Introduction to Hope in Dementia Care

What's worse than false hope is false hopelessness. And there's way too much false hopelessness. 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 that 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. I think all of these are realistic and we can expect that and we can strive towards that.

It is even possible that we 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.

Meet Dell Museo and His Background

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 the late 1990s. 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 multimodal protocol that, you know, I think everyone who knows what I'm about in terms of multimodal interventions as kind of used through the Bredesen Protocol, you'll see immediately why I'm so excited to have Del here sharing his story as a care partner for Dorothea, and of course, Dorothea's story of stabilizing, not only stabilizing, 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. And 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. And Dell'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 want to 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, the indifferent. And I'm curious, your background is impressive with the skiing and wilderness leadership and wellness education.

your 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 Forrest Gump just happened to end up at the right place at the right time. And I would say that's probably my life's journey. I just sort of stumbled upon the right place, the right time, connected with the right people.

Meditation, Zen, and Caregiving

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

I mean, you were, you were thinking about wellness well before it was all over social media. 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 think the modalities are more effective. It's more grounded, but they had to start somewhere. And in those early years, it was these people that were my teachers, they were pioneers and there was no path to follow.

They were groundbreaking. I just kind of followed behind and I'm doing this. I'm curious, I meditate daily. It's a big part of my life. I'm 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 at someone who is destined to have a meditation path, I wouldn't be that person either. The reason that I actually first got interested in meditation was when I was in scheme competition.

And a what competition? When I was competing in skiing, I was, uh, it was back in the early days of freestyle skiing and I was competing in the moguls and the, you know, pro mogul tour and all that.

And there was a competitor who was very, very good. And he was a friend of mine and I would copy whatever he did. And one day we were just chatting and it was asking him that, how is it?

It's just so chill all the time. And he was telling me that he had this meditation place. And it actually helped him, especially when he's in the starting gate and we have all the butterflies in their stomach and all that.

And he could just kind of calm and center and then be ready to go. And I thought, well, this could be helpful. And that's why I got into meditation. It wasn't for personal transformation or spiritual growth.

It was just so I could compete better. And then I found that, well, it actually 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. 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.

And it was a very, very enriching experience and that 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.

You know, I wish 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 and there were times when things came crashing down and it was pretty stressful and the meditation practice really helped get me through it.

Recognizing Dorothea's Decline

to imagine that if you didn't have the meditation practice, if you hadn't had the deep experience at the Zen Center or with the Dalai Lama or, you know, any of these litany of experiences that you accumulated over the years, that you would have been less patient as a care partner, that you, you know, there would have been more frustrations.

It would have, you know, things would have bubbled over more frequently and it would have been an even less joyful connected experience. Yes. Yeah, certainly.

So I think we're all on the journey, right, of learning to be more patient, more tolerant, 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 her care shift, where you went from thinking, okay, the conventional medicine is what we're going to do.

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

I was probably quite early on, but at that point I was 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 wasn't really impressed with the options that were available.

I didn't really like the prognosis. And it was in about 2007 that it really became clear that I I found that the prognosis that she got was it was very depressing.

It was 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 it could and that we could do better than that. So it would have been 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 care 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 to 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 of her from 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.

And that takes me back to my outward-bound days. And that's what outward-bound is all about, was 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 can do way more than we ever imagined we could.

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

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

Her being learned, of course, really helped her because that helped her develop a 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 was another part of it. And I think since she was young, and it was just part of her story as she was growing up, she had to be adaptable.

And she got really good at being adaptable. And it wasn't being adaptable and just struggling through the changes. It was like, OK, well, this is what we're doing now.

And she would just step into it with full force. And 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 applying the Bredesen protocol, it's like that commitment, that determination, that sense of hope, that adaptability, that willingness to change the lifelong learners It's sometimes like the type A, and I'm like, all right, I'm going to figure this out and get this done.

I'm not going to accept no for an answer kind of person. Those people really seem to get the most benefit out of this. And 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 this by, 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 it can expand beyond this group of incredible women.

Will you talk me through Dorothea'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 the last quarter of her life, what did her daily routine look like?

Not the intervention so much, but how was her memory affected? What were the deficits? What were the

challenges? And then as you implemented the intervention, did things get better?

What did you notice? I know the mini mental status exam, that went up, but I want people to kind of paint a picture for people what her life was like.

