Introduction and Randallu2019s caregiving story

We know that this craniosacral for us, I don't know how it is for other people, but this has been the best, most improvement over all things. This is it.

this is where I'm feeling like I am a person again talking to a Person. Welcome back. Today's episode is a deeply personal and moving conversation with Randall Mapstead, a devoted husband and caregiver to his wife, Linda.

Randall opens up about their journey from the early signs of Linda's cognitive decline to the difficult search for answers and ultimately to discovering alternative therapies that have brought them hope and healing.

With honesty and heart, Randal shares what he's learned about disorientation, over-stimulation, and how our environment and even our diet can influence the course of this disease.

He speaks candidly about the emotional toll of caregiving, the unexpected moments of joy and the power of connection through touch, music, prayer and just simple presence.

This conversation is a reminder that even in the face of heartbreaking challenges, love, creativity, and persistence can make a profound difference in your experience.

If you are a caregiver or you know someone who is caregiver, I hope that this episode offers insight, comfort, inspiration. Let's listen in. Randall, I'm so delighted to have you here.

Would you share with our listeners your story? How did your interaction, your experience of Alzheimer's start? Well, Dr. Heather, started with recognizing there was something wrong with my wife, who is now 81 years old, about six years ago.

And it only happened once in a while, maybe two or three times during that year. She's just said something out of the blue that didn't make any sense at all.

And then one time my son was over and she said, something not of blue. He looked at me as if he just went, what's going on dad? So after two years, this only happened three or four times in a two year period.

I thought, you know, I need to take her somewhere that somebody has seen this type of behavior before. The answer was UCLA neurology department. So we went down there, we met with the neurologist.

I was hoping for Parkinson's. So, when we talked to him, I explained what was happening. He identified it as Alzheimer's dementia aphasia, substituting one word for another word.

Well, 15 minutes later, he said, you know, there's no cure. Goodbye. That was it. Well, we booked another appointment and we went down again a couple of months later and I brought it all up again.

He goes, well, I'm going to contact the psychiatric department that we deal with and they're going give her some tests. Now, it wasn't the MOCA test, and I don't remember the names of them now, but there were three increasingly more strenuous tests that she was going to go through.

And it was done on Zoom because it during the pandemic. And there were three different women that I met with. And the first one was maybe a half an hour long.

The doctor said, Mr. Mapp said she's going to turn around and ask you what the answers are. Don't answer her and don't write it down in a piece of paper and try to escape me hearing you talking to me.

All right, so we went through that and immediately the first question she was asked, she turned around and looked at me. And the lady said, I'm going to leave you in the room, just don't answer.

Well, during that time period, the doctor held up another sheet of white paper and it had five African animals in a black outline that everybody could recognize.

My wife Linda could not recognize them at all. It was a camel, a giraffe, lion, and maybe a hippopotamus. She couldn't recognize him. So the lady asked her several more times, did she recognize it?

Finally, she said, oh, I think that one's an lion. But I knew from that instance, we were in big trouble because she didn't exhibit that type of memory loss or visual memory that she could see.

So that was pretty much the end of it. We had two more tests that were harder than the other ones. And once again, that Was the End of It. Then they sent me an evaluation of those tests.

The only thing they had to offer me was to watch some of the UCLA caregiver videos that we're available. Well, I watched one of them, but it was in lecture form, which was fine, But I was already doing that.

Then we moved from Bakersfield over to San Luis Obispo where we now live and things went like this. Before that, you know, still functional, dress yourself.

Every habit that we have, she could still accomplish. We got over here, it started going down. And we still had no recourse, but I went down to the Sansum Clinic in Santa Barbara, saw the neurologist there.

15 minutes later, the same thing. Well, you know, there's no cure, goodbye. I mean, that was it. But Dr. Heather, this strange thing, and I don't think I've ever mentioned it during any of your classes.

So Dr. Bredesen was or still is the head of the neurology UCLA research department. But does research talk to the clinicians, the people that meet with the patients?

No, they don't. In his book, was five years on the New York Times bestsellers list at the time I was down at UCLA. It was on The New-York Times Bestsells List.

Did they tell me about his book? No! It's very frustrating, right? Your story is like so many others I've heard going to neurologists and feeling like it's a dead end.

Early symptoms, UCLA visits, and lack of answers

I'm curious, when you were doing this with Linda, going down to UCLA, noticing that she was having some changes of her speech, maybe misplacing words, did she notice that was she having this happening?

What was her experience like? The answer is, she did not know something was a matter with her. Because one day when my son was over here, She asked him, Eli, is there something wrong with me?

Yes, mom, there is. You're having memory problems. She's never asked that again, but she does know there's something. Recently, I mean, in maybe two weeks ago, she said softly to me, i want my body back.

I wouldn't know if she needs her brain. Well, she probably does, but her body is still fine. She walks a little bit slower, She can do everything. she can feed herself and that kind of stuff.

So yes, another time she would say, I want to go home more than just once. And I looked it up and sure enough, it said, i don't want go to a physical place.

I went to get home here. The person that my thoughts think. I want to go back to being myself. I wanna feel at home. So you went to a couple of neurologists, tried a few times and kept getting this sort of dead-end answer.

Come back and we'll assess the changes and keep track of her decline more or less. Did they offer you any medications or any solutions at all? No, not from the two neurologists, but now we're on to how I found you, how we found Dr.

Bredesen, and how i found the Dr Bledesen coach who had been trained right next to our town. So, in December of 23, our daughter calls up, Dad, dad, I've found it.

Dr, Beredesen's book, you've got to get the book. And then the first week of January, dad, I found this lady down in San Diego named Dr. Heather, and she's given a special on her 12 week class.

You got to sign up now. I signed up right away. And that's how I met you. Then just listening to you talk, there were other Dr. Bredesen coaches, if you will.

