treatment.

If we don't, we aren't serving that person. We're serving some artificial something. And we have to figure out how do they fit into this other thing. And it's not my job to jam them in there.

It's my job to support and see what happens if we do that. And then I go with what we got, you know? And we change over time. Every story is a little different.

And then, yeah, to your point, it's dynamic. It changes day to day, hour to hour. And so being there with the skill set to meet each of the challenges as they arise is such a big part of what can make us experience more joy and less suffering.

Yeah. And what I would say is the other piece of that is we've got to build a system that's better at supporting people who want to be in support, want to offer care, want to do this so that they're more skillful and less distressed.

Because to watch carers struggle so much and then push an agenda, because it's what I said I wanted back whenever, but now I'm changing my mind. And it's like, okay, So I hear that.

All right, well, let's try a modification here. Let me switch up a little bit and quit asking you to do what you've said no to. Because when I've said no, I mean, I'm not saying no arbitrarily.

It's like, yeah, no. Then we got it. OK, so you're saying no to that. Well, listen, I know you're not going to like this either. However, I'm going to ask for a big favor.

Do it for five minutes. and then we'll go do something you do enjoy doing. Can we try that? There's some negotiation going on. But always with genuine curiosity and respect and creativity.

Yeah. And I think that people have too many ideas of like, well, people living with dementia can't negotiate. Yeah, met my folks because they're pretty good at this.

I would say. And if you don't learn how they negotiate, you will find that it just feels like an argument. It's like, no, that's what they call negotiation because we keep pushing and they keep pushing back.

And it's like, if I don't want to push back, quit pushing and saying, so no change in clothes right now. I hear you. Can you come help me then? Well, yeah.

What do you want me to do? Well, here. I need to do some laundry. Could you put these in for me? Oh, shoot. I wish I had one or two more things to put in there.

Oh, Heather. Look. Oh, good grief. Now, this is one of your favorites, but what in the world? What? Is that Vaseline? Ooh. You know what? I don't want to do it while it's on you.

Go ahead. Here's a fresh shirt. Put this on and then let's spray it with the spray, but I don't want you to do it while you're in it. Here, slip that off.

There you go. Slip it off. Good. Okay. Now, here you go. And you've reoriented so that you're not right in their face. twist it away to the side so that it doesn't become combative, they don't feel threatened, but it's a way to redirect and make it a good idea, maybe even their idea.

Yeah. I mean, and so I let go of that task and I switched to something related. So it wasn't like off the wall kind of thing. I went to laundry, but then we realized, oh, shoot.

Now, you know, you got something on there. Now, what I'm not going to say is that I'm the one that had Vaseline on my fingers and I rubbed it on your shirt when I was just, you know, doing something.

But if my goal is to get her out of a shirt she's been in for two weeks. Oh, man. And people have tried other ways. I've got to come up with something different or it's just the same button heads.

Personal brain health, joy, and resources

And that's where I'm super curious about possibilities. When people say I've tried everything, it's like, so you've run out of capacity right now, I hear you.

So let's figure this out. I don't know, I may be stuck too, but I know we had to try everything, but I know that you've tried everything you can think of.

What gives you the most hope right now in this world of aging and brain change? Exceptional people doing exceptional things. Right now, the basic level of what's available to people living with brain change, whether institutionally or whether individually, it's not where it should be, needs to be, where I want it for me.

But I do see exceptional people doing exceptional things. So there are these amazing opportunities that are out there. But you have to seek them out. You have to find them.

And then you have to follow through. And they're there. But they are not available the way I would love to see them available. And they need to be available for people wherever they are and whenever they are.

And it's such a large space with so few exceptional people doing exceptional things. But people are out there doing it. and to find one another and support one another and point one another out is a starting place to build community.

Can you do that now? Do you have a list who comes to mind? Well, I think people who are doing things, when I say I want somebody to work with my person who's going to help me preserve and they live wherever you are, I would say talk with Heather, see if that's a possibility.

I will work with some of the folks who are over in the Netherlands. We have some communities here that we're doing work with. We have a group over in Australia.

who is choosing to do some really creative things and different ways of being and they're making a huge difference, they actually had the hospital say, we're calling you because you haven't sent us any admissions in the last several months and we're concerned.

And they said, we just don't need to send you admissions because we're not having the episodes we were having before. And And they're like, what? Wait, but you're still doing dementia.

It's like, uh-huh, yep, but we're doing it a little differently. And we're not needing that kind of support anymore. I was like, wow. What is the name of that group?

It's actually, oh, you would ask. Starts with an R. That's all right. We'll put it in the show notes. Send it. Yeah, you want to put it in there because all I could think is Renaissance and that's not, Rembrandt.

I was going to say it was Renaissance and it was related. I had to do the, I'm, you know, a little, I'm over 70, so I had to do the little word association to find that one.

Rembrandt. And they're in Adelaide. So they're a great group that we're really enjoying our work with. Halekaluke in Hawaii, they have three locations, a community there that's really, and it means, you know, growing and learning together.

And they're a great group there that really supports all kinds of wonderful work and outreach and community. There are some of the geriatricians in Hawaii that we have found that are super supportive of families and learning and building in community.