Well, you know, prior to the first signs of dementia, she was a pretty sharp person and, you know, she had a very, very good memory, very organized. And she was just, you know, she was an active person who, she lived alone in a very big house, but she had a number of friends.

She had a pretty good social life. She was still taking classes and 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 would have been even into the very beginning of the first signs of dementia.

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

Life in Residential Care

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 became quite noticeable in 1998. 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.

So 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 then 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, and 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 home, 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. And then it got to the point where I couldn't really leave her much more than an hour at a time because she'd get into mischief.

And 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 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 become thousands of dollars every month.

And it just kept growing and growing. And 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 she? Yes, she was. This is in Canada. What did 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. It was not the best environment for someone who is still relatively healthy. What do you think it was? Do you think it was the food?

Do you think it was the way she was treated? Do you think it was the lack of exercise or that there were TVs everywhere? Was it distraction? Was there something specific that you think really didn't suit her?

Or is it just more vague in general? No, I think there were very specific things. First of all, 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 had all kinds of projects on the go, and she had 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 feet.

It was really small. little single bed. It was like smaller than a motel room. I used to say it was like a prison cell. 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 were 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 was the 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 the 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 bed early.

But 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 be just back in her room, just hanging out.

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 be kind of 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 of the really good healthy food she was getting, that was taken away.

And then plus all the helpful supplements that she was on, that was taken away. So she lost, you know, whatever benefit she was getting from that.

Building the Integrative Cognitive Wellbeing Program

And then she was of course 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't really accept that, so I kind of snuck in, and that was a good thing. 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 week.

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. She loved to be outdoors. 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 a secured unit so she couldn't even get out of the unit and she's kind of a free-range kind of person. So that worked against her too.

So 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 think 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 not interested. It's not her.

And she goes downhill. And so let's, 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, the supplements getting back in there? What started her turnaround?

What did you do? 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 doing and I looked at the program and it 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 first thing was to remove her from further harm. And when I refer to that, I mean, removing toxins, allergens, you know, 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, and if we see that there is danger, it's imminent, it's right there, and it's 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 the 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 was. 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. You know, if there weren't… Mycotoxins, we would do what we could to remove those and just introducing like clean air, water, you know, if EMFs were an issue, removing that.

It turned out they weren't really an issue 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.

In her case, because she had a very severe gluten intolerance, there was damage to her digestive system and to her gut. And so there were pathogens, there was 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.

And 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 had a really, really good naturopathic doctor.

And both doctors in tandem worked on that in partnership with the facility. And the dietician in the facility 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 a difference in her cognition, her test scores went up, it made a difference in her abilities, and it made a difference in her mood. And she didn't have as many of the mood swings and it made a huge difference in 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 clothes that she liked and she was happy with that.

But that's also an indication that there was something helpful that was happening. And so that was just one little move, you know, one little factor, but that factor, that one 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.

So it was like really upping the quality of her nutrition, more whole foods, 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 supplementation, and that was working alongside 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. And then she got the whole body exercise.

And 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 with the other part of her body, or she might be on her exercise bike and she might 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 did, 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.

And then, of course, I had mentioned the living environment. Well, one of the breakthroughs, there were two huge breakthroughs 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 could come home and spend the night, and it would be an overnight.

So it would actually be two full days with an overnight in between. And she did so well. that eventually I was able to, um, to get like permission so she could come home once every 10 days and come home for one of these extended weekends where she, we would, I'd pick her up right after lunch from the facility.

We'd come home 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 in her home.

She'd be all over the community doing stuff. And that was a huge, huge part of it. And 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 was like this generic olive green and beige, and her colors were sky blue. So everything that could go into sky blue became sky blue.

So 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 up 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 she'd have 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 40 Hertz sound.

Nutrition, Smoothies, and Daily Support

40 Hertz light, the gamma cadence in light and sound also, gamma and theta frequencies, the 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.

And the chair, it was so impregnated 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. So 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 big TV screen and there was the 40 Hertz flashing light, which she didn't like. So that was impregnated inside the sort of kaleidoscope and it was beautiful.

She loved watching that. And then she wouldn't even notice the flashing. And then we'd have the 40-hertz sound. And it would just be this just, you know, a soothing meditation experience for her.