I know there's another word for it. So I just typed it in, Dr Bledesen coach, Alzheimer's dementia guy popped right here, just down the road from us, called him up, made an appointment.

And that's when it all started coming together that there was now help. The strange thing about the two neurologists, they didn't even offer me blood lab work, they didn't offer us heavy metal tests, They didn' offer environmental toxin tests.

They did not offer as gut zoom, you know, examining the poop to see what, no test, just hello, goodbye, there's no cure. That was the most frustrating part once we found Bredesen and you and the doctor.

So we started with you, and that's when I knew there was hope. There was hope we were going to get. We went down and saw this doctor within two weeks after listening to you talk, and I explained what was going on with her, the aphasia, this and that, samples.

Okay, well, we're going start her on blood lab work with Vantage America. And they tested the nutrients as in vitamins and minerals and other stuff, your lipid panels and all of that kind of stuff.

What is in the bloodstream that's flowing, but also how is it being stored in cells? two separate tests showing you what's going on. And that was highly beneficial and we identified certain vitamins and such to take care of those problems.

Then the environmental toxin test came back and she tested high for MTBE, which is an additive in gasoline that's just found everywhere, in the air, on the ground, and in water.

The heavy metal tests came So there's low, medium, and high for heavy metals. She was off the chart for lead. High for cadmium, chromium tin, two other metals I'd never even heard of.

Oh, well, we're getting somewhere. There's hope on the biology part of helping your brain and your body. We haven't got to helping the brain for the memory parts that have maybe already died, something like that part.

So he was able to start us on chelation therapy, to pull out the heavy metals, pull the environmental toxins stuff. And then he gave us other type supplements to use also that had nothing to do with chelation therapy.

They were the Pectisol. We're using Peptisol, we're use Vibrenza, or using Gastric Acid. Were using other types of supplements like that. And so that all started in February.

And I'm going to say within one month or two months, she was really low in vitamin D and all of a sudden you could see improvement just in certain areas.

The aphasia thing continued on, but things were improving and then they started leveling off. I want to understand, what have you seen improve? So you started the interventions with the doctor.

You started coming to the coaching program and learning about more of the lifestyle-based pieces. And at that stage, was there anything tangible? What could you say improved for Linda?

I'm going to go straight to craniosacral. And then I'll backtrack. So we started craniosacral therapy in January and then, I found somebody right here in town that we got along with and we were going once a week.

The first treatment, she's 81 years old at this time. I think the word is chatty Cathy. The lady's working on her with her hands and stuff. She's just going on and on about stuff and we couldn't tell what she was even talking about.

It went the whole hour. And I'm going, this is an improvement. So that's not typical for her. Linda doesn't take it. No, no, and this was not a typical.

She calmed down, wasn't much talking. And when she was done, she got up and she looked at the therapist and said, what is your name? And who are you? She said who she were.

Then she stood and looked directly at me and say, who were you and what your is name. I'm going, this is an improvement. Meaning she is actually able to put thinking to voice and ask a question.

That's the improvement, putting voice to questions. Excellent. Those are the kinds of improvements that we saw. So then the next time, maybe the third or fourth time much more calm.

She actually laid there the whole time. And the therapist lady whose name was Laura, she said to her, well, how are you feeling, Lynn? Oh, I'm happy. I am ready to get up.

Well, only 20 minutes had gone by. We had to convince her to stay on the table. just in that 20 minutes on the third or fourth session. She got to that point where she was happy that because she's been a happy, joyful person all of her life anyway, very positive all the time, no matter what.

So I thought this is good. We're getting some place. And then by the fifth one, the guy who expressed Alan from one of your classes, he had taken his wife and he has said what happened to her.

His explanation was way better than my explanation. Mine was. She was able to converse with me. She could instigate conversation. If we were at the beach, she could tell me about how beautiful the seagulls were, the ocean coming by.

So you stop and talk to the people that were walking their dog. she's initiating what was going on in her life now. Yeah, so you guys have been on this path, this journey for a while.

At first, it sounded like it seemed pretty hopeless.

Finding Bredesen care and beginning testing

And then you started doing some of these lifestyle changes, working with the Brutus & Train provider. It seems like you really saw a shift when you've started the craniosacral therapy.

For people who are listening who don't know what that is, I want to just take a minute to describe it. Craniosacre therapy is actually Personally, for me has been profound intervention.

I struggled with TMJ when I was in college, I couldn't open my jaw. And so I went and saw a craniosacral therapist named Runa Basu up in the Bay area.

After seeing many, many providers, and I would see any dentists and psychiatrists, therapists and medical doctors. acupuncturist and massage therapist, I was desperate for help.

And after seeing Dr. Basu for just an hour, it was 80% better. My jaw was able to open. It wasn't clicking. it wasn'

popping. I wasn''t in pain. This was such a life-changing intervention for me that I've always had a deep interest in it, and so I have been trained to do craniosacral.

It isn't the primary modality that is used these days, but I often refer people to it. And what's happening is very light touch, so it's a manual therapy.

Has to be done in person. I typically recommend providers who have trained by a gentleman named James Jellis. Jells is an envy. And the providers can sense what the cerebral spinal fluid or that fluid that bathes the brain and the spinal cord that flows up and down.

There's a rhythm to it. The providers consents that movement of that fluent. They can also tell if there are what we call lesions. If there's some sort of tension between the bones and how the bone connects to each other.

And then at a manual level, we're stimulating the craniosacral nerve roots. And this is where our parasympathetic nerve-roots are. So this what helps to put us into that rest, digest, and most importantly in this case, heal state.

As we get that cerebral spinal fluid flowing, as we go into a parisympathy healing state, It's easier for the brain to rinse the toxins. It also can make a big difference in balance, as you mentioned, mood, energy levels.

And over and over again, I've had patients and participants in our coaching program say that they notice a bit difference and their loved ones who are suffering with dementia and Alzheimer's, and you were certainly among them.

