Introduction to Dementia Care Philosophy

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

There's life after the diagnosis. It's lots of years of life, so let's talk about how we want to live them. 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 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 help to 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, and it has been a while, so it is good to see 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 want to just 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.

And I said, well, give her to me and let me see what can happen. What are you doing with it? Why is she doing better? I don't understand. She has a plateau.

And it's like, well, because we do things together, it is a shared agenda. Not I have, I'm going to increase her strength or range of motion or I am going 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 what made sense, not what's regulated by Medicare.

So, 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 in long-term care and head injury, looking at, wow, this is really curious.

I wonder why that is happening. Let's figure it out. Then let's find 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 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 a sense of compassion and humor. But really, it's that sincere interest in figuring out what's doing 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 and I was asked to come in.

The husband and the wife are really struggling. Wife is living with a young onset, primary progressive aphasia, plus some frontal lobe 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. 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 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.

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

Yourself, probably. Your self and your spouse. However, if you think you're younger than that, you are 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, you know, could there be glare in making that be more of an issue?

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

Curiosity in Real-Life Home Assessments

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 gets up there's something for her to clean up because she likes to 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 am asking the person, the woman, tell me about the girls. In that moment, she goes, oh, no, what you're talking about. Then her husband says, 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, and she'll go, yeah, that is how it is.

Interesting. Yeah. This is really empathizing with her, really getting into her experience. What might she be thinking when she looks in the mirror, when passes a mirror?

When she sees her reflection in 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 our life and she is 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 more recent pictures and same with her husband. It's really good 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, 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 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 now seeing them in a 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, or those two things? Would they ring a bell if the came? Or could we check in 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 their emotional things, or their social things the brain picks up on that.

And when I belittle you or make you feel small or 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.

Of course. And I'm sorry, but I just don' really like feeling that way. 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 may get angry or might try less or get smaller and not want to engage.

None of those things are healthy. No, those are helpful. So why encourage it? Why foster that? Right. I think that there's this shift in how we think about it.

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

Are there other common mistake that we can kind of think through and highlight here so that people can have some tools or at least be turned on to some shifts in their approach to make them more effective and compassionate and make everyone's experience of this more joyful.

Less hard. So here's another one that happened. At the same situation. She had not taken her pills yet. Okay. And she had two large, one was a fish oil and one a big calcium pill.

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

And she says to him, guess what, what do you think she said? I already took them. I don't need it. Yeah. So then he goes, no you did it, now he's standing and talking.

Okay, so I said name, let me say Heather. Oh shoot, looks like Son of a gun, some of your pills are still here. In

fact, all of them are there. But some are here, tell you what, 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 she spit them 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. That's what happened. She broke apart some of the capsules. When she broke the capsule apart, the ones that have the outside and you can bite down them and all the fluid comes out, she was like, ew.

And, did she like 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 got swallowed.

So then they're saying, don't spit them out, Don't Spit them Out. It's like, I think it's already over. I mean, you know, so again, it is this corrective action, that it that idea of, well, this 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 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 taken in? chew a little bit, and then swallow it, then add fluid.

You know, fluid before fluid after, but don't put it in fluids. Solids and 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 oils 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 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, what are you doing?

And it's like, not a good plan. And its similar, but it is 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 because, 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 are not liking the pattern, Not blaming the person and recognizing, wow, we need to change the patterns.

All right, where she's doing it, when she is doing, who's around when 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 got. And she's like seven years in. She's got a habit now that's chewing things. 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 pill 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 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. What have you got? Have you? 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, ooh, Heather. Getting my attention. But I put that little question mark at the end of Heather, which meant interjection. Have something to ask you.

And you paused. Yeah? I mean, you're doing that. What? And then I gave a vision. Didn't say anything, I did the visual. Now I didn't put the vision here.

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

So instead of having the waterbottle right directly in from of your, underneath your faced, say, with your shoulders square. Tell us about that, how this orientation of the body changes our response.

Communication Mistakes and Better Cues

Yeah, so when I'm 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 won't you take it.

