Introduction to Cognitive Decline and Anosognosia

in that orbit of a patient struggling with cognitive changes who lack self-awareness around it, how can they distinguish between what's driving that and how they can help and support that patient to make good decisions?

So that, of course, is my favorite question because I talk a lot in my book, Navigating Memory Loss, about the condition which is called anosognosia. It's a mouthful of a word, anosognosia, but it's neurological term which has been around for about 100 years.

Most people, I think, are familiar with it around psychiatric diagnoses. People understand that someone with a diagnosis of schizophrenia might stop taking the medication because they don't see where they're needed.

That's anal agnosia. They don't see that that medicine is keeping them in a functional state. So when you have damage to the brain, if you had a neurodegenerative illness, which is destroying cells, as you destroy cells you disrupt connections or networks in the brains.

And those networks are really what allows us to think and function. at the level we do. And so there are networks in the brain which facilitate what we think of as referential thinking.

So I can think about, you know, my exercise schedule that I did this morning, and I could think the exercise that did 20 years ago and see where there's a difference.

I'm different. Welcome back to the Think Well, Age Well podcast. I am your host, Dr. Heather Sandison. And today I have the pleasure of speaking with Dr Catherine Madison.

She's a board certified neurologist whose career has been devoted to helping individuals and families navigate one of the most challenging journeys in medicine, cognitive decline and dementia.

Dr. Madison is currently serving as the Medical Director of Seniors at Home and Rhoda Goldman Plaza. She was the founding director of the Ray Dolby Brain Health Center in San Francisco, a pioneering center focused on brain health and cognitive care.

What makes Dr. Madison's perspective especially meaningful is that her expertise extends beyond the clinic. Like so many of the families she serves, she personally experienced the heartbreak, uncertainty, and complexity of caring for a loved one with Alzheimer's.

Those experiences caring for her own mother shaped not only her approach to medicine and patient care, but also inspired her book, Navigating Memory Loss, Essential Questions and Answers on Alzheimer's and Dementia.

So today, we're going to explore what every family should know about memory loss, dementia, the diagnosis, brain health, caregiving, and how to live well in the face of uncertainty.

Dr. Madison, I'm so grateful to have you here. Welcome to the Think Well, Age Well podcast. Thank you so much, Heather. It's my pleasure. You've spent your career caring for people with cognitive impairment and I'd love to start with your own story.

What first drew you to neurology and what keeps you passionate about this work? Neurology was always a great puzzle. And because I love learning, that seemed like a, a career path to follow.

I've actually dabbled in many different things. in the field of neurology. I really concentrated on dementia alone over the last 20 years or so. And that was indeed shaped by my personal experience.

When we moved back to California, my mom was just starting to come down with cognitive impairment and confusion. I went down that path. I'm the youngest of four, but because I am the doctor and the family, of course I was expected to handle everything.

And as many women can understand, I had three small children and a husband to take care of. So I really understand that feeling of being in the trenches and looking so closely down at your feet to make sure you don't stumble, that you're not sure if the light coming over your shoulder is from the sun or the moon, because you just can't take your eyes off of putting one foot in front of the other.

Yeah, that sandwich generation, right, where you're expected to raise children, work, and care for an aging parent. How did you do it? Well, there was a lot of juggling.

You know, I must confess there were several years there where I wasn't working full-time, because if you are working a 40-hour week, it is virtually impossible.

And I make sacrifices or compromises with advancement of my career to try to keep that balance. Yeah, there's trade-offs always, right? Caring for your mother with Alzheimer's, I mean, it gave you this perspective that no medical training can provide, so when you…

describe that trade-off of balancing your career by going to part-time, but it was almost like in the trenches training. It must have changed when you went back to full- time or even when went to see a patient in that part time that you were working.

Must have change the way you related to patients. I think it changed significantly because I understand the perspective from the other side. And I'll share another personal story with you.

When I was in medical school, I ended up in the hospital with a severe gastroenteritis that got me so ill, I had to be hospitalized. And the experience of being in a hospital really taught me a lot.

when I'm trying to share a diagnosis, that's always the most heartbreaking. When I knew I was going to have to meet with the family and share that the testing all looked consistent with a diagnoses of an early stage dementia, it really took some grounding to come into that meeting.

And you have really approach it with openness and shared some vulnerability there. with the patient and their family and then just kind of choose a path that seems to fit their needs.

