Opening on realistic hope in dementia care

What's worse than false hope is false hopelessness, and there's way too much false helplessness. And I think realistic hope, is that we can provide an environment and activities and good nutrition and all the factors that we've been discussing where most of those factors can result in more good days than bad days.

It will slow down decline. I think that's very possible and probable. They're going to definitely have a better outcome. All of these are realistic and we can expect that and strive towards that.

it is even possible that it can go beyond that Welcome back to the Think Well, Age Well podcast. I am your host, Dr. Heather Sandison. Today, I have the pleasure of welcoming someone whose life reads like the blueprint for what integrative, person-centered dementia care can look like.

if we truly embrace our human potential. Del Museo is a wellness consultant with over 40 years of experience in health and performance and in whole person transformation.

His career has taken him from ski coaching and outward bowed instruction to guiding international adventure travel, directing the health center at the Aspen Institute, creating wellness retreats and teaching anywhere from California to British Columbia.

But Dell's most profound work emerged not on a mountaintop lodge or in an executive conference center, but unfolded in the day-to-day, often gritty grind and reality of caring for his mother, Dorothea.

She developed dementia in late 1990. And drawing on his lifetime of training and wellness and whole-brain learning, movement, integrative health, connection with nature, and human resilience and transformation, Dell developed what became the Integrative Cognitive Wellbeing Program, or ICW program, a multi-modal protocol that, you know, I think everyone who knows what I'm about in terms of multi modal interventions as kind of used through the Bredesen Protocol, you'll see immediately why I'm so excited to have Dell here sharing his story as a care partner for Dorothea, and of course, Dorthea's story of stabilizing, not only stabilising, but improving her cognition.

Her mobility, her posture got better, she regained old skills like playing the piano, And she lived vibrantly and independently into her hundredth year.

She had a 22-year journey at the symptomatic level of Alzheimer's disease. And this is virtually unprecedented. We do not hear about this.

Dell Del Museou2019s background and path to caregiving

I was just sharing with Zell before we hit record that I had thought of Judy Benjamin, who I've interviewed here on the podcast, as patient zero. But Dorothea was actually getting the benefits of this before Dr.

Bredesen was talking about this. And so I think she's one of the very first long-term multimodal dementia interventions ever recorded. Del's book, Up and Down and Even Sideways, captures this remarkable journey with honesty and rigor and deep humanity.

It's reading it, it's about the love letter and this blueprint and these directions for what can be possible. So today, Dell is teaching and consulting and mentoring others who are seeking a better path for dementia care.

And I am absolutely thrilled to have him here today. Welcome Dell. I feel very honored to be here. I wanna start with just your origin story because many adult children fall into this role of caregiving and they bring themselves to it, right?

The good, bad, the ugly, be indifferent. And I'm curious, your background is impressive with the skiing and wilderness leadership and wellness education, meditation, you're Zen experience, living in a Zen center for a couple of years.

How did these things kind of come together to prepare you for the challenge of caring for your mother. I think it was more serendipitous than any. It wasn't planned that way.

So sometimes I think of myself as, if you remember there was a movie a number of years ago, it was called Forrest Gump. And Forst Gumps just happened to end up at the right place at right time.

I would say that's probably my life's journey. Just sort of stumbled upon the place, the time, connected with the people. and it was just from one thing to another.

And it wasn't a six inch arm in the beginning, it just unfolded this way. So you, I mean, you graduated from one of the first wilderness or excuse me, wellness education programs.

You also have, some wilderness training, wilderness health training as well, but the wellness, education, programs early on. And I'm curious, that whole with Instagram and Facebook and all the social media and the coaches out there.

I, mean you were, thinking about wellness well before it was all over social Here's how you've kind of seen that evolve over the past several decades.

It certainly has evolved. My first exposure was in the late 70s, early 80s. And I look back at some of the beliefs we had and our understanding of health and wellness back then, and it has come a long way.

I think it's much more realistic now. I thinks the modalities are more effective. It's more grounded. But they had to start somewhere. And in those early years, these people that were my teachers, they were pioneers and there was no path to follow.

They were groundbreaking. I'm curious, I meditate daily. It's a big part of my life. I am so just fascinated that you've spent a couple of years living in a Zen center and you mentioned in the book that this really had an impact on you throughout your life, would you expand on that?

It was a pretty deep experience. I'd actually had a meditation path before that. If I was to look at someone who is destined to be a caregiver, I would not be that person.

And if I look someone, who was destined, to have a mediation path, i wouldn't be, that, person either. The reason that I actually first got interested in meditation, was when I, A what competition?

When I was competing in skiing, it was back in the early days of freestyle skiing and I competing on the moguls and the pro mogul tour and all that. And there was a competitor who was very, very good and he was friend of mine.

I would copy whatever he did. One day we were just chatting and it's just so chill all the time. And it actually helped him, especially when he's in the starting gate and we have all the butterflies near something and all that, and you can just kind of calm and center and then be ready to go.

And I thought, well, this could be helpful. That's why I got into meditation. It wasn't for personal transformation or spiritual growth. it was just so I could compete better.

Then I found that it had an effect on the rest of my life as well. So I'd already been doing that for a while. I was overseas back in the mid-1980s and actually had an experience in…

My wife and I stumbled upon the Dalai Lama's monastery and that started a whole chain of events as well. So I was already interested in pursuing that a little bit more seriously and the opportunity came about in 1988. And I

became involved with San Francisco Zen Center out at Green Gulch Farm out in Muir Beach.

It was a very, very enriching experience and it still is with me. That was part of my life. How did it impact your life as a caregiver? I wish it impacted my life a lot more than it did.

I wished that I could have been calmer and more patient. And patience is not one of my virtues, but I'm working on it. But there were times when it would.

There were time when things came crashing down and it was pretty stressful.