And then if I bring it towards you, it's like, whoa, what are you doing? Even right now. 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 wanna do is back up. That's a primitive brain reaction. I mean, the reality is 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. But this is what I want you to pay attention to.

Then I am actually going to demo. Taking a drink of water. Mm-hmm. And if you're still hesitating, go, 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.

Look at me. You know, when you get dehydrated and you Get impacted, you know what I'm saying? You don't want one to 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. If you have a partner you can roleplay this with.

I mean, you saying my name and doing it, I'm sure just ratchets up the intensity of the 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' think I am skilled. That set up is a failure set-up. Instead, 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. I want to come with me. All right. 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 are 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, can use your help. Come on and then you start to shift away. What's the message about the conversation at that point?

Well, you just sort of, I don't know if it's intuitive or again, it is this reflex, but you're just wanting to follow, right? Yeah, because we're not going to stay here.

Look, we are going. And so there's a visual plus a verbal plus physicality to it. 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? It's dramatic. I mean, and it's so fun to watch when people go, it worked. She did it. I mean, well, at first she wasn't interested, so I let it go.

And then we went in that living room and we were, and she helped me vacuum. She hasn't done that in years. 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.

Then they're energized. When they are energized, the energy between both of us gets better. I said, Wow, yeah, that's huge, but it didn't last. 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. Brain change. You did it for yourself and for. 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 their not tired and irritable and at their wits end all the time.

And helping them recognize before they need help, 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 and watch it. But I also get the chance go take care of me a little bit so that when I come back, my brain is a healthy, sustainable mode.

So, I got my exercise. You know, they can't exercise like we used to. We used run together. That hurts because now I could walk. She can walk, she can 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 run for me, for my brain fitness and my health.

If we don't start respecting ourselves, we'll just have the next generation. We just perpetuate this phenomena of dysfunction. 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 is 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.

Or a heart attack. 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 that knows their picadilloes 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. And it is a force. You have to force yourself into a space of discomfort.

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

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

If it doesn't work, I'm willing to shuffle around and give it a try. 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. But if I ever need her, I could call her.

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

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

It means, wow, did you get what just learned? Or are you still ignoring what we just learn? And so helping people, I think we underestimate the impact of dementia on the care partner and how it impacts their brain.

And their brains keeps thinking it's either all going to work out or it'll never work. It's like both of those are false. 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 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, 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 back in three hours. What did I tell you? I said, Jon's gonna be back because there's no training, there is no prep.

It's just I'm willing to do it, I'm doing a home visitor thing, but it's not a good match. 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.

Oh, I took care of my mom. Tell me more, 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 are 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, and go out for a walk, hike.

And so all of a sudden they've got a new family. The new families are people who are also experiencing some brain change.

Supporting Caregivers and Building Community

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 a long really, well.

And it gives us a safe way to take some time and to feel comfortable. we're not imposing, we are lifting each other's load a little bit. 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. 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 are not going order the junk that is on the menu. Pick a place that has decent food. It's finger food for people who are having trouble with utensils.

Will pick things that you can pick up and eat. But I don't have to explain that. Yeah. I do not have constantly explain myself. 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.

Yeah. The number of times I have people that can hear and talk about, it sounds like your brain is changing some. Sometimes getting words in is really challenging or getting word out.

And people go, yeah, I can't, 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 to something and they go, well that was better. It was like, hmm. 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 am changing.

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 going to 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 say I told you no, leave me alone.

I might have done that before, but I wouldn't say they hire 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.

And it's, like well, it means I felt captured, trapped, and my brain still has capacity to try to protect me. What you did made me feel trapped and endangered, so I'm reacting to that.

So I am learning I don't like you. That's the new pathway. Because I did not like you before but now I don't like and it's like now. I see you and I start anticipating that I'm not gonna like You which is not a good place to be And this is very preserved where we see this over and over again that if you get off on the wrong foot And the people who are have these brain changes going on Don't always remember exactly what happened, but they remember the feeling they Remember, they don' like so it is important to approached 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.

It's like, I think she's holding on something. Probably not what you think. She's going on too, but she is. So that's a change. You don't want that. Let's talk about your brain.