So you guys have done how many sessions now? Well, it started in January and it's now the first of May, so we were doing once a week. After every session, I would try to have Laura, the therapist, explain to me what she was experiencing.

So recently, with one of the last ones, she said that in the beginning, Lin's brain or It felt brittle. That's how she could explain it. It just felt brutal.

And now after three months have gone by, everything is more fluid, and everything's more flexible. Everything is spongy. She's feeling more of the cerebral spinal fluid flowing all the time.

So our daughter calls one, two, three, four times a week on Zoom. and using my phone, and she's going, you know, Dad, Mom's improving. Before when I would talk to her, I had to initiate all the conversation.

I have to talk about stuff that was going on in the day, if she barely could respond to me about anything. What we're experiencing now is she can start off the conversation, well, hi, Jade, how are you?

How are your flowers growing? She could start the whole thing and her daughter actually notices all that. So we know… that this craniosacral for us, I don't know how it is for other people, but this has been the best, most improvement over all things.

This is it. this is where I'm feeling like I am a person again talking to a personal. Wow. That is a big deal. I mean, Randall, that's a bit change for your day to day experience.

I'm curious, are there any resources as a care provider, as, a partner for someone struggling with Alzheimer's, Are there resources you wish you had come across sooner?

Yes. Deeper snow. I listened to you all for a whole year talking about Tipa Snow, and it just kind of went like this past me. I wasn't ready to listen to Tipas Snow.

So last week I listen the three or four YouTubes on Tipus Snow I didn't go to her website. And I just looked at that, but I was already looking at it.

For those who are listening to this, Tipis Snow is just the most amazing person who knows about Alzheimer's dementia. And she doesn't lecture on how to be a caregiver.

She role plays the different scenarios that we the caregivers find ourselves in. Truly amazing. One of them was the family needed to take the car keys away from the husband.

And she went through role-playing on how she finally got the husband to hand her the keys, not the family members that were there, but he handed her of the key because she role played with them.

She also role play with this lady. who was in a care facility, was using a maraca, and she kept shaking it at this chair. She was disturbing other people in the room.

she was just disturbing everybody because it was so much noise. And on top of that, she wasn't caught in it, at the same time, so the rumor was smelling.

They tried to figure out what she was doing. So they looked at her background while this was all going on, and she had been a person who cleaned houses or made of some sort, but she a cleaning person.

They figured out when she's shaking it at the chair, She was thinking that she was cleaning the chair. They handed her some cloths, and they said, here, I'm gonna hand you these cloth, so now you can clean.

And she motioned to her how to do that, how clean the chairs. At the same time, she reached up and she got the Merachi thing and took that away from her.

She started praising her, oh, you're so good at cleaning a chair! She's role playing. That for me, I could duplicate what she did. And she that for so many scenarios that I watched, it was the most amazing thing.

I was ready for it because I really am at that stage with my wife. It's not that things are deteriorating a lot, but role playing. Just to get my to wife get into the shower sometimes.

to take off her clothes. It's not that we haven't seen each other naked before, but it is in a more intimate setting per se. And Tipa actually addressed that in one of them.

She goes, and getting somebody to go to the bathroom on time, which there's some incontinent and I had to program myself. Okay, Randall, we're going to to exercises with everybody.

You're gonna go use the bathrooms. No, I'm not pulling my pants off. But Teepa helped me to understand that even though we're married and intimate, we've been around each other, it's still an intimate thing between two people.

I used her example of how to get her to take her clothes off and to go to the bathroom. Going in to takes a shower is another story. And I finally figured out, okay, Lynn, come over here and get this T-shirt out of the drawer instead of me doing it.

Chelation, supplements, and early improvements

You open the drawer, you take the t-shirt out. Here's the pants that you're gonna wear. Go in and get them off the hanger. There's diapers that have to wear, so now I'm putting the onus on her.

She has to take care of that part. We go in, we put them in the toilet. Heres your clean clothes that your gonna put on. No, I am not taking my clothes off.

I know, but we have go, no I not takin' them of. Okay, well I gonna help you, take them, No you are not. So it took me a while to understand, this was happening before I met Tipa.

It took a little while for me to know how to make it happen. Okay, I said this and I say that, and then when I got to

the frustration level, there's a picture of the Divine Mother in our bathroom.

Divine mother for my is, it's just a pictures of one of our women saints. And I would go, okay, Divine Mother, I've had it up to here. You have to take over.

I know that you can do this for Lynn. Would you please do that? Cause I'm at my level. Boom. Right off. Now it doesn't always happen. Sometimes the Divine mother makes me go a little bit more because I have change in here also.

It's not just the scenario or the circumstance that I want my wife to change. And I got this from Tipa Snow. I couldn't put words to it what I'm saying until I met Tipah.

There's a couple of themes in what you just shared. One is being ready. Being ready for the information or the coaching. So I cannot recommend Tipa Snow enough.

For those of you out there who are care partners for someone suffering with dementia or Alzheimer's, she has a wealth of knowledge and information and coaching, her background is in occupational therapy, but she is a whisperer of people who were struggling with dimension.

One of the other themes that you mentioned was meeting Lynn where she's at, right? Going into her world versus trying to force her back into yours. And in my book, we talk about connection over correction, instead of telling her, forcing your reality down her throat.

You're just meeting her where she is, getting into her world, and that reduces the risk of things kind of falling apart, right, of the wheels falling off and things escalating emotionally.

You can stay on the same page even though it takes discipline and it take creativity and takes patience. And you've been in that situation over and over again.

So let me continue on with that part of it. So we probably could take 15, 20 supplement pills in capsule form. You want to use capsules so they have powder in them that you can break them apart and put them in smoothies or food or something because it just becomes on.

I make breakfast, I was giving her breakfast and I were giving here the four or five pills to take. And then she was having a problem that she wasn't swallowing them, she would start chewing them.