Meditation, Zen practice, and caregiver patience

The meditation practice really helped get me through it to imagine that if you didn't have the meditation practice, if hadn't had the deep experience at the Zen Center or with the Dalai Lama or any of these litany of experiences that you accumulated over the years, that would have been less patient as a care partner, there would've been more frustrations, things would be bubbled over more frequently and it would been an even less joyful connected experience.

Yes, certainly. So I think we're all on the journey, right, of learning to be more patient, more tolerant, and more compassionate. And yet every dose helps.

At what point did you think, you know, I want to get into Dorothea's story, but I'm curious, At what point did your sort of perspective on her treatment, on care shift, where you went from thinking, okay, the conventional medicine is what we're going to do.

We're gonna get this diagnosis, go through the process there. When did you flip the switch on that and go, we need to design something completely different?

I was probably quite early on, but at that point I living about a thousand miles away from her, so it would only be when I'd be home for either vacation or visit the family or spend time with her.

So I wasn't on the scene full time, but I could see what was happening. I was aware of the options, and I weren't really impressed with the option that were available.

Uh, I didn't like the prognosis. And it was in about 2007 that it really became clear that I, um, I found that the prognosis that she got was it was very depressing, it very negative and in other aspects of health and wellness I had seen healing and breakthroughs and people getting better and I saw no reason why this couldn't be the same even with Alzheimer's and with dementia.

I didn't know that it could be but I really had a hunch that could and that we could do better than that. So it would have been like around 2008 when it really became clear.

Also at that point, there were discussions about her going into residential care. And when I saw how bad residential was, really didn't want her to have to be in that environment.

It turned out she did go in and we had to make the best of that. And then when that happened, it became really clear that what was out there just was not working and there had be a better way.

You described Dorothea as resilient and adaptable and really a glass half full optimist from really from childhood, right? What you know from her childhood.

How do you think her life story shaped her trajectory with dementia? Well, I think her life story dramatically shifted her direction and her ability to weather the Alzheimer's journey a little better than some people.

First of all, she knew that she could do things. And she had succeeded many times in her life. And so there was

that knowingness. I think it's important to have that.

That takes me back to my outward-bound days. What outward bound is all about is that we have a lot of limitations. Most of them are self-imposed limitations and we try to navigate through life inside those limitations until we discover that we can go way beyond that and we could do way more than we ever imagined we would.

And for her, she was already pushing those boundaries. Part of it was just the way she is, who she as a person, part of that was circumstance, like she had to.

But I think that was a big part of it. She was pretty optimistic person generally. I thinks that's really helpful. Um, she was open-minded and she open minded and learned at the same time.

Her being learned of course really helped her because that helped to develop pretty high level of cognitive reserve. right from the very beginning of her Alzheimer's journey.

She came into it with the fuel tank full and that was really helpful. So that another part of it. And I think since she was young and it was just part her story as she's growing up, she had to be adaptable and she got really good at being adaptible.

And it wasn't being adaptable and just struggling through the changes. It was like, okay, well, this is what we're doing now. And she would just step into it, you know, with full force.

So having that ability to adjust and adapt to situations as they unfolded, I think, was something that helped her as she was going through all these changes with dementia as well.

Yeah, we hear there are these characteristics that certain personality types basically do better with these multimodal interventions. And certainly with my experience in applying the Bredesen protocol, it's like that commitment, that determination, and that sense of hope, adaptability, willingness to change, the lifelong learners.

Um, it's sometimes like the type a kind of like, all right, I'm going to figure this out and get this done. I've not going accept no for an answer kind person.

Those people really seem to get the most benefit out of this. And my, my hope is that. You know, this translates into supporting people who don't just have that personality type, right?

That we can help other people by creating memory care or long-term care environments that are very supportive. That, we do sort of the interventions that we're going to talk about here by default, rather than as the exception.

And I think that it takes these early adopters, people like Dorothea and some of the other survivors of Alzheimer's to show these stories, to inspire others so that they can expand beyond this group of incredible women.

Will you talk me through Dorthea's day-to-day life? At the early stages, how did you first know that there were memory changes going on? And then through the arc of her story and to get to the last quarter of life, what did her daily routine look like?

Not the intervention so much, but how was her memory affected? What were the deficits? Like what were challenges? Then as you implemented the interventions, did things get better?

Well, prior to the first signs of dementia, she was a pretty sharp person and she had a very good memory, very organized and an active person. She lived alone in a big house, but she has a number of friends, a good social life, and was still taking classes.

going to seminars and going on adventures. She was traveling around the world up until I think it would have been, I'm just trying to think of, yeah, it even into the very beginning of the first signs of dementia.

So she had that, but she was just an active person.

Recognizing Dorotheau2019s decline and rejecting the prognosis

What became noticeable was she started to forget things. Of course, she'd get more confused. Bills didn't get paid. things didn't get done. That was very out of character for her and so this would have been around 1997 or so is when it became noticeable to her family and then it become quite noticeable in 1998. So It was just that she wasn't as sharp, she couldn't remember, She couldn' t organize herself as well, and the confusion that started to increase.

So that's how it began. She was able to live on her own, again by herself, in a big house, for another, let's see if I've got this right, I think it was another two or three years after that.

That would have taken us till about 2003. And then the family, you know, we would be discussing her her progress or decline and what we needed to do next and the decision was made that she had insisted she wanted to stay in her own home.

So we split the home with the upper floor being her world and then the lower level we had transformed into quite a nice large apartment and it started with her granddaughter moved in and her husband and they were her care partners to begin with, and that was the first couple of years, then we had an actual caregiver come in after that.

So she was able to continue staying in her home, even though it was just the upper part of her house, for another four years. But what happened was that near the beginning she could be left for six, eight, ten hours on her own and she'd be fine.

And then that became four hours and three hours, and then two hours. It got to the point where I couldn't really leave her much more than an hour at a time because she would get into mischief.

Mischief is a word that most people that knew her would use quite readily because that was what her life was all about from that point on. getting into mischief and she would get into all kinds of little misadventures and sometimes have to be rescued by the neighbors and so it was getting a little bit more hazardous and there was mood swings and you know there were difficult periods that began to happen more frequently.