I think one of the most important things to understand is up until now, it wasn't a real specific diagnosis. This whole field is changing in the air around us, real time.

right now and that's fabulous and so again now doctors walking into that room they don't have the feelings I had when we had no cure because now we actually have we now have treatments but I'm sorry Heather where were we going with this?

You know, what is it important for families to understand? And I think it sounds like you're saying hope, right? 10 years ago, 20 years, ago when you as a doctor provided a neurologist, provided diagnosis of a dementia pathway testing consistent with the early dementia, there wasn't a lot of hope.

It was basically this downhill side. And now there's more interventions available. So there there is kind of more hope there. There's there are more tools in the tool belt.

And then are there other things that, you know, that patients might think about? Or I feel like often this comes up with cancer, right? Patients in that room, once they hear the word cancer they can't think clearly.

They hear nothing else. Your head shuts down. Everything shuts Alzheimer's. And I think now like with the pita testing, I've had several people come to me who have full cognitive capacity, they are still working, and they have

an Alzheimer disease diagnosis.

They go through sort of a similar experience of like, should I quit my job? Do I need to put my affairs in order even though I'm in my early 50s? 60s or late 50s.

And I think that an understanding, I thing maybe one of the things you're speaking to is like, there's a spectrum here. An Alzheimer's diagnosis doesn't always mean a dementia diagnosis or doesn' mean that dementia is happening in the next few days, right?

That there can be a process and that there could be lots of interventions there along the way that a provider can support you with. Everything you said there is completely accurate to our current terrain.

We do have treatments now and we speak of it as a spectrum. We now know that neurodegenerative illnesses begin decades before there might be any clinical signs in terms of the blood tests which are available out there right now.

The recommendation is that people not get those as a screen because we simply don't know what to do with the information. The blood tests are approved to help confirm a diagnosis when somebody has some early cognitive changes.

Dr. Madisonu2019s Personal Journey into Neurology and Caregiving

But the case that you are referencing there, if somebody gets a positive blood test and then they're in their early 60s and it's like, do I change my my whole life.

And as you very well know, there are things you can do to make changes in your life that will alter that trajectory. That is the hope that we have today.

In addition, in the field of neurosciences, You know, there are well over 100 drugs being studied right now. And I do believe within the next several years, we will have a treatment cocktail that will approach neurodegenerative damage to the brain from multiple facets, with inflammation being one of the major ones.

I'm so happy to see that being focused on because I myself have been interested in the gut brain access for decades. Yeah, it's so exciting, such an exciting time with the advancement of science and technology.

You know, one of the things that comes up for a lot of patients is this lack of self-awareness. And I think sometimes, especially the adult daughter, sometimes the spouse, other people in the family, relating to that patient feel like maybe the patient is in denial.

So, how can a family member or someone in that orbit of a patient struggling with cognitive changes who lacks self-awareness around it, How can they distinguish between what's driving that and how they can help and support that person to make good decisions?

So that of course is my favorite question. because I talk a lot in my book, Navigating Memory Loss, about the condition which is called anosognosia. It's a mouthful of a word, anosognosia, but it's neurological term which has been around for about 100 years.

Most people I think are familiar with it around psychiatric diagnosis. People understand that someone with a diagnosis of schizophrenia might stop taking the medication because they don't see where they're needed.

that's anal agnosia, they don't see that that medicine is keeping them in a functional state. So when you have damage to the brain, if you had a neurodegenerative illness, which is destroying cells, as you destroy cells you disrupt connections or networks in the brains.

And those networks are really what allows us to think and function at the level we do. So there are networks which

facilitate what we think of as referential thinking.

I can think about, you know, my exercise schedule that I did this morning. And I could think of the exercise scheduled that they did 20 years ago and I couldn't see where there's a difference.

I'm different. You mentioned an adult daughter and obviously I pick on the women because we're two thirds of their cases. It usually is a daughter who's caring for her parents, although I've seen sons do phenomenal jobs as well.

But I would have a daughter bring in her mother, and I always ask about exercise, because that is one of our cornerstones for brain health. And an older woman would say to me, oh, I walk every day.

Mom, you haven't been walking every for a year. Well, if you understand anasognosia, You would understand that the mother and the daughter have different perspectives here.

Because of damage to her brain, the Mother cannot reference these two events in time, her walking a year ago and her walk yesterday. In her mind, she's lost the ability to make that comparison, so they're the same.

And when people can understand that, It allows them to approach communication with someone who has cognitive impairment from a completely different perspective.