And I'm going, what do I have to change? Something had to changed. Then it dawned on me. Sometimes she still was chewing some food. So what would she do with the pill?

She would chew the pills, right? Follows in a sequence. It dawn to me, all right, You have to give her the pills before you serve breakfast. Now you have your drink, here are the four or five pills, and I have say this, pick one up, put it in your mouth, take a drink and swallow.

I had to say that. And sometimes I'd have demonstrate that I pick a pill up and put in my mouth and take it drink. That solved the problem. Not all the time, but it was a step forward and now she could swallow the pill without any problem, And the thing I looked about swallowing pills, because I look at them on YouTube, Because the capsules are pushed together, there's air inside those capsuls.

So when you take a drink of water, they kind of float in the mouth. It doesn't always float back, so we've worked on that. So I figured that one out. And then when I saw Tipa Snow talk about role playing, I did it.

I knew it myself. Hallelujah. Somebody's confirmed that I'm on the right path to help her. Well, it's the curiosity, Randall Ray. This is such an inspiring part of who you are is you just deeply care for Lynn and her well-being.

And because of that, you're curious. Chief of Snow talks a lot about this. How do I get curious about what need isn't

being met? How I do get about the world that they're living in and meet them there so that their experience is better, so they are living a less stressful experience?

Craniosacral therapy and renewed connection

And I see so much of that in your relationship with Lynn. Okay, so now that brings me to caregiving. And not only you have said on your classes, the caregiver needs to have at least eight hours or one day off completely to themselves.

Amen. I'm good with that and that is excellent advice and people should take that advice. But the training that I've had from monks and nuns is a little bit different, and I have expressed that on your classes.

So I wrote these down to make sure that was gonna give it right. In our culture, we have these phrases, it's better to give than to receive, that we become a more happy person in giving.

You have to actually practice that. We just can't take it in and go, uh-huh, okay, well, whatever. So I have to practice that. I'm still practicing that, I am 78 years old, and I've been practicing since I went to Sunday school at five years.

This is a lifelong journey. The next one is there is the phrase, life is chiefly service. So now I have to give unconditionally, no matter, Lynn, what you do to me to make me frustrated, I'm gonna give, give and give.

And that is service. So life is chiefly service by giving. For those of you who have experienced what service means, and I'll leave it up to you to figure that out.

But now, we're gonna talk about Mother Teresa. If you want to join her sisters missionaries of charity, one of the four requirements are wholehearted free service to the poorest of poor.

Now, I had to translate that into my situation. We're not the poorest of the poor, but the wholehearted free service for me is you really have to work on expanding your heart.

This is not intellectual thinking. This is love out of the heart. Wholehearted, that's the word she uses, wholehearted. You can't have a little black spot in there somewhere.

But once again, this is a lifelong practice and I'm not perfect. The other part of it is it's free service, which means it unconditional. Once again no matter what Lynn does to frustrate me with her behavior, because she doesn't know she's behaving that way.

She doesn t know. What's in a blue moon? She'll say something about that and just go, No, I'm just doing the best I can. And I also have to tell her that Divine Mother loves her and the Divine mother is taking care of her.

Because there's another phrase. The phrase is, God is the doer, not I. Every time I think that I'm the doer, and by God, Lin, if you don't take this pill, I'll think I am not doing right by you.

It makes me feel bad. I want you to take the pill because I need you get better. And you're not doing it, and it frustrates me. And I get angry about it.

Sometimes I shout at you, then I have to apologize for it." But yes, that is the part. For those who are listening, it's just lifelong practice. Even Dr.

Heather has been as sometimes she's not perfect. I am far from perfect, we all are. We're human, right? We're human and this experience is, it is ripe for.

practice, right? Every day is a practice. And certainly with caregiving, it's a reminder of vulnerability. You mentioned, you know, the poorest of the poor.

I think people who are struggling with Alzheimer's and dementia, they are in such a vulnerable state. Showing up in service of them day after day, after a day.

It really is remarkable work. Caregivers out there do it sustainably. This is part of why I encourage people to take time off is because we want that balance.

We want it to be a fulfilling experience. I hear many people who have had the experience of caregiving, they wouldn't give it up for anything. They're so grateful that their spouse is around, that they're parent is round, but they get to make memories and have this time with them.

But it's also extremely stressful. And you mentioned the frustrations, kind of these micro griefs that each day, instead of having Lynn there to have breakfast with you and for you to leisurely discuss the news or what you're looking forward to, you are her caregiver.

She's your dependent. And she's no longer your wife in the same regard. Even having to take her to the bathroom or to get her undressed to shower, It's a very different relationship than the one that you had with the woman you married.

Well, you're right in that aspect if you look at it that way. But she is my wife. There's no changing that no matter how that is. The other thing I wanted to say about the missions as charity for Mother Teresa, Those ladies who commit themselves to being that kind of a person, they have to smile while they're holding the hand of person that's going to take their last breath and they are going hear that last gagging sound.

If they caught not smiling and break down in tears, which is a human thing and I'm all right with that, but the person who's dying, They don't want to see you crying.

that person has to smile. So sometimes in the morning or other times during the day, I'll go and look in a mirror. What do you look like, Vandal? All right, for those of you who are paying attention, someone taught me with this one time, take your two fingers, And push your smile back into place.

Put a smile on, no matter what. Fake it to you. So this is another interesting thing I want to say. It might not make any sense. Sometimes it doesn't make it me, but nobody knows why my wife has developed this.

But sometimes I look at it, it's happening because you, Randall, need to change. You need to get out of the intellectual stuff that you've read the Bible.

You've heard the Bhagavad Gita. you think intellectually the stuff you have read, you can do. And when you truly look at it, You are not doing it. It's all this thinking blah, blah blah.

The loop memory going around and around. it's happening because you Randall has to change because we both know that we're going to leave this planet sometime.