And then as things were going downhill, it required more and more caregiving hours. And as most everyone who's in this world of taking care of somebody with dementia, we know how expensive that can become, and it can becomes thousands of dollars every month.

It just kept growing and growing, eventually things kind of deteriorated. She got taken out of her home against her will and then she was put in a residential care facility.

And then things really plummeted. I know that you learned a lot about the environmental impact, the emotional stress, and what did that, I think her scores even plummeted when she went to that community.

What did it reveal to you about this system? And was she in Canada? Where was? Yes, she was. This is in canada. And what'd you learn about that system.

Well, in a nutshell, what I learned is that system is in need of some upgrading and repairs. It's a work in progress and there's lots of improvement needed.

I guess that would be to put it gently. Um, it was not the best environment for someone who is still relatively healthy. Can you speak to, like, what do you think it was?

Do you thing it's the food? You think is was the way she was treated? Or do think was it the lack of exercise or that there were TVs everywhere? Was it distraction?

Like, was there something specific that you really think didn't suit her? Is it just more vague in general? No, I think

there were very specific things.

First of all, you know, she lived in this, what was a 3,000 square foot house, but after we split it, her world was about 1,500 square feet. Her yard had a huge yard.

It was like a park. She had all her neighbors. she had her organic garden that she tended, She has all kinds of projects on the go, and she has an active life in the later years.

All of that was taken away. And then her world became this very generic, sterile, little, tiny room. So she went from 1,500 square feet down to, I think it was something like 230 square foot.

It was really small. little single bed. It was smaller than a motel room. I used to say it was like a prison cell. Well, it wasn't that bad, but it, was really tiny.

So I think the fact that her life had been condensed down to this little room, that was a huge factor. For some people, It doesn't seem to be that big an issue.

For her, it was a huge issue and I met other people within that facility and they were going through the same thing because they we're coming from a home that felt really good.

That was their home. They had created this space that was theirs and now they're in something very generic. So that a first part of it. Life was more regulated.

When she was at home, she got up when she felt like it And in this facility, at least at that time in the early years, they all had to get up around the same time, usually a little earlier than she was accustomed to.

They'd be put to bed early in evening. She's not an early evening person. she used to stay up till 10 o'clock and couldn't understand why anybody would go to bedtime early.

But, you know, the whole place is basically shut down. All of her friends were sound asleep. There wasn't anybody to do anything with. And so she'd just be back in her room, just hanging out.

Dorotheau2019s personality, resilience, and cognitive reserve

And so in that way, it was quite lifeless. There were some recreation programs. Most of them were not very good. They tended to be more directed to the lowest common denominator, which would be the people who were really struggling, like maybe not at her level of ability and cognition.

So everything would kind of be dumbed down, at least in her eyes. And, so that was really frustrating because she felt like she was being treated like a child.

And of course, for her, that would be something she was very resistant to. The food was, it was mediocre, tuitional food. At the very beginning, all of her like, so all the really good, healthy food she's was getting, and that was taken away.

Plus all helpful supplements that she is on, THAT was taking away, she lost whatever benefit she getting from that. Then she separated from her family.

At the very beginning, there was this practice at this one facility where they wanted the people to get accustomed to living there so they didn't want any family visits for weeks on end.

I didn' really accept that so I kind of snuck in. And that was a good thing, but, you know, hopefully that practice has changed. But even after that, her family visits would be, a few hours here or there.

Now, fortunately, Her family were near enough that everybody could visit at least once or twice a week. So again,

in her case, she had a family visit seven days a Her fellow residents, they'd be lucky if they saw their family once a week.

So it can be really a lonely experience too. They also never really got to be outside. And she was an outdoor person. She loved nature. But because of safety parameters and that they didn't have enough staff to supervise The residents, if they decided to go out into one of the courtyards or somewhere that was interesting, they couldn't let them do that because there wasn't anybody to accompany them.

So it was a very contained life. It was secured unit, so she couldn' even get out of unit. And she's kind of a free-range kind person. That worked against her too.

I think all of those things, and the main thing was the lack of stimulation. Dorothea's story is a happy, hopeful one. So I want to switch gears here into that.

But I think it's good to paint this picture because I, I thinks a lot of people listening can relate to this, right? Okay. Mom goes into this facility in a locked unit and the food isn't good.

There's not the right type of stimulation. She's that interested. It's. And she goes downhill. Let's switch to the part where it gets better. Right. You eventually created the ICW program, which predates all of these other multimodal dementia protocols.

Walk us through the early components. What was part of this? Was it nutrition, the nature, or the supplements getting back in there? What started her turnaround?

it was many things. There were 10. It was a 10-part program. Again, I did not know what I was doing. What was so surprising and delightful to me was in 2014 when I learned about the work that Dr.

Deal Bredesen was so similar to what I'd been doing. And that was the first time that I realized, so maybe I am on the right track, because I really didn't know if this stuff would work.

It was like everything that i had learned over the years, I just threw at this, like I threw the kitchen sink at it. Well, I can tell you that the 10 parts of the program and what we did, the first part, you know, again, this is really, it's kindergarten compared to what you're doing.

But the 1st thing was to remove her from further harm. And when I refer to that, removing toxins, allergens, hazards, exposures, and this kind of went way back to, oh my, outward bound days and my wilderness leadership days, and first aid and all that.

What we learned was if we come upon an accident scene, the first thing we want to do, we assess the situation of course, if see that there is danger, it's imminent, is right there and it is continuing, It doesn't do a whole lot of good to start applying first aid if they're still in contact with a 240 volt electrical line.

The first thing you got to do is remove the lines, so remove danger. So that's what I referred to with removing from further harm. And in this case, the further harm would be if there was a toxic exposure, which I suspected there could have been.

It turned out there were. And are there things that she's allergic to? And, in her case it was food allergens and just other hazards, other exposures that could be detrimental to her going forward.