How can your bring change? Talk about change. Let's talk about the healthcare system. 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 health care 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 be financial institutions as, well we've got to sort of really start in the social institutions.

We've gotta start realizing, yikes, we And healthcare 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 screened our brain for function.

We need quit avoiding things that, it should never be this sort of like, yeah, don't know what my baseline is actually because I haven't had it done. I don' t know why it is.

Why would I know it? 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.

Like I can be really pretty, I personally could be pretty impaired and still would be able to do that because that's the kind data I hang on to. I mean, not a hard piece of data typically.

When I cant do, that we're way past the beginning of the cycle of being helpful to me. And to 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 providers says, well, you're MCI. Really? I can 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.

Or something, a head injury. Being able to dress yourself, toilet yourself. Unless something acute is going on. That's a later phenomenon. For most people, there's nothing mild about mild cognitive impairment, right?

Yeah, it's just a disservice to call it that. It'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 is just mild?

And my family is like well no, she's MCI and it like she can't put a meal together anymore. I mean, she, She's eating junk food. She is eating crap. she's going and buying these ho-hos.

He's never eaten ho ho's. I don't know what she is, you know, like what is going on here? And it's like, well, I'm compensating for my distress by doing comfort foods.

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? Ah. Yeah, she has early dementia and it's like, so that's part one.

Yeah. Changing the nomenclature. I'm doing screening. Really screening for ability and say, I 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 a person said, well, no, I didn't set up an appointment with you, the client was like, yeah, you did.

No, it never was set-up. 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 testing, it's self-report, self test. I mean, there is no system. 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 do not have systems 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 your finances? And I asked 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 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, you know, become a victim of this. Sign over your house. Yes. Oh my gosh.

It's just absolutely not. They can't catch them. That's the fastest area of white collar crime we know about. I would say the bad guys are figuring this out a lot more than the healthcare 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 want 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. 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 their 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 are getting straight messages about how many points on a paper test, what's that going to for you in daily life. I'm really curious, but let's move on.

But I am super curious about whether or not that's delivering at the price tag what is promised. I 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 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 are not in early state.

They are much more involved. If you were to watch them in daily life, this is, because I work with people in the program, so they identify as being in an early That's, I mean, they're needing guidance to go from activity to activity in a day.

They're needed 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.

That can't function. I means, that to me is not early state. that's something different. And it all focused on Alzheimer's.

Brain Change Language, Screening, and Systems

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 life.

My experience is we could see some really significant improvements in abilities. When we help people live into their purpose, they find a new purpose.

They live in to that purpose they, find pleasure and joy in that. 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.

It's not the career they handle. Many of my folks can say, this isn't how I was. This isn' what I used to do. But this means something. I'm doing well, I am keeping myself going.

And you ask their partners and it's like, yeah, maybe 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 became new people. So we got all the drugs off them. Can you give us the big examples of what they are doing and how their finding purpose?

Yeah, so I have a former physician who actually helps me do podcasts and recordings. 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's switched and then it was switched to a frontal temporal demand.

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, I had somebody who had posterior cortical atrophy and actually were told, You're not degrading as quick as we though you would, so you can't have post corticulatrophy.

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 community.

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

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 is doing here really matters to him. It makes a difference for him." And so we have people who help us clean the building.

When they're done cleaning, they go, well, I need to go do X, Y, and Z. The partner's like, she hadn't wanted to go do that for a while. And it's, like yeah, just got energized by getting the right support at the time.

When that happens, the chemistry of brain changes. It's such a dynamic phenomena, this idea of this downward progression of craft. 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, ooh, Heather, would you help me cut up these apples?

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

Let me have you do this. And I'd rather have eat apples without a lot of sugar than I would have stock up on three cookies because you're stressed. Do you see that diet plays a role in people's experience?

Yeah, what have 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, she is like eating sugar, like nobody's business. She never used to be that much of a dessert person, hips, she's just into it. She eats a whole bag.