Its just going happen. and you wanna leave a better person than what you've been all your life. You need to change. Your wife is gonna go, maybe she's already changed in here because, and now we're gonna get to some of the caregiving.

I've taken her over to play ping pong because you've talked about you should go do dancing. You should sing, you shouldn't make up songs, all sorts of these activities.

And we used to played ping-pong, but we stopped and we go play Ping-Pong. She's like the person that I knew. So she can beat me in Ping pong. It's a, how can her memory tell her hand to react at this time?

And then she's just, she was going over, woo-hoo, I'm getting you out there. She's the person again. It's truly an amazing thing. And the other day when our daughter was visiting, who's 55, and granddaughter was over here, I had some music playing.

I have Blue Danube on that you can do waltzing to. So our Donna got up and started dancing. So then she got the granddaughter who's seven. She got up and started dancing.

And then put her hands out to mom to get up, and got her to dance. My wife, she's just dancing around the room, having this great time. Like she'd never had Alzheimer's in her whole lifetime, but she is back.

So I'm telling other people, Whatever it is, those activities involve them. I don't care what it. If you listen to Dr. Heather's 12 week class, you'll get the information that I'm trying to give.

Well, I think there's a lot there. Creating spaces, right? Tipa Snow talks about creating an environment or shining the gem. so that they sparkle, so they shine in that environment.

And you are creating these experiences for Lynn where she can sparkle and shine. She's very familiar with ping pong, you're exposing her to something that she knows, she's got that muscle memory, it's in there somewhere, to dancing and music and people she loves and is comfortable with.

It's not going to work every time, every day in the same way for everyone, but when you create that space instead of putting her in overwhelming situations with a lot of people or trying to get her to play pickleball when she's only ever played ping pong.

You're reintroducing things that she is familiar with where she feels like she can win. We see this with gardening.

Teepa Snow strategies and caregiving mindset

Well get people who have gardening experience in their previous lives and they'll get in the garden and then they put their hands on the dirt and know what plants need to go by what and their watering and They're just back in an old routine, and they feel that confidence, like you were describing her celebrating her wins.

And that, you know, again, it takes creativity, It takes effort, knowing someone, loving someone to create that for them. Okay, next topic I like to talk about, I call it disorientation.

So now we're moving to a different subject. Uh, so for those people listening, uh, want to, talk, about what causes dis orientation in my wife, Linda.

So the first time I noticed it, we went on a lot. This is probably two or three years ago. We drove from the middle of California to Eugene, Oregon, 750 miles.

Things were pretty good until we got halfway. And that's when I first heard her say, I want to go home. I'm going, Lynn, we're only 300 miles from your daughter's house.

So this went on for a little while and I thought, you know, okay, well, just stop replying. Maybe I'll just go away. And it kind of did. So then we got into Eugene.

She actually could remember a street that our daughter lives in. Oh, she lives just up the street. Turned in this driveway. Well, Okay. Then while we were there, things were pretty good.

Everything went smoothly. We didn't have any problems. that I'm mentioning now, because this was two or three years ago. So things are pretty good with that.

Then on the way home, randomly sized, instead of driving straight down Interstate 5, I want to go down the Oregon coast and see the scenery. Well, as anybody has driven the oregon coast, and driven out to Eureka, you know, the road goes like this.

Very windy. All right. We get to San Jose, because I could drive from there to Santa Jose and I'm on one of the freeways heading to the Santa Cruz to our son's house.

She starts breaking down in tears. And I just go, what's the matter, Lynn? She goes, I am a horrible mom. I let my son go. I couldn't understand what she was talking about, but she in tears that she had become a horrible mom, that didn't make arrangements or something for her son.

I'm in the car driving, my cell phone is here, I can push the button to make the call without doing that, so I called Eli, my son, Eli. Mom's freaking out on there.

You need to talk to her. So we talked to. All right. It helped a little bit, but not much. And then she said, that wasn't Eli she didn't believe. Cause I said you just talked.

No, it wasn' him. Right. That's disorientation. Then I discovered more dis orientation. For me, the dis-orientations took place. with visual memory ability, the speed of the car at 70 and 80 miles an hour, watching scenery just flowing by you.

The memory can't take it. That's what I came up with. It just couldn't. So then I experienced more disorientation. If, and this is recently in the last four or five months, maybe the six months.

If I want to go shopping and I leave when it's still daylight and she's in a car because she goes everywhere with me. She's never alone. She doesn't know where we are.

She does know the road that she always tells me, turn here to go into the park. Turn here, to to the house. she's not saying that. I pull in the driveway, she wants to know, where she is.

Well, we're home. Oh, and then we went into house, well, who lives here? Well we do. We sleep in two different beds. But she walks into my bed, She didn't which bedroom was her.

Disorientation. It took a while for her to come out of that, If I leave when it's dark and I come back when its dark, the same disorientation. It's a visual thing.

She can't see where we're going, that directions or the place, because I'll ask her, Lynn, do you know where are we? No. Do you know where we are now?

No. Do recognize the street? That's what disorientation means. And then I knew we were in big trouble because at Christmas time we went to the Nutcracker Suite Ballet here in town.

It's two hours with a break. I'm sitting next to her, our son, granddaughter. We're all sitting together and we're back on the balcony level. But for those two hours, does Lynn talk at all about what she's seen, how wonderful it is or this or that?

She says absolutely nothing. And we left there to go home in the daylight. It was still maybe like two or three o'clock. I got onto the freeway instead of the residential streets.

Well, why are you turning off here? Well this is where we all turn off the Freeway to go home. Oh, well I think you missed the turnoff back there. So then we turn on this street.

Lynn, do you know where are we? No I don't. Okay, I get up the stoplight to turn into the mobile home park. Do you where were are? And I do not know were we are.

Same thing. Turn on the, Do You know Where We Are? no I Do not recognize it. turn in the driveway. No, no, No. and then it dawned on me it was the same thing.