So, before we start, we're able to really start anything else. We just had to take care of that. Then the second thing was the remediation. So that would have been like, she was on a very gentle, but it was a detoxing program just so, especially with her gut and all that.

Pathogens were removed. Mycotoxins, we would do what we could to remove those and just introducing like clean air, water. If EMFs were an issue, removing that, it turned out they weren't really an issues for her, but they can be

for some people.

But just taking care of whatever that toxic load was. And then once that was done, then the third phase was restoring and rebalancing the gut.

Life in residential care and why it worsened

In her case, because she had a very severe gluten intolerance, there was damage to her digestive system and to our gut, and so there were pathogens, all kinds of the wrong kind of bacteria.

And she was not quite celiac, but extremely gluten intolerant, so there had been damage to the veli in her lower digestive tract. And so all of that needed to be healed.

Of course, the primary way of doing that was to put her on a gluten-free diet, which incidentally Both of her doctors, she had a really good medical doctor and she a had really, really a good naturopathic doctor, and both doctors in tandem worked on that in partnership with the facility and the dietician in the facilities was wonderful.

And it was like almost instant. It was within 24 hours. She was gluten-free and it stayed that way for the next, I don't know how many, eight years or whatever.

And that was a dramatic change. So I will finish the list here, but I just wanted to just kind of interject for a minute with what happened with the removing gluten.

That measure in itself made a noticeable difference. It made the difference in her cognition, her test scores went up, it made it difference her abilities, and it make a difference to her mood.

And she didn't have as many of the mood swings and made huge difference on her body. Prior to that, People thought that she was gaining weight and she actually had a waist of 44 inches, which is pretty big for somebody who's not even five feet tall.

And within three weeks of going gluten-free, that 44-inch waist went down to 39 inches and she could get back into her clothes again. And so, you know, that's kind of nice to be able to wear her close that she liked and was happy with that.

But that is also an indication that there was something helpful that was happening. So that just one little move, one factor, but that factor did make a really big difference.

So just getting back to the list here, sorry. So the next thing would have been once her gut was healed and she could digest her food and assimilate her nutrients, then it was getting the right nutrients into her.

It was like really upping the quality of her nutrition, more whole foods, a more locally sourced fresh food, and just being really careful with that. Then I'll just mention We weren't able to go ketogenic with her at that time, but there were some meals that she would have that were close to being a keto meal, and she was taking exogenous ketones as well.

And then getting into the supplementation, prudent, careful supplementations, that was working along side, her naturopathic doctor and her medical doctor.

They knew what she was taking. And there's a little story that goes with that. I don't know if we'll have time, but I can tell you about that too. Then she got the whole body exercise.

When I refer to whole-body exercise, it's everything from aerobic exercise to resistant and in her case that would have been with hand weights and increasing the resistance over time and dual purpose exercises where she would be doing one thing with part of her body and another thing the other part her of body or she might be on her exercise bike and she may be counting to a hundred or something like that.

She did these exercises that were called cross crawl exercises where we're crossing the midline. And that was something I'd learned way back in my ski coaching days.

She didn't, you know, creative movement Tai Chi on a very basic level. she did some Aikido moves. We would have these sticks with. sort of banners that that she would be able to do lots of you know creative movement with but then she'd get that whole body movement and she enjoyed that too and we'd do it to music and She liked that so and then of course she was a walker and We would go on long walks in nature And then the next, this would have been the seventh thing was the mental stimulation, hugely important.

And it was challenging her brain and in many different ways and increasing creativity and working towards developing neuroplasticity. Then of course, I had mentioned the living environment.

Well, one of the breakthroughs, there were two huge breakthrough in her life at this point. One, it took, you know, It took a lot of pushing on my part but was able to get her home.

And it started out that she could come home three or four days a week for a few hours each day and a couple times a month she can come and spend the night and it would be an overnight.

So it'd actually be two full days with an over night in between and she did so well. that eventually I was able to get permission so she could come home once every 10 days and come for one of these extended weekends.

I'd pick her up right after lunch from the facility. We'd come and she would not return until bedtime. the following day and that whole time she'd be in her home.

Well, she wouldn't just be at home, should be all over the community doing stuff. And that was a huge, huge part of it. Then the other thing was trying to recreate some of her favorite elements from her home into her little room in the residential care center.

That also made a difference. So we replicated her colors because it just, you know, it was like this generic olive green and beige, and her color were sky blue.

Everything that could go into sky-blue became sky Blue. The bedspread, the curtains, everything that we could bring in that was blue. We brought in some of her furniture, her plants.

I set up a big screen TV with a sound system and she enjoyed that. And we set it up like sort of a little project station. She had a table in her room and so there'd be little projects like she'd have a writing project and an art project or something she was building.

So she'd have something creative that she could be doing there and then the other part of it was that making sure that She got really good restorative sleep Which was pretty easy for her.

She just happened to be one of these lucky people that sleeps well and Then the final thing was introducing some new technologies and so that would have been like the the 40 Hertz sound 40 Hertz light, the gamma cadence in light and sound also, gamma and theta frequencies, that near-infrared light radiation sort of set up a sort-of a total immersion experience for her, where some of those were combined.

And there had been some studies done at the, it was the Baycraft Medical Center in Toronto and Ontario, Canada. I'm also involved with this. and they had developed this special chair.

And the chair was impregnated with these speakers that could actually replicate 40 hertz sound waves. It was so impregationated that when they would turn up the volume on this 40-hertz music, the vibration would actually go through the chair.

So it wasn't just that they were hearing the music. They were feeling the Music through their body. And I thought, what a great idea. She had this favorite chair in her bedroom and I didn't tell her I was doing this, but I gutted the

Chair from the inside out and fastened some really big speakers that could do 40 Hertz.

and then had surround speakers around her. And then in front of her was a big TV screen and there was the 40 Hz flashing light, which she didn't like.

So that was impregnated inside the sort of kaleidoscope and it was beautiful. She loved watching that. Then she wouldn't even notice the flashing. And then we'd have the 40 Hz sound.