There was a really nice publication put out in the UK called Dementia Truths, where they interviewed individuals with impairment. They interviewed family members.

care providers, professionals, and they explored this question, what is truth? And they tend to promote in that something which I believe firmly in, that you can have different realities.

If someone's brain is changed by an illness, a neurodegenerative condition, their reality is different. than yours and mine. So if you want to try and find a solution to a problem, you have to approach it very differently.

Try to find reality that is acceptable to them, but meet the mutual goal. My good example is when we had a woman who had, she had an early stage dementia, this was several years ago, and we needed to move her out of her high rise, condominium in San Francisco where she'd been for decades and she didn't want to leave because the view was so lovely and everything, but she wasn't safe living there.

And so we came up with the theory, and some people call this therapeutic storytelling. We came they had to replace the windows because San Francisco had changed the building codes.

And if you've ever been in San Fransisco in a high-rise, you'll know that this isn't very plausible. Those old single pane windows and that fog is rolling in.

It's freezing. So we got her out of the condo and into a care facility where she eventually assimilated extremely well. In terms of a construction on the window, wow, there were delays in permitting.

Then they needed supplies. We had contractor issues. Then there was a labor slowdown and then, you know, we just kept rolling this along until it faded away.

Yeah, this is such a great point. I think we call it connection over correction, right? It's how do we get on the team if the goal is their best interests are at heart, right?

What we want is what's best for that person and the safest place for them is in a care community or living with loved ones. There's something that they're resistant to.

How can we meet them where they are? How we can create that shared reality that works for everyone? And also, I think the flip side of that, and this is really well explained in learning to speak Alzheimer's, that book, it's I, think from the 90s, Joanne Conocoste.

The idea is that if we go in and correct them, right? If we force our issue and we're right, then what we do is we degrade the relationship and it spirals into defensiveness and now we escalate emotionally rather than diffusing.

And it's in all of our best interests, right? Everybody's going to have a better day if we can diffuse. You'll never win an argument. No, because you live in different realities.

Correct. And so because, you're the one with cognitive capacity, it is up to you to find the energy and the creativity and to let go of some ego and meet that person in their reality.

And understanding that there is a neurological condition which is driving their resistance, I think really helps people. Just saying meet them in their reality is really hard.

But if you understand that, there's a physiologic basis for their actions, then I think we can ground ourselves better and approach it more reasonably and definitely get a better outcome.

Hope, Early Diagnosis, and New Alzheimeru2019s Treatments

And more compassionately. Yes. When we say this is their brain, not my person, my mom, or my husband, then that all of a sudden makes it a little easier to cope with, I agree 100%. That's what I stress in my book.

I weave anasognosia through all the book, just keeping it in people's mind that don't forget about this. Now, there can also be denial. I think the most denial is from the family members and friends.

We all deny it. because we don't want to see it happening. That's interesting. I'm sure you've had patients where I'll ask a person with full cognitive capacity what their exercise routine is, and they'll share something that their husband or wife then jumps in and says, well, you don' really do it that many days a week.

So I think there's our aspirational projection of our identity. And then there is what's closer to reality. Where's the line between something pathological that you would call Anasognosia.

There you go. And maybe denial or a projection of an aspirational view of ourselves. I think that's all normal. We all want to aspire to be our best selves.

and be seen that way by others, including the provider we're giving this information to. Oh, I heard that so many times. A partner will say, they just put on such a good show for you.

You should see what I deal with at home. And I would always say there, I believe that you deal with something very different than I deal at home. I think it's really unconscionable if the provider doesn't acknowledge that what they're seeing in the office can be very difficult from what's going on at Now, you've worked alongside a variety of dementia care approaches, really an impressive spectrum of interventions, including lifestyle-based interventions.

And I'm curious, your experience, Dean Ornish is up in the Bay Area, and you have some familiarity, I think, with the Ornnish Lifestyle Medicine Program.

But I am curious what your experiences with that was like. I want to take a moment to share something really exciting with you. This is something that's been a long time coming for us.

At Solcery, our mission has always been to make dementia rare and optional. To give people real tools, real answers, and real hope when it comes to brain health.

But one of the biggest barriers we've seen over the years is access. So many people need this care. They're motivated, they're ready to do the work, but they simply haven't been able to afford it.

And this is why I'm incredibly excited and proud to share that we are now participating in Medicare's Guide Program. This means that for the first time, eligible patients can receive ongoing support for cognitive decline,

Alzheimer's and dementia through Medicare, with significantly reduced out-of-pocket costs and support from caregivers.