So much movement of the dancers on the stage. It's like a hyper stimuli. It was just going on like, this is what she saw versus it wasn't just the prominent ballet dancers in the front doing whatever they did.

There was them, but everybody else was moving in in back too. Right, the way her brain is working right now, she'll

get easily overstimulated. And we see this, you know, many families struggle They want to make those memories with their loved ones.

They wanna go see the new house that their adult child has bought and is living in, or they wanna to go to that wedding, they want go Europe one last time.

And the risk is disorientation, as you're describing that things get worse, that there's overstimulation. It's also very stressful. Travel is stressful, you mentioned.

humans are not designed to go in cars and planes and trains, right? This is such a new development in our evolution. And so that hyper stimuli can have a really big impact on the nervous system.

We see this with children as well, and so it's assessing, evaluating for you and your loved ones, your family, is that trip really worth it? And I've had families say, yes, I got that last trip to Europe in with my mom and we have all these pictures and the grandkids were there and it was so worth it.

But my mum hasn't been the same since we went. And the exposures to the viruses and dehydration and time zones and lack of sleep, these can be really, really hard.

There's no one right answer for each family. But I think going in knowing that you're going to want to set aside extra time, that your going want go a little at a slower pace and be aware of this risk of hyper stimulation and to give people that downtime, make sure they're well hydrated, well rested, and that they have everything they need to recover as quickly as possible.

So, yes, I would love to go back to Hawaii. I've got enough points to Randall, it's not worth it. Changing diapers on the plane, five hours on a plane.

Anxiousness, frustration on her part. She can't get up and walk around. You're locked into a seat. And not only that, Randal, when you come back, you have memories, she won't have memory of it, You can mention that we went to Hawaii.

So she'll say, When was that? Randall, it's not worth it. Just go down 10 miles to Pismo Beach. You could be on the beach there. People come on vacation on Pizmo Beach all over the world.

just be happy and going there, you don't need to take. And we used to go to Yosemite camping for the last two previous years. you can't go camping anymore.

It's just, You can remember. when she's not going to remember and having to get up at two o'clock in the morning and chase the bears away and get to the bat, this is not worth it.

Right. And what she might be left with is the feeling, right? We see that many people suffering with Alzheimer's, especially in later stages, they're not able to process the information, so if we give them some harsh news, some sad news or they feel anxious because something is unfamiliar or overstimulated, they don't have the cognitive capacity to process the news or to processes the experience.

And so they're left with that feeling, that unprocessed negative emotion. And that isn't worth it, right, for many people. Now, sometimes there's ways to work through that and navigate it.

But I hear what you're saying is sort of this acceptance that we're in a different phase, and my expectation is no longer that she's someone who can deal with the stressors of travel.

And so we're going to enjoy and appreciate what's right here in our routine. Go down to the beach and talk to people who have the dogs and love on the doggies and have their grandkids come to us so that we can stay in a more reasonable routine that suits her.

Ah, but Randall is smarter than the average bear. What do I do to take care of that problem? Let's get out the family photo albums. She still knows who those people are.

She lived with her grandmother. We talk about her grandma, we talk our mom, We talked about all the pictures and we can say she can remember stuff by looking at the photos.

Disorientation, travel stress, and overstimulation

So we sit down and look at a photo book at least once a day. I'm happy to look because we have them. We're seven, eight years old. We got photos back when we were one years-old.

When you had little corner stickers, you put the photo in there. Now, we're happy to do that. There's other times though, and this happened the other day.

She lived with her grandmother and her mom when she was maybe eight, nine, 10, 11, 12, because they didn't have a house to live in. So she is all over her grandma all the time.

And she has this really nice photo on her dresser. But yesterday she found that photo and she wouldn't let it go. She was going to go find her Grandma.

Then how are you going do that? Well, I'm going walk. Okay. Go ahead. So I watched her go down the stairs. Now we're in a mobile home park. So I figured she's going to walk over to her son's house, which is one house away, what she usually does.

No, she went past his house. Linda, I think you need to come back. She still has the photo. I tried to explain to him about the photos and this and that.

Well, you can drive me. Okay, well, we'll get in the car. Where do you want me to go? Well I don't know, but just take me there. So whatever, I'm using the word nostalgia here.

Somehow she was lost in a nostalgic memory of her grandma, and she wasn't given up. I had to go over to Home Depot to buy some stuff, she Wasn't going.

If she Was going, She had To take the photo. Okay, bring the Photo… I didn't say leave it in the car., I knew better. Bring the Phot with you. We got in there, we have to Go.

Lynn, I have to go. Then I thought, all right, you're smarter than ever. Lynn you take the cart. So now she has the photo. She's controlling the car. Now she can't go anywhere because she's got control of the card.

I can continue buying what I needed to buy because I was over there to by boards. Her bed is a single bed and it's on a frame. Then there's the box mattress that's probably this tall, and then there is the mattress.

So when she goes to get out of bed, her toes barely touch the ground. But the other night, soon after she went to bed she yelled out, help me, I went in, she's hanging on the bed one foot on And I'm going, all right, so I got a hold of her and we solved that problem.

And then going Randall, this can't happen again. She could not only fall out of the bed, she could hit the dresser that's over here. Okay Randall, you're smarter than the average bear.

What are you going to do? Take the box springs off the frame and stick it in the closet. Go buy some boards to lay down on the fring. Put the mattress on in frame.

Solve the problem. Now she can take her legs and put them on to the floor. She can stand up. If she does fall out, we're only going fall this far. Not this FAR.

It's happened before sometimes too. She wants to know where her mom is. Well, your mom and my mom, we both went to heaven some years ago. Oh, well, okay.

And then I go on to tell her, but your mom and my mom, their names were Ruthie. We had two Ruthies. I said, they're both in heaven right now. They're having a tea party with Jesus.

He's telling them stories and they laughing their heads off and having great time in Heaven. This is what's gonna happen to everybody. You're just gonna have this great times.