And it would just be this just, you know, soothing meditation experience for her. But she was getting it from all directions. She was feeling it. she hearing it, she seeing it and I can't quantify how effective it was, but I do know that she is noticeably more clear afterwards.

I have so many questions. First of all, how did you discover all this? Were you reading scientific papers, like hot off the press? The thought of someone getting into ketosis for cognitive function in 2007, 2009, I didn't even know people knew about it at that stage.

The 40 hertz, a lot of these pieces are things that we know now, but people did not know then. So I'm curious about that. And then I was also curious, did you end up moving there and walking, being her care partner day to day?

Like who was responsible for making sure she got in the chair and did all, got the exercise, that her diet was right. When she was at home, had her memory improved so much that she able to stay out of mischief?

She never stopped getting into mischief. She probably got into more mischief because she had more energy and she knew she could get away with it. That's great.

The first part of your question was, how did I learn about some of this stuff? I tend to be kind of a research junkie. So yes, I was looking into everything that came out on a daily basis.

I don't want to exaggerate, but I think this is pretty close. I probably spent at least two hours every day, like five days a week at the least, just doing research.

every day. And these things would come up in the library and all that. Some modalities I had already known about. Just to be clear, I didn't do all of this in 2009. This was a progression.

There were some things that started then and some thing followed later. The Exogenous Ketones I believe was in, oh, I think it was about 2011 and it because I was reading about Dr.

Mary Newport and her work and that really made sense and then the more I looked into it I thought, wow, yeah, there could be something to this. So I just went with that.

And then I learned later about getting on a ketogenic diet, but we couldn't do it because most of her time was still in the residential care facility.

Building the Integrative Cognitive Wellbeing Program

Was I there every day with her? No. I had two siblings and they would come in and take her on outings and stuff, so she still got that when I wasn't there.

But it would have been about four days a week. that I was with her and in those days, of course, just about every one of those day she would come home.

She wouldn't necessarily be home all day and through the evening, but she'd come in the early afternoon, sometimes in late morning, and then she return usually just at bedtime.

Just get her tucked into bed and she'd go to sleep. And so her functional day was with me in her own home then,

but she was still living in the residential care facility.

We couldn't take her out like all the time. She needed to spend time there. That was part of the arrangement. The other thing was she did have friends there and occasionally there'd be activities that she'd really enjoy and she take part in those.

So I didn't want to take her away from anything that should enjoy being there. And those were helpful too. I wouldn't wanna say that her experience there was all negative.

There was some really, really wonderful care aides, nurses, management staff, really good people that really cared about her. And they were doing their best, but just the system itself didn't lend itself to, you know, her optimizing.

It certainly sounds like you, you know, on the spectrum of communities, that you had some, a very responsive nutritionist, somebody who was really responsive in the kitchen, willing to make these gluten-free meals.

There were people that once you articulated what you wanted to do and what was important to, to Dorothea and your family, they were willing execute and really work with you rather than fight you on it, which is huge.

I don't think everyone runs into that, but. certainly part of what made it work. Now you discovered essentially like what you described is that she had a severe gluten sensitivity allergy, maybe even celiac.

I'm not sure if you ever discovered exactly what that was, but that is having a big impact on not just the circumference of her waist, her brain, her skin, you know, of course her gut.

And after removing that, that sort of had this outsized impact. It sounds like also the environment, getting her back home made a big impact in her mental status and her cognitive status.

But I think that you also in the book, at least, you emphasize that there's not a single intervention that did the trick. Maybe there were some that had a bigger impact, but it's really about the synergy of all of them coming together.

So talk a little bit about is the importance of a multimodal intervention and And on how that impacts neuroplasticity, I think part of the reason I'm selfishly asking you to do that is because I, think so many people are looking for that silver bullet when the way Dr.

Bredesen describes it, it's a silver buckshot, right? It's like we want as much as possible. And that, is overwhelming for a lot of people. help us navigate that.

I wish there was an easy solution. Me too. For myself, it was, you know, an all-encompassing It was a big task, and I wouldn't wish that on someone else.

It's a lot for one person to have to do. I was fortunate in that I able to be there and to it, but it really does take a village. That's what I'd like to see more of, where it's an integrated program, also an integrative team that can work together on something like that.

I'm hoping that in the future that could be more of a possibility and that's what I am really campaigning for. In her case, I would most definitely say it was everything rather than one or two things.

It was the synergy. And the word synergy, and I think most people know what that means. Okay, so I guess the easiest way to describe it would be that the whole is greater than the sum of the parts.

So, in mathematics, If it was synergy, two plus two wouldn't equal four. Two plus 2 would end up being six or seven or eight. You know, it would it end being much greater and much bigger than if you just added those parts together.

And I saw that with her. I've seen that in other experiences in my life as well. i'm a firm believer in that. and I think that's where the magic happens.

Yeah. So I can't say that you have to do everything because I did have a client for a couple of years. She was a few years younger than Dorothea, but the two of them were very similar.

This woman, her name was Doreen. she had also been a school teacher. And she also had a life that was similar to Dorothia's. So she was the right kind of person for that approach as well.

With her, my contact was very limited because it's expensive and her family were able to hire me for a while, but again, it was just very limit. So she only got a limited part of the program.

Some of her were kind of trained in some of the basic things. So they could implement some these things when I wasn't there and that was helpful. She had an absolutely wonderful personal living environment and I think that helpful to her.

And she was lucky because most people that are in a facility could never dream of what she had. It was this corner suite, it was 778 square feet, two bedroom, 2 bathroom, a little kitchen, dining room, living room with wall-to-ceiling windows that overlook the valley.

It was palatial and it was her home. And it's was all the best stuff from her homer brought to this. So she never felt that she was taken out of her homes.

Her home moved with her. How stunning, how amazing. Yeah. I wish that was possible for everybody. Anyways, in her case, that is a possibility and that's helpful.