We are not just opening the door, we are expanding our team to meet this need. We now have two new nurse practitioners trained in our functional root cause approach to brain health.

They're working alongside us with our teams to deliver this care in a way that's personalized, comprehensive, and deeply supportive. This is about reaching more people earlier and staying with them longer on their journey.

It's about supporting caregivers who have been carrying too much for too long. And it's about making sure that the cost is no longer a reason that someone doesn't get the care that they deserve.

If you or someone you love is experiencing memory loss or cognitive decline or has been diagnosed with Alzheimer's or dementia, I want you to know that there are options and that now there's more access than ever before.

You can learn more and see if you qualify by visiting salseri.com or calling 760-385-8683. This is just the beginning and I'm so honored and excited to be able to bring this announcement to you today.

Well, I actually worked with Dean for almost two years on his lifestyle intervention. I was the neurologist running the program. And so I had a very, very good and positive experience with that. I came into it with a open mind because I think that's the way we should approach all problems.

His intervention is very similar to Dr. Bredesen's, which I know you've also spoken with Dale Bledesen. And I believe in all of those approaches, and I think they really can help.

It's implementing a change in diet. which then changes your gut biome, which affects your metabolic health, inflammatory status, and again, this whole process of inflammation, Which is now being talked about.

We're dampening that. combined with group support, regular exercise, meditation, and he always added the extra ingredient of love and community. And some nutrition, some nutrients, right, were included in that.

Correct. That's what differs. You're going to find a tremendous number of opinions on what exactly are the right additional nutrients that one should add to their diet.

I don't try to give advice there, Heather, because there are simply so many different opinions. You know, some of them I take myself, I, take the E and the D and C and K and things like that.

But, you know I then over the years, Dean would always offer me to get into the program and do the vegan diet I must confess though, I never quite did that.

Understanding Anosognosia and Meeting Patients in Their Reality

I tend to follow more of the Mediterranean or the mind diet, and then I cheat. Well, it's interesting, right, because we, we use a ketogenic approach.

So I, Dr. Radisson is my mentor. I absolutely follow his work all day long in my clinical practice and in what we do. And we spend a few hours a week reviewing patients with him.

so definitely that has been our approach and I know that what's really hopeful about it when I saw the, the Ornish paper came out. the week before my book did, which was really fun.

And there are these two alternatives in terms of diet. People are so dug in around their diet that it was like this breath of fresh air to be like, okay, don't go keto, go vegan, or maybe go back and forth.

There's not gonna be one perfect diet for this. I think it's pretty well established that the Mediterranean diet and the MIND diet are both great for reducing risk, but you're not going to get reversal of cognitive decline.

And what you guys saw with the vegan diet, with these more drastic dietary interventions, you do see improvement in cognition. And so I think that it depends where you are, right?

And for you, Dr. Madison has great cognitive function, still working. You don't need to worry about, maybe you're in that luxury of prevention, same as I am.

So I go in and out of ketosis. I'd go plant-based sometimes, especially in the summer when it's hot. But I think you and I are probably both a little more vata and could use the grounding of some meat.

And we saw in the recent trial that was published that it looks like even people with APOE4 positive status with high genetic risk for dementia do better with some unprocessed red meat, so I debate in the field around this and we don't know exactly what the right thing to do is.

I suspect that it's going to be pretty much your diet, right? A good, high quality, unprocessed diet with variation, with room for you to go to Italy and have the gelato or to a birthday and enjoy the dessert on the table, and so it is not quite so rigid.

Do you have a brain health prescription for the average adult who's looking to prevent cognitive decline as they age? Yeah, I think it's the one that we all agree on.

Ornish approach, as we said, you know, vitality is based on keeping your brain stimulated, being involved with novel learning, social connections, the regular exercise, which then also needs variety, a healthy diet.

concentrating on unprocessed foods, vegetables, nuts, legumes. For me, there's some meat thrown in there as well, but basically you want to try and make everything yourself as much as you can.

And then I think we understand now you really need a good night's sleep. Sleep is not a passive process. We consolidate memories from during the day. And with the recent discovery of the glymphatic drainage system, we now understand that we drain toxins from our brain during our deep sleep.

So it's a combination of all of those things. Then we also have to throw in the mindfulness. which will help us sleep exactly and help focus as well. It's a fairly extensive, yet simple solution, Heather.