And so the disbelief in somebody's voice is, I've tried to get her to stop. It's like, tell me about that. Why tell her it's not good for her? That's fine.

How's that working for you? I mean, but sometimes it's amount eating, sometimes nighttime eating. But I see a lot of not drinking fluids, particularly water.

I just like water's off the radar. And people are like, I try to make her drink, and I tell her. 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. You'll be amazed how many times people will eat it and like, well, it wasn't my favorite.

It's like I'll hear ya. not your favorite, here's the good news, it is good for you. So here is 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. That I just wanna provide opportunities for best life if we can. But I see a big difference when we do that.

People will acknowledge, you know, controlling my diabetes with activity and exercise, and I am not on anything really anymore for that, My hypertension is better now that we're participating in this program that were doing.

It's like, cool. And there are other people who are like yeah, no, I just want to eat sugar. All right, well that's a different care plan. I mean, we are just going to have a difference care plans 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 are 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, you can hardly do any thing anymore, that's a very common thing. And I go, wow, okay, so you've seen huge changes and you see huge losses. Okay, so I'm gonna work with her and I want you to watch and 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 go, how did you get her to do that? She never does that. So you want to know what some of the skills are I am using. Because this skill, this isn't magic, it's skill.

Here's where I wanted you try something. You be her, I'll be you. Let's role play it and 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.

Cause you know, like in one, it was like, we get into arguments and I said, okay, are you standing like this when you do the argument? Are you using your hands?

Now take your hand and put them around your eyes like and now let me do that. It's like oh, that is really awful. So if you are really focused in on you, your much more intense.

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 going to happen as much, because I just 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? Yeah. 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 are other brain changes maybe happening?

But then what other health things have you got going for you and the environment and how you're going to use your time? I mean, put the puzzle together because it is 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?

That there is a treatment that is possible, and it's not always drug-based, it does involve people, places, 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 light. This is like what you didn't know yesterday.

Well, you know one piece, but you don't what the future holds. What's going to happen today? I don' 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 wanting to have yesterday.

This is not going to happen. Yesterday doesn't come back. There's tomorrow, there is today, yesterday's done. Let's move forward. And, you know, sometimes people have to sit with that for a little bit.

Lifestyle, Purpose, and Non-Drug Support

If you need to set with it for little, let's do that, but then let us come and let 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, like how do we create an environment? How do you create a world where this person shines?

All of their abilities that are remaining are really accentuated by what we do, how we it, where we are. You've trained thousands of people to help support loved ones, but also to have 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. I personally am very doubtful that will find a cure to all the different reasons that brains change, deteriorate, struggle for a long time.

It's going to be really tricky to find all of the bits and pieces that are going make a difference. Louis body is really very different 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, it is there.

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

I think it's a little tricky because now with the latest treatments of diabetes, it sort of like, oh, look, a new med, this one is going to take away all responsibility and accept 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 us get a little curious before we all jump on away. I mean, that's just like, hmm, let is look for an external rather than let look in the mirror and go, okay, Teepa, what could you choose to do that might make a difference for you in a long run?

Because it isn't just about one condition. Right, 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 look it like, can 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 I can 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 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 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 go, ooh, hey Teipa, as I'm trying to climb a ladder, 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. You know, and if I say no, I've got to get this first. OK, well, let me hold the ladder for you while you go.

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

In an inclusive environment, there's room for all of us. There's a rub there with safety. How do we keep you safe but make sure that we're controlling you?

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 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 am 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, OK, well, I mean, you can't fall far because they always hook you in.

But me saying that, doesn' make you feel safe? It's really about the individualization and knowing the person. I know people talk about client-centered, but I truly, truly believe, and I that's part of your life story as well.

We have to individualize support and care and treatment. I mean, if we don't, we aren't serving that person. We're serving some artificial something. And we have figure out, how do they fit into this other thing?

And it's not my job to jam them in there. It's my own job, to support, and see what happens if do that. Then I go with what we got. And we change over time.

Every story is a little different. 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.

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 offer care, wants 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 is 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 say no, I'm not saying no arbitrarily.