But she only got part of the program and yet she seemed to be succeeding. The whole thing got shut down after two years because that's when we had COVID-19 and I wasn't able to see her anymore.

But at least in those first two year, I saw some really good positive changes. the main thing was that her stabilization. She did like not just the MMSE test but also the MOCA and the SAGE tests.

her score did not go down, not even one point over those two years. And that's not very common when that happens. Again, she was able to do things that she hadn't done before.

She was learning new things also. So, I think given the exposure to the rest of the program and given more time, you know, maybe as well as Dorothea. I don't know.

But I know in the little bit of time we had, it seemed to be very helpful. Sometimes the supplements are overwhelming. I'd like to get into that, but one of the things that you did that I think is really helpful for people, care partners who are feeling some overwhelm is you created this super nutrient dense smoothie to help to, get in the nutrients that are so necessary for cognitive function.

Tell us about that breakthrough. Yeah, I was pretty excited about that one, and that seemed to be helpful too. And I think it was so much easier for her also.

Can you imagine? At one point, she was having to swallow 13 different capsules. For somebody that's in their late 90s, that was a lot to swallow. She didn't really enjoy it.

I don't think anybody would. Yet the substances, what was in those capsuls, was helpful. The other thing is I didn't know that she was able to fully assimilate the capsules.

Maybe she wasn't. But I just, you know, our digestive systems become a little more compromised as we age and especially when somebody is in their 80s and 90s.

So the thought was, wouldn't it be great if it could just be like something that she drank? So I worked with her naturopathic doctor and we came up with a smoothie.

It started, it has to have a base. something that, you know, we add everything to. So the base was a greens drink, and it was one of these whole foods green drink.

I know that there's at least three or four brands in the US. There's a least a couple of brands that are doing exactly that. So the actual, it was a powdered drink.

It had all the green foods. The kale, the broccoli, spirulina, blue-green algae, everything green. And it also had a number of different vegetables. I think it had some fruit in it as well, in a powder form.

But the base was a fermented base, so they were already pre-digested, and that's what made a really big difference. because of the fermentation, it really improved the assimilation of nutrients.

So there was this powdered base. Then what I did, and this is so basic, but it was the only way I knew how to do it, is I took the capsules that she would have been swallowing and I'd open them up and dump them into this mix.

And then I would figure out two weeks in advance or maybe 10 days in advanced. So I would take 10-days worth and pour exactly that amount in, then mix the mix.

Then the mixed would go into, well it would have been 20 packets because she got one in the morning and one the evening. And so there was like a funnel and the powdered drink mix would into the packet.

The packet would be sealed and then whenever she would or it could be done with a snack.

Nutrition, gluten removal, and the nutrient smoothie

At the end of that meal, packet would be opened up, the contents would poured into a shaker bottle, or when she was at home, it would been poured in to a blender.

And then in that shakers bottle or blender would something like a fruit juice that she enjoyed. And then the whole thing would be mixed. And what we'd end up with is it tasted really good and she enjoyed drinking it.

It was never done on an empty stomach. So it was always done with food because it is food. All she would have to do is just drink this drink that she And that was it.

Again, I can't measure how much improvement there was, but it was just one of these factors that she seemed to do better once we got her on that. You write really beautifully about the role of purpose and humor and kindness and autonomy.

These emotional and relational factors, how do you see them affecting and shaping Dorothea's success? I think that's a really important factor that is often overlooked.

You know, we all seek meaning in our lives. It's just, it's, a human need. And what often happens is that, you know a person has, they've got a purpose.

They're the patriarch or the matriarch of the family. they have got the Family to be responsible for and take care of. If they got their career or if they're doing volunteer work in the community, They've, got, their volunteer that they are doing.

And all of these things help establish who they are as a person. They can identify with these. And when they go into this dementia journey, a lot of that falls by the wayside and then a of it is taken away once they into something like residential care or even assisted living.

At that point, there isn't something that they need to do. You know, it becomes a life of leisure. And I think in our society, when we think of retirement, we often think about leisure, you know?

We're going to play golf every day, or we're gonna play pickleball or tennis, and those are all good things. We are going travel, relax, sleep in in the morning.

But after a while, Those don't really have purpose. And it doesn't give the meaning that our lives really need. So what I tried to do with Dorothea was bring that back as much as possible.

This is just a really simple one. When she was at home, she had chores that she has to to. There was this big whiteboard and it was in the kitchen and had all her chores.

Now these were easy chores like, you know, I don't know, dusting the tables in the living room or something like that, which is an easy task for her even in her late 90s.

And she enjoyed it, but it would be something that it was a chore that she would do and she was responsible to do it. I made it seem to her that we're counting on her to do this.

If she doesn't dust that table, well, nobody else is. And of course, all that stuff would have been taken care of, but I didn't tell her. So she would this list.

if she didn' get it done, who cares? But she wanted to. Then there would be things like after a meal was done. She would often help out with the dishes.

But one of the things that would happen is that, we'd have to unload the dishwasher and there was cutlery. There were three different sets of cutlery.

The three sets had to be organized into these categories in these drawers. I would stumble on it sometimes. Anyways, that was her task. She would have to sort them out and she would do that.

And she felt like she was doing something. There was this place that we used to drive to on the weekend and like on a Sunday afternoon and it was at the edge of this farm in a vineyard and they had all kinds of fruit and vegetables and we had to buy all the organic food for the week there.

And it was a beautiful place and it had this patio and there were chairs out there. And she would often just sit out at the edge of that patio. She would be the greeter and she'd greet people as they were arriving.

It's just all these things that kind of gave her, you know, just this little sense of purpose. I saw that she just really came alive with that. So as much as possible to give people purpose, now within the residential care facility, There were times where sometimes there'd be residents who would help folding the towels or helping to set the table or something like that.

So there were occasions once in a while when somebody could actually have some purpose, but that's as far as actually doing a task. The other thing is something that we often stop doing when someone is showing signs of dementia is we stop asking them for advice.