But she was getting it from all directions. She was feeling it. She was hearing it. She was seeing it. And I can't quantify how effective it was, but I do know that she was 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'm 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? And when she was at home, had her memory improved so much that she was able to stay out of mischief?

No, no. 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, you know, 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 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 and 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 things followed later. The Exogenous Ketones, I believe, was in, oh, I think it was about 2011, and it was 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.

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 days she would come home.

She wouldn't necessarily be home all day and through the evening, but she would come home in the early afternoon, sometimes in the late morning, and then she would 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 and we couldn't take her out like all the time.

Like she needed to spend time there. That was, you know, 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'd take part in those.

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

There was some really, really wonderful care aides, nurses, management staff, really, 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, you have 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 you, to Dorothea and your family, they were willing to 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 was having a big impact on not just the circumference of her waist, but probably her inflaming 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, in 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 The importance of a multimodal intervention 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 to do as much as possible. And that is

overwhelming for a lot of people. and help us navigate that.

I wish there was an easy solution. Me too. For myself, it was an all-encompassing challenge. 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 was able to be there and to do it, but it really does take a village. And that's what I'd like to see more of, you know, where it's an integrated program, but also an integrated 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'm 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, 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, I don't know, in mathematics, If it was synergy, two plus two wouldn't equal four. Two plus two would end up being six or seven or eight. You know, it would end up 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. She also had a life that was similar to Dorothea's. She had a can-do attitude. She was open to possibilities and she was very adaptable.

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 limited.

So she only got a limited part of the program. Some of her family members were kind of trained in some of the basic things. So they could implement some of these things when I wasn't there.

And that was helpful. She had an absolutely wonderful personal living environment. And I think that was 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, two bathroom, a little kitchen, dining room, living room with wall to ceiling windows that overlook the valley.

And it was, it was just, it was palatial and it was her home and it was, it was all the best stuff from her home were brought to this. So she never felt that she was taken out of her home.

It's just her home moved with her. How stunning, how amazing. Yeah, and I wish that was possible for everybody. Anyways, in her case, that was a possibility and that was 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 years, 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. And again, she was able to do things that she hadn't done before.

She was learning new things also. So I think, you know, given the exposure to the rest of the program and given more time, I think, you know, she would have done 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, I think she was having to swallow 13 different capsules. And for somebody that's in their late 90s, that's a lot to swallow.

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

Maybe she was, 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, as 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 at least a couple of brands in Canada that are doing exactly that. So the actual, it was a powdered drink.

Purpose, Humor, and Human Connection

It had all the green foods. So it had the kale, the broccoli, the spirulina, the blue-green algae, everything green. It also had a number of different vegetables.

It had, I think it had some fruit in it as well in a powdered form. But the base was, it 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 the nutrients. So there was this powdered base. Then what I did, and this is like, it's 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 I'd dump them into this mix.

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

Then the mix would go into, well, it would have been 20 packets because she got one in the morning and one in the evening. And so there was like a funnel and the powdered drink mix would go into the packet, the packet would be sealed, and then whenever she would have a meal, or it could be done with a snack, at the end of that meal, packet would be opened up, the contents would be poured into a shaker bottle, or when she was at home, it would be poured into a blender.

And then in that shaker bottle or blender would be 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.

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

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's often overlooked. You know, we all seek meaning in our lives. You know, it's just 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've got the family to be responsible for and take care of. They've got their career, or if they're doing volunteer work in the community, they've got their volunteer work that they're 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 lot of it is taken away once they go into something like residential care or even assisted living.

And 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 of leisure.

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

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

So, you know, this is just a really simple one. When she was at home, she had chores that she had to do. And 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.

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 that. So she would have this list.

If she didn't get it done, who cares? But she wanted to. And 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. And there were three different sets of cutlery.

And the three different sets of cutlery had to be organized into these categories in these drawers. You know, I would stumble on it sometimes. Anyways, that was her task.

And 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 this wonderful, it was at the edge of this farm in a vineyard and they had all kinds of fruit and vegetables and we used 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 and she would be the greeter and she would 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. And 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 for 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. And giving her as many choices as possible, but also asking her advice. Because then she felt like she's able to give back.

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

In fact, it seemed to almost 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 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 that were homeless. you know, that she was 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 were strangers, not that they were people in need, that they were just, they were friends.

And she'd ask them things and, and you'll laugh with them and tell them how, if it was a guy, she'd tell him how handsome he was, or if it was a woman, how beautiful she was.