Maybe Jesus will meet you there and have a teaparty with you too. maybe you'll have birthday party for you. So she's good with that. It helps her to get past Where did both of our moms go because they're not here?

This is really common for people struggling with Alzheimer's, right? That desire to go home. Where's mom? Where is grandma, whoever they were close to as a child?

And usually when they ask to get home, sometimes what they are referring to is not the home that you've lived in for the past 30, 40 years where you raised your children, of course, but the one that they grew up in from their nuclear family.

And I typically coach people, again, instead of trying to correct them. And it sounds like you've found a way to tell her that mom's in heaven and having a tea party, which is lovely.

She responds well to that. But often if we remind people that their loved ones are gone, this can be kind of re-traumatizing. So just go into, all right, let's go see grandma.

Let's find her, get in the car, go for a drive. Or if someone's at home and they want to go home, All right, let's go home, get in the car, go for a drive and come right back home.

You can go around the block a couple of times and then pull in to the driveway, all right we're home." By that point, sometimes if there's significant short-term memory loss, they might have already forgotten and their nervous system can get back into that rest, digest and heal state.

We can't get them back there. Just giving them the comfort. What is that unmet need? It sounded like what you were describing was that Lynn's unmeant need was You've said nostalgia, but it's the comfort of her grandma, right?

Of that familiar maternal feeling. And so how do we get her some of that? Is it a hug? is it agreeing, if we can say, yes, and let's go get in the car.

Yes, grandma. Whatever the story is, again, this takes tons of creativity and presence, which you exemplify, Randall. OK, so now I'm going to rewind a little bit.

We're gonna go back to when I started with you in January of 24 for 12 weeks. And I also listened to Dr. Bredesen's movie, Memories for Life. In that movie he talks about his first patient called number one.

Judy, yeah. She's walking across America right now. Patient zero. Yeah, patient zero, so somehow she found Dr. Bredesen. she started practicing his protocol and he didn't see her again for three months.

Three months later she finally contacted him. Way better, she could go back to the job that she had as a government employee, doing whatever it was she was doing.

Everything was fine. And in my head and listening to you, I'm going, wow, maybe in six months, things are going to get really better. Whoa! And then six must went by, and I go on, you know, Maybe you need to on the three year program.

Maybe this isn't gonna happen as fast as what it seemed that it could happen. And it helped me immensely to change that because it wasn't happening. All right, I'm on the three-year program.

It could be the four- year program, but now I just keep thinking. The rest of your life program? Yes. We certainly, we see miracles happen. I talk to people all the time who we get them on a plan and I see them a month or two later to review their labs and they're already improving.

That is huge and that's fantastic. And it's not the expectation, right? It's about expectation setting. What we see over and over again is that people most of the time improve.

Sometimes it happens in three to six months, sometimes it happened in two to three years, and more often than not, if they fall off the wagon, they start eating the junk food, not getting as good of sleep, have a lot of stressors, a disorienting trip.

something shifts and they fall off the program and then slide back downhill again. This really takes a lifelong commitment. It's not something that you do for six months and things are cured, things She has sustained her improvement.

She now is a Bredesen-trained coach. she helps other people achieve what she did. And she was able to keep her job for as long as she wanted to. Now in her 80s, she's retired.

She has not fallen off the white, or when she has, she's gotten right back on, right? And that's why she is doing so well. I really appreciate your point of, we struggle with this, because we want people committed and to be all in.

Rather than taking bite-sized, little anybody steps to get into this. I want to dive in fully and really get the benefit of the program. But I think sometimes the expectation is I'm going to see full recovery really quickly.

And that's, although possible and we've seen really, really remarkable results, it's not guaranteed and it shouldn't be exactly what's expected. Okay.

I am going rewind back to the second driving trip that we took to Eugene and came back and she fell apart. Prior to that, we were on this upswing.

Routine, photos, and practical problem-solving

Her energy level here was just amazing. Everything was, I couldn't believe it. I mean, she was getting back just to being almost a normal person again, like we normally are.

And then we took that trip the second time and we came back. It takes the wind out of your sails. And then I heard you talk about the Marama people, what happened to them during COVID, and everybody had to be isolated.

It took them 12 weeks to come back out. Thank God that I hear you say that, because it took her almost 12 week to almost come to the time before we left.

Yeah, so I think I'll tell this story real quick. At Marama, the residential care facility, I opened in March of 2020. We were really fortunate we didn't have any cases of COVID amongst our residents in that first year, but about it was January of 2021. We had a resident who got COVID and she had it tickled in her throat.

Of course, we found out on a Friday afternoon that it was positive for COVID. And by Tuesday, she was symptom free. She did great. she actually was sharing a room with her husband.

He didn't even end up getting COVID to keep COVID from spreading throughout the building. We isolated everyone for 10 days from each other. Now they were still getting their organic ketogenic diet from the chef.

They were getting meals delivered to their room, breakfast in bed. We were getting the red lights to them, but they

were doing that in their rooms. They were out for walks with caregivers.

We're getting physical engagement and the cognitive engagement. But they weren't getting social engagement from their peers. Now again, they're seeing caregivers, it wasn't like they are completely socially isolated.

But in those 10 days of social isolation from their peer group, we had three falls after not having a fall for six months. We had people suffer with incontinence that was new.

Basically, people up at night, their diurnal rhythms were off, the circadian rhythms where off. They were wandering around the house confused in the night.

which we hadn't had happening. We saw significant drops in cognitive function, and it took a full 10 weeks for us to get everyone back to baseline. After just 10 days of social isolation from their peer group, it wasn't even full isolation.

So this was an experiment that you couldn't have ethically created. But it was so eye-opening to me, one, to your point, how long it takes to recover from a stressor.

You can tack on a week for every day. And then also how important it is to have peers. not just to be socially connected, because I think as we age, I remember for my grandma, the people who surrounded her were the People she was paying, right?