We don't ask them their opinion. And that was really important. Anything that we were deciding on when she was with me, she would be part of the decision.

And her opinion really mattered, no matter what it was. Giving her as many choices as possible, but also asking her advice. Because then she felt like she's able to give back.

That was the way she lived her life. You shared that there were moments where her wisdom surprised you even. Can you share like a moment when having dementia didn't diminish her humanity?

In fact, it seemed to almost like amplify it. Yes. Yes, it did in some surprising and delightful and sometimes very humorous ways. Yeah. Her kindness towards others was something that surprised me.

She sort of softened at the edges as she was getting older and as the dementia was, you know, as her decline was increasing. And she took a real liking to people that were, she's always campaigned for the underdog.

So when we'd be taking a walk and she'd encounter people who were homeless. you know, that she would just like, just, like glue. She'd go right to them and strike up a conversation.

And she treated them like they were long lost friends. Not that they're strangers, not that there were people in need, they just were friends and she'd ask them things and you'll laugh with them.

If it was a guy, she tell him how handsome he was or if it's a woman, how beautiful she was. So that part of it, and that, She did that more as she got older.

than she had even prior to that. So that was something that kind of increased with her dementia. She had a sense of humor, but her sense to humor and her ability to just be kind-of silly, that also increased.

I guess because she wasn't self-conscious as much. You know, like all the All the things that bind us, the social etiquette, those aren't really holding her back as much.

It's just silly things. There was a time when she had been home for the weekend and we had to go back to the care facility. I needed to organize all of her stuff and repack her suitcases and get everything packed in the car and her laundry and all that.

That was going to take me almost a half an hour to do. And so I thought, well, I'll find a TV show for her. She liked to watch documentaries and educational TV, but we couldn't find anything.

Purpose, humor, and preserving Dorotheau2019s humanity

The only thing we could find that would fill that half hour gap was an episode of The Simpsons. And at first, she wasn't really that thrilled. She thought it was really stupid.

And there was one point I came by and asked her how it's going. Oh, this is the stupidest show she's ever seen. Anyway, but she hung in there and she watched the show.

And then I got everything done and we got in the car and were driving to the facility and I asked her, was there anything that she liked about it? And no, it was really stupid.

I said, well, were there any characters that you remember? Immediately she said Bart Simpson. I said, okay. And somehow Bart Simpson had made an impression on her.

I bet you know where this is leading. Anyways, so we get into the care facility at like 930 at night, everybody's gone to bed, all is quiet, and she leads the way and go down the hallways and then into her unit.

And there at the nurse's station were some of the nurses and the care aides, and they were really good to her and very welcoming. And she hadn't been there for a couple of days.

So she came up to the nursing station and one of them said, well, welcome back, stranger. And with a big smile on her face, she said, eat my shorts and then walked off to her room.

And it's like, where did that come from? That is great. You know, you, I want to sort of expand the conversation to You had a relatively good experience in a long-term care facility.

There was a real partnership, it sounds like, between Dorothea, the care partners that were there, that the staff there and then you, her adult children.

But you also candidly talk about the harm that can be caused by psychotropic medications that are used. as

sedatives, I want to dig into the current model of long-term care.

It's just fundamentally misaligned with what people who are experiencing dementia actually need. And this is near and dear to my heart and my career. But I wanted you to describe, what does a better system look like?

Well, I would say, first and foremost, a better system would be exactly what you're doing. You know, Murama is, it's the model right now. It's fantastic.

I love what your doing and I think the whole world needs to know about it. So, but you know what, as you it, that's a big undertaking. That's pretty expensive.

And then a lot of people can't afford to go to a place like that. with the residential care system as it is. And now I'm speaking directly to the way it was in Canada, but, you know, I lived in the U. S.

for 30 years and I know the system there, and they're both very similar. So both systems are based on a hospital model, understandably so. But, you know, we go to a hospital because we have an acute condition.

We go there for a few days or if, worst case scenario, We might be there a for few weeks and then we're out of there, then were back home. Were not living there.

It's not set up for place for people to live. Its an acut setting where people can get treatment. But that same environment is the environment that's the base for almost all residential care facilities.

And that hospital environment or hospital-like environment does not, in my opinion at least, does work for people who have dementia, especially people, who are relatively healthy and have Dementia.

It's institutional. There's not enough freedom. there's no enough stimulation. It is really based on let's keep these people as comfortable and as safe as possible and just be with them as they decline and give them this safe, comfortable environment until they die.

And the expectation is they're going to decline, and they are going die And I think that's fundamentally the wrong direction to go. I thing for a lot of these people, they could be like Dorothea.

And if she had not had the hip fracture and the fracture didn't even do it, it was the complications after the surgery. If that hadn't have happened with her, she most definitely could have lived another two years, maybe four.

So she could've lived to 104. She's somewhat unique, but she's not that unique. I think with a similar approach, I thing many others could do the same thing.

But that doesn't happen very often in residential care. Not set up for that. The other part of it is that staffing is a huge issue. in both countries.

And so with this desperation to get enough staff in there, sometimes not the best choices are made as far as who becomes one of these caregivers or care partners.

The training is very basic and it's just the fundamental, the skills that are needed to, again, to keep these people safe and, you know, for the functioning of the facility and the basic care.

But it doesn't really get into the psychology of care, it certainly doesn' t get in to human potential at all. And so they're understaffed, they are under trained, you know, as far as recreational programs, very, very lacking, and they re lacking in imagination.

There is so much more that can be done than the programs that are currently offered. And then, of course, the food services. The food service are institutional.

They're feeding a large number of people and they try to give the best food they can, but a lot of it is prepackaged and canned and it's not the freshest.

And it certainly is not whole living food. Of course they don't get any supplementation unless it comes from a family member. And they don't get exposure to nature.

In most facilities, they won't even get to go outside and get the healing energy of sunlight, which we desperately need every day because there's not enough staff to outside with them and to supervise and make sure nobody gets hurt.