And so that part of it, and 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 of 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, all the things that bind us, you know, the social etiquette, you know, those aren't really holding her back as much and just lots of, you know, and just, 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, you know, 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. And she used to watch, she liked to watch documentaries and educational TV, but we couldn't find anything.

And the only thing we could find that would fill that half hour gap was an episode of The Simpsons. And she'd never seen The Simpsons before. 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 was going. She says, 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 we're driving to the facility. And I asked her, was there anything that she liked about it?

No, it was really stupid. And I said, well, were there any characters that she remembered? And immediately she said, Bart Simpson. I thought, 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. It's 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.

And so she came up to the nurse's 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.

Rethinking Long-Term Care and Realistic Hope

And it's like, where did that come from? Simpson, oh my god, how funny. That is great. You know, 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, 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.

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 want 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 you're doing. And I think the whole world needs to know about it. So, but you know, as you know, it's a big undertaking.

It'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 is 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, and 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, you know, worst case scenario, we might be there for a few weeks and then we're out of there. Then we're back home. We're not living there.

It's not set up for a place for people to live. It's an acute 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 not 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 not enough stimulation. It's really based on let's keep these people as comfortable and as safe as possible and just be with them as they decline and just give them this safe, comfortable environment until they die.

And the expectation is they're going to decline and they're going to die. And I think that's fundamentally the wrong direction to go. I think 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 have lived to 104. Well, she's somewhat unique, but she's not that unique. I think with a similar approach, I think 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 doesn't get into, it certainly doesn't get into human potential at all. And so they're understaffed, they're 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 services 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's prepackaged and canned, and it's not the freshest.

And it's certainly not whole living food. And 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 don'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 go outside with them and to supervise and make sure nobody gets hurt.

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

It's a paradigm shift that there is potential for these people to heal, for the residents to heal, for the community members to heal. 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, I think, was the first person that I heard this with, yes, we have to be careful not to give false.

And I understand. But at the same time, what's worse than false hope is false hopelessness. And there's way too much false hopelessness. 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 we've been discussing, where most of those factors that can result in more good days than bad days, probably a healthier, a more vibrant life span or health span that 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 can go beyond that. There's neurogenesis, there's also neuroplasticity that can lead to neurogenesis, that can 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 can say that certainly 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 more and you're getting more.

You're going way beyond that, which is fantastic. That's where we need to go. But even prior to that, even without those resources, we can still 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, about possibility, about 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 message? Be open to possibilities. That's what I would say.

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

Well, yeah, I want everyone to find out how they can find the book. If you would, it's upside down and even side, sorry, maybe you should say it real quick here.

I've got it in front of me. Yeah, that was, that was right. You had it. Up and down and even sideways. And where can listeners learn more about you, your work, and 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 I, you know, it's 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, at 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. I think it is, I think it is a doable project and I'd like to, to really see something like that happen.

And I'd love to be involved with. And of course, you know, anyways, the book, it's 266 pages. Hopefully, it's an enjoyable read. That's what I'm doing so far.

It is a story. It's a 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. And all you have to do is type in the title, there it is there, and it will come up on amazon.com.

Fantastic. They're very fast at shipping an ode. Anyways, that's the book.

Closing Thoughts and Where to Find the Book

Of course, in the book is contact information for me so you can reach me. If somebody did want to reach me, I program this as luminescence. 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 from within, but it's maybe a little more dim these days.

And maybe we can turn the volume up and that light can shine. And so it's that light from within emanating out. And the term is luminescence. Incredible.

And we'll put the link in the show notes as well. Del, thank you not only for sharing the science and strategy behind this integrative cognitive well-being program, but also like the heart and the devotion and the 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 refuse to accept that nothing can be done, and when we honor that whole person and we choose hope over resignation.

Her journey and your unwavering commitment to her and your advocacy for her and your creativity, your problem-solving just 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 that I hope that this, this conversation encourages you to trust your instincts. We didn't even dive into that, but it's, it comes out in the book, like trusting your instincts, challenging old narratives, not taking these values, 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, let's actually do the healing, not just wait for things to progress.

And there's so much that we can do to change the trajectory for ourselves, for our families, for our communities. And 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 and everything that you do.

And above all, thank you for sharing Dorothea with us. 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 story.

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

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