It's like, yeah, no. Then we got to, okay, so you're saying, No to that. Well, listen, you know you are not going to like this either. However, i'm going 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 were living with dementia, can't negotiate. It's like. They're pretty good at this.

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

And it's like, if I don't wanna push back, quit pushing. So, no changing clothes right now. I hear him. Can you come help me then? Well, yeah. What do you want me to do?

Here, I need to some laundry. Could you put these in for me? Shoot, 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 want you to to it, while you're in it. Here, slip that off. There you go. Slip it off, Good.

Okay. and you've reoriented so that you're not right in their face. Twist it away to the side so 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. 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. Then we realized, oh, shoot. You know, you got something on there. Now what I'm not gonna say is that I am the one that had Vaseline on my fingers and I rubbed it on your shirt when I was just doing something.

But if my goal is to get her out of a shirt she's been in for two weeks. And people have tried other ways. I've gotta come up with something different.

Or it's just the same button heads. And that's where I'm super curious about possibilities. And, you know, like when people say I've tried everything, it's like, hmm, so you've run out of capacity right now.

I hear you. So let's figure this out. You know? I don't know. Well, I may be stuck too, but I know we had to try everything. But I that you tried to everything you could think of.

Right. Yeah. What gives you the most hope right in this world of aging and brain change? Exceptional people doing exceptional things. I mean, 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 to find them, and then you 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 and whenever they.

It's such a large space with so few exceptional people doing exceptional things, but people are out there doing it. To find one another and support one and point one other 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, talk with Heather, see if that's a possibility.

I will work some of the folks who were over in the Netherlands. We have some communities here that we're doing work. 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 are 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 Dimensions.

Like, yeah, But we are doing it a little differently and we aren't needing that kind of support anymore. 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, send it my way. Yeah, you want to put in there because all I could think is Renaissance and that's not, Rembrandt.

Dementia-Friendly Environments and Personal Aging Tips

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

And they're an Adelaide. They're a great group that we're really enjoying our work with. Halei Kaluke 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 Hawai'i that we have found that are super supportive of families and 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.

So it's these little pockets of, you know, whales who are 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 Wales, I thought of a large mammal in 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 be 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 do feel hopeful hearing about all of these pockets of places around the world. This is not just in North Carolina or just San Diego.

Yeah. 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 of that space. I work physically doing things because I believe in using the body that we're given and making use of it.

But 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. And I do stay away from a lotta 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. So, and vegetables, I love my veggies.

Though I do like them cooked anymore. I'll be honest with the raw stuff, there are certain ones I liked raw, but I can't do the broccoli or cauliflower anymore, just I've developed that sort of aging phenomena where it's like, yeah, that doesn't agree with me anymore!

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

Being with the 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, you're not going to believe this." And it's like, tell me more.

Those moments when people have their ahas, whatever they are, they have that ability to become excited about the possibilities of next when they've mastered something, when somebody shares something and is 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. And it's, like

okay, let me learn, so that when your feeling that sense of not equal or less, it 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 remembered or not I can help it become life again. So all that's fun. I love, it is fun to have things happen where you're like ooh look, 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. Thanks for your 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 wanted them to is about teapot snow.

Because 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 channel. Tell everyone about your books, about resources you still see. You were talking about people you've seen today. If they want to be in touch and learn more about 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 go there, and if your 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 folks and like in bathroom shaving, in that 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 yeah, 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-P-A, Tipa Snow, S-N-O-W, just like in the winter. So tipasnow.com and Positive Approach to Care is the name of her group.

Teepa, thank you so much for sharing your experience, your wisdom, and your insights and all the contagious curiosity and hope and joy that is just exuded through our conversation.

Thank you, Thank You, for being here. Mutual, mutual. Thank you so much for listening to the Think Well, Age Well podcast. If you enjoyed today's conversation, please take a moment to subscribe, leave a review, and share this episode with someone you care about.

It's one of the best ways to help others discover tools and inspiration for aging well. To stay connected, get bonus

resources and never miss an episode, head over to drheathersanderson.com and join my email list.

Until next time, keep thinking well and aging on purpose.