So I do want to emphasize that, you know, caregivers, care partners, staff, everyone's doing the best they can. Yes. It's just, it's like a conceptual framework shift.

That there is potential for these people to heal, for the residents to feel for, the community members to.

Why long-term care needs a new model

And I think that that really shifts things because we certainly have seen that at Murama, people who have experience in senior living, they're expecting a downhill trajectory and it really takes a mindset shift.

It takes seeing it, it takes people to get better. And then there's like this aha, and now every resident is treated differently because you see that potential.

Yes. I want to know, how do you respond to critics who might dismiss this as a one-off or false hope? Your book has a counter argument in there that we use as well, but I'd love to hear it from you.

Well, I'm going to use your counter-argument, and I think it was in Dr. Bredesen's work. It's one of the people on his team, it think, was the first person that I heard this with, yes, we have to be careful not to give false, and I understand that.

But at the same time, what's worse than false hope is false hopelessness. And there's way too much false hoplessness. I would prefer to see something that I refer to as realistic hope.

And I think realistic hope is that we can provide an environment and activities and good nutrition and all the factors that more good days than bad days, probably a healthier, a more vibrant lifespan or health span.

They'll probably live a little longer. Probably it will slow down, decline. I think that's very possible and probable. they're going to definitely have a better outcome.

i think all of these are realistic and we can expect that. and we can strive towards that. It is even possible that we could go beyond that, there's neurogenesis, neuroplasticity that can lead to neuro genesis that could be leading to the possibility of improvement.

the possibility of some level of reversal. Now, personally, I can't say that anything I did led to a reversal, but I could say it slowed the decline dramatically and made for a much better, much higher quality of life, and I think we can safely aim for that.

And I think in the coming years, we can aim for more. In a place like Marama, you're already aiming for and you are getting more, going way beyond that, which is fantastic.

That's where we need to go. But even prior to that even without those resources, there's so much we could do. We can do a much better outcome. So wrapping up our conversation here, I'm curious, if Dorothea could give one message to the world about aging, about dementia, possibility, hope, what do you think she would say?

Boy, that's a really good question. Well, why don't we start with you? What would you say if you had one? Be open

to possibilities. That's what I would say.

I think she would, let me say something similar. Of course, she'd tell everybody that she loves them up and down. Eat my shorts, maybe. Yeah. And incidentally, if you don't mind, I'll put in a plug for the book here.

Oh, yeah. I want everyone to find out how they can find the books. If you would, it's upside down and even side. Sorry. Maybe you should say it real quick here, got it in front of me.

That was right. You had it. Up and down, and, even sideways. Where can listeners learn more about you, your work, or maybe even bring you into mentor their organizations?

First of all, I would be honored and happy to do something like that. One of the things that is one of my next projects is I'd love to actually develop a pilot program in a facility and try some of these things out.

And just see if, you know, again, we're not going to get to the level of what you're doing at Murama, but get a little closer, at least, least a better outcome.

And I think that that would certainly be possible. I Think it's practical. It will cost a Little more, But not a whole lot more. Think It is, I, think it is a doable project and I'd like to, um, to really see something like that happen.

involved with helping create that. And of course, you know, anyways, the book, it's 266 pages. Hopefully, It's an enjoyable read. That's what I'm hearing so far.

It is a story. it is story about a remarkable woman, but it also it goes into the story of her dementia journey. This is one person's journey, And it also, there's many insights and some practical tips that are embedded in this.

The title again is Up and Down. And even sideways, it's available exclusively on amazon.com. All you have to do is type in the title, where it is there, and it will come up on Amazon. Com.

Fantastic. And they're very fast at shipping an ode. Anyways, that's the book. Of course, in the books is contact information for me so you can reach me.

If somebody did want to reach, the program is luminescence.

Realistic hope, future possibilities, and closing remarks

The reason I used that That particular word was that luminescence is essentially the light from within. And my feeling is for a lot of us, especially dealing with something like dementia, we still have that light within, from, within but it's maybe a little more dim these days and maybe we can turn the volume up and that late can shine.

So it is that, you know, that that Light from Within emanating out and the term is luminesscence. Incredible. And we'll put the link in the show notes as well.

So thank you not only for sharing the science and strategy behind this integrative cognitive wellbeing program, but also like the heart and the devotion and humanity that shaped your mother's remarkable 22 year journey.

You just show up with so much dedication and commitment and compassion and your work really reminds us that we are not powerless. That environment matters, that connection matters and that even in the face of cognitive decline and an Alzheimer's diagnosis, people can surprise us and delight us, and continue to grow and laugh and connect and have a really fulfilling life.

Your mother's story shows us what's possible when we refuse to settle. When we refused to accept that nothing can be done and when honor that whole person and we choose hope over resignation.

Her journey and your unwavering commitment to her and her advocacy for her, and, your creativity, you're problem-

solving just to acumen. I mean, it's incredible and so inspiring.

But it invites all of us to rethink what dementia care can be. And to imagine these systems that really support people living in vibrant, meaningful, amazing ways at 100. Like, It's just incredible.

So I want everyone listening, I hope that this conversation encourages you to trust your instincts. We didn't even dive into that, but it comes out in the book, like trusting your instinct, challenging old narratives, not taking things that use value, especially when they're not hopeful, and seeking out root causes, really emphasizing environments where your loved ones can thrive.

you write in the book, time doesn't heal, healing heals. And it's like, yeah, obviously, like let's actually do the healing, not just wait for things to progress.

There's so much that we can do to change the trajectory for ourselves, for our families, our communities. So I just cannot thank you enough for your work and your courage for giving the world this example of what's possible when we lead with compassion and curiosity and commitment in everything that you do.

And above all, thank you for sharing Dorothea with us, like even her personality and her, she just comes through in this story in such a vivid way. And so I'm just beyond grateful to have had you here today, Del, to share this store.

Thank you. Well, I feel very honored to be here with you, and thank, Thank You. 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.