We have a woman in Malaysia who's making a difference in a Muslim community that she is part of with family carers who have felt trapped and now have ways to communicate with each other and find support with one another.

It's these little pockets of whales who's choosing to be a dementia-friendly nation and building skill sets for becoming a dementia-friendly nation. Wow, in the UK, how incredible.

When you said whales, I thought of a large mammal in the ocean. No, but you mean like W-A-L-E-S? It's a country, yeah, like that country, Wales, yeah.

And we've been working with them like eight or nine years now, and they've been spreading and building and really developing programming. that makes a big difference for their folks and they're finding that.

Families really feel the difference. I really feel hopeful hearing about all of these pockets of places around the world. This is not just in North Carolina or just in San Diego.

All over the world. How exciting. Deepa, at this stage, you mentioned you're over 70. Really, it's rare exceptions that we invite someone who is under 70 on the show because it is about aging well.

And I'm curious, what do you do personally to support your own brain health and to age well? I participate in yoga four to five times a week. I do walking, running, depending on the environment and how hot it is outside because I'm a great believer in being out in nature.

I live out in the country and I love being out in that space. I work physically doing things because I believe in using the body that we're given and making use of it.

I try to eat decently, probably not the absolute best, but more plant-based than meat-based and more fresh than a lot of processed. I do stay away from a lot of processed stuff because it's like, ooh, okay, let's not do that.

But I also drink a fair amount of height water. and I like to add some flavors and fruit and that kind of stuff, and vegetables. I love my veggies, though I do like them cooked anymore, to be honest, with the raw stuff.

There are certain ones I like raw, but I can't do the broccoli or cauliflower anymore. I've developed that sort of aging phenomenon where it's like, yeah, that doesn't agree with me anymore.

I love living with purpose, so I live with purpose. I try to take breaks. from doing things, and I try to connect with people that are making a difference and I feel good about.

And being with people I enjoy and challenges that I get to feel successful at. Wonderful. Thank you for sharing. What brings you the most joy? The moment when somebody goes, oh!

you're not going to believe this." And it's like, tell me more. Those moments when people have their ah-has, whatever they are, they have that ability to become excited about the possibilities of next.

When they've mastered something, they've gained something, they've discovered something. When somebody shares something and it's like, wow, that's really cool.

And then they tell you again. They tell you again because when you gave that reaction, they felt valued. So for me, that's a lot of fun instead of like, well, you already told me that.

It's like, yeah, but there's something about our connection that made it really valuable to share again. It's like, okay, let me learn, let me learn. So that when you're feeling that sense of not equal or less, it's like, Heather, do you remember that time?

I know you may not, but there was this time when you were able to get somebody to X and there's this, did I do that? It's like, you sure did. And it's like, oh, well, that sounds good.

Yeah, I agree. Whether you remember or not, I can help it become life again. So all that's fun. I love, you know, it's fun to have things happen where you're like, oh, look, I moved all the gravel.

It can be that simple. Look, the gravel's spread. There are no longer dips in the road. And it's infectious. Thank you for sharing it. Thank you for sharing your enthusiasm and your wisdom today.

I want everyone to know, so I'll tell you when someone gets a diagnosis of dementia in their family, the first thing I want them to know is about teapot snow.

Because it is such a, you have created such valuable resources and I constantly am saying, I don't really want you to go down the rabbit hole on too many things on YouTube, but Teepa Snow's channel is one to subscribe to and to just keep watching the videos because you're going to get more and more from the repetition, but also from these really unique insights.

So there is a YouTube video or YouTube channel, but tell everyone about your books, about resources you still see. You were talking about people you've seen today.

So if they want to get in touch and learn more from you, either one-on-one or through resources that are available, where can they find more? Yeah, if you go to our website, tipasnow.com, the name is so weird, no space.

But if you go there, and if you're interested, we do a 30-minute complimentary consult with people. We have a number of books. We just redid the dementia care partner guide and updated and expanded on that.

We also just updated Accepting the Challenge, which is now a streaming content area for people who are more in the professional world or in the family world plus the professional world, which happens a lot, where you want to help others sort of get a handle on what is this thing and how do I support?

And it was, some of the footage is 20 plus years ago of us working with people living with dementia in real time in a community. So you get to see Melanie Bunn, who's a nurse practitioner and I, working with folks and like in the bathroom shaving, in the bathroom brushing teeth.

in the dining room, having a meal, making banana pudding in a group, walking down the hall, dealing with someone who I was told, be careful, he'll hit you.

And yet we get up out of the bed and go to the bathroom, change clothes, put them on, come on out, head to church. So those are the kinds of things we have available.

Little short clips and then longer pieces. because everybody has different needs. And for those of you listening, it's T-E-E-P-A, Teepa Snow, S-N-O-W, just like in the winter.

So teepasnow.com and Positive Approach to Care is the name of her group. Teepa, thank you so much for sharing your experience, your wisdom, your insights, and all the contagious curiosity and hope and joy that is just exuded through our conversation.

Thank you, thank you, thank you for being here. Mutual, mutual. Thank you so much. Thank you so much for listening to the Think Well, Age Well podcast.

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