It was her doctor, it was the physical therapist, It Was the person who would drive her to get groceries, or the Person who Would deliver groceries. The person Who came in to help her clean her house.

It She basically had hired, right? Like the caregivers at Marama, they weren't her peers. It wasn't that peer-to-peer relationship that I think is so important to our wellbeing.

I want to talk a little bit about the keto diet. So whatever Dr. Heather says about keto, follow it. Follow it as best you can. Then you have to watch out for the sugar.

You have to watch out that you wanna have your mom or husband or you want to have a birthday party for them. So now they're gonna eat cake. Cause everybody knows it's a happy birthday.

You want have cake? Well, let me tell you what, eating cake causes disorientation and then you have suffer through that part of it. It wasn't good. And we have a keto chocolate cake.

There's a recipe in the book. So if you need a celebratory meal or a celebrity dessert, there are options. But yeah, we see this over and over again, that people who are on a ketogenic diet, who're doing well on that, their blood sugar is stabilized and we seeing improvements.

And when you fall off and you indulge at that party or on the trip, It is a big difference. It's not fun. So come prepared. This is part of the struggle with traveling is that you have to eat what's in the airport or eat at the convenience store when you stop for gas.

Go prepared, bring fat bombs with you. My brother teases me. I have emergency meat sticks in my bag, the chomps. Those are great to have around. Having some sort of keto snack Keto calories that you've got with you so that your well prepared and you're not desperate for food.

Okay, so I want to bring up memories. So we've been practicing Kriya Yoga Meditation with Self-Realization Fellowship for 50 years. And in the first three months of 2024, we were driving three hours down to the Lake Shrine in Santa Monica, where we would go to church once in a while.

and everything was pretty good, driving down and driving back. But as soon as she sat down, it's not like being at a regular church because we actually start meditating right off the bat before the minister starts giving his normal talk.

Lynn sat, I'm still looking around and looking at people. I want to see who's there. Lyn has already focused on Jesus right of the back, she's already got her eyes closed, her palms in prayer, and she is already saying a prayer.

And I am just going, Wow, this is truly amazing what memory can do. She was already there with Jesus, and I'm still looking. It's just this tricky thing.

she did have a CT scan at UCLA originally. it showed absolutely nothing wrong with her brain, zero. So having a CTS scan, you'd have to talk to Dr. Heather about that kind of stuff, but it will show I'm saying this for a reason.

It'll show what parts of the brain, the cells have already died. And those are not coming back. Probably the MRIs. Yeah. So MRI also. Right. What I want to get at this part of it is, don't keep thinking you're talking to somebody.

Long-term expectations, diet, and meditation

Your loved one who has Alzheimer's, Don't think that you are actually talking just somebody and you getting through to them. because you have the executive functions, you the intellectual functions.

There's 3,100 million functions that your brain does and any one of them could be missing. So you're not talking to what you think you should be talking.

That's all I'm getting now. You have to be aware of that stuff, the way you talk and bring things up again. And then you mentioned what still inspires me.

If I had a hat, Dr. Heather, I would take my hat off at this point and I'd throw it on the ground. And so what inspires me is thank goodness you allowed me to join these classes every single time because it's your energy.

I call it the warrior talk. You give the lawyer talk to everybody. I have to let you know that. I call it the warrior talk because once in a while I had to go have counseling with the minister.

These guys, they're monks and nuns, and they give you the lawyer talk. Now God loves you too, you get with it. That's what you do for everybody. Those are the inspirations that I gotta have that input because we're just human beings and stuff just slips away someday.

Or maybe I ran into somebody that made me wacko in the head and I got upset about something and then it drove me over the cliff and got wack at my house.

Yeah, I've got to have the input and fortunately it comes once a week from you. Thank you. Yeah, it's about showing up and coming back to it, right? We're not perfect.

We are human. And we're going to veer off track. So it is like, how do we have that ritual of coming-back? And for many people, that's going-to-church.

Maybe it a support group. As we care for someone with dementia and Alzheimer's, very easily to become isolated, life gets busy. Our days get full just getting through the minutia of meals and getting dressed and showers and this bed.

all of these pieces take so much more energy and effort that it can be easy to relegate things like getting together with others, not a priority anymore, right?

But it's so important to re-energize us, to recommit us to, like, reinspire us. Randall, I'm curious to hear from you. Looking back on this six-year journey that you've been on with Lynn, what do you wish that had known sooner?

I know there's a song. every time under heaven there's a season. Everything happens the way it's supposed to happen. You could have regrets. Regrets don't help anything.

It's just as stupid as word you ever heard. Either did it or you didn't do it. And now that you're thinking about it, do That's what I have to say about all of that.

Everything is just moving the way it's supposed to move. That that's all I can say it about it. You can look back and think, oh, I regret this and that, but it just move in the ways it supposed it move?

That beautiful. I'm going to state it a little bit differently. If there's someone out there listening, who's in this situation, the scenario that you were six years ago, hearing their wife say things that are nonsensical, misplaced words, say hamburger when they mean chicken, Something like that, misplacing keys more often, spending more time looking for their purse and their phone and they're belt and anything around the house, maybe missing appointments that they get their hair done every Wednesday and all of a sudden they don't show up one week.

If somebody is noticing that what advice would you give them? Dear Lord, give me more love to love you with. I am your servant. Help me always, Lord. You are my all.

Amen. Beautiful, thank you. Thank you, Randall. It's such a privilege to have you showing up over and over again, because I can say this stuff all day long, but you are the expert in the experience of caregiving.

Closing reflections and advice for caregivers

And hearing it from somebody who's actually living it rather than someone just trying to teach it, it adds tremendous value. You add so much empathy and so inspiration.

Really, the way you take care of Lynn, she's so, so lucky to had you and it's an inspiration to the rest of us. Thank you. Thank You and much love to you!

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