If you think about it, all of the things that you and I are talking about here, they're simple. They're sort of common sense, but uncommon practice is one of the ways we talk about them because I think society isn't set up for that, right?

You can sleep when you die and convenience foods are cheap and easy and convenient, and you're encouraged to sit at your desk and just plug away and grind away, be as productive as possible and buy this and that.

support the socialization and prioritization of sleep and good food and movement. And so we're kind of against the grain in terms of what society is supporting, but it's so worth it.

You know, I'm sure you've had this experience personally, and maybe you can speak to watching patients go down this path. But there's upside that's more than just improvement in cognitive function and brain protection.

I think I see people just living more full and engaged lives. Do you see the same? I do, but you also have to recognize that people will only do what they're willing to do.

And in practice, I would always say, you know, we can only put our hands out and offer interventions and such. And so then a lot of that is, as a provider, really bringing yourself openly to the meeting with your patients for a conversation.

It's not you walking in there and telling them what to do. because that's not going to work. And so I think we will continue to forge ahead personally and professionally in setting example.

When we're working with patients and families, laying out options and saying, well, do any of these work for you? And this is the one I recommend the most highly.

given your situation and can we work on figuring out a way to make that fit into your life? Because again, you can recommend everything, but if it doesn't fit in to someone's life, they're not going to do it.

Yeah, it's interesting, right? That's always the rub. And I think that, you know, we try to balance both because we want it to be easy enough for someone to get started, and then hopefully, they'll get that positive feedback and be able to layer more and more on.

When someone's struggling with cognitive impairment, We've thought about this because of cost. We thought this about because a bandwidth. we thought of this with support.

There's all kinds of constraints that we can come up with. But if you're asking for the miracle of an improvement in cognitive decline on an Alzheimer's path, then we've got to be all in.

We've gotta do as much as we can yesterday. And so I think there's balance in how that is presented, that it can't be self-righteous and it cannot be too rigid.

It has to encouraging so that people are inspired to actually do it because it doesn't work if they don't. Right. It's a challenge. I love having this conversation with someone else in this space because I think it really is, there's way to navigate it and it's not easy.

And it is not cut and dry. Its nuanced and depends on the person in front of you and so many variables. Right and we all do better when we've got feedback.

When we got positive feedback and that's why working with a group can generate better results. Yeah, we said that in our coaching programs too. When you watch someone else, they, for us, it's like getting into ketosis.

We often see there's this light switch, like all of a sudden they're more articulate, more present. And when you see that happen to someone, all the sudden you're like, okay, maybe it is time for me.

Or you start exercising and you their body changing and maybe you haven't fully committed and it like okay. All right, I'm off. Let's do it. Which is really fun.

It's part of the magic, that group dynamics. I agree.

Lifestyle Interventions for Brain Health and Dementia Care

So easy for me to be telling people about this, but when you watch it happen to someone else or you hear it from someone who's implemented, That's a game changer.

I'm curious, you know, sleep is one of my favorite topics. I'm curious, you know, do you do that? And also, what are some practical things people can do to improve that deep and REM sleep that you were discussing to support long-term brain health?

I would order sleep studies on anybody that I thought might have a sleep apnea. I can't say I reward them on everybody. But if people report non-restorative sleep in the morning, I wouldn't frequently order sleep study.

I did a sleep-study myself, because as I said to the pulmonologist at the time, I say, Jim, ordering sleep studies on patients, and I should see exactly what I'm asking them to do.

And I am really glad I do it, now I know exactly how it is to go through sleep studying. So I think it's useful to order them. Unfortunately, you can't go by the thinking that it's only people who are overweight who're going to have sleep apnea.

As you mentioned, sleepapnea is a problem and it gets worse with aging. as I would say, particularly to my male patients, that it's not us women who sag.

We all do with aging and all of those soft tissues in the back of your throat sag and they can block your airway when you're trying to sleep at night.

And so I've seen people who were very thin who have sleep apnea. Now you need to do that kind of diagnostic testing though before someone has the level of impairment that they're not going to be able to use a CPAP device.

Although for the people who are getting into these lifestyle interventions, generally weight loss. will do the trick for those whose sleep apnea is being caused by excessive weight.

For sleep hygiene, that's something we can always counsel people on. And even though we focus on hours of sleep, and research is suggesting that it isn't necessarily the hours sleep that are as important as regularity of the sleep.

So for ourselves, With a little bit of effort, we can follow a regular schedule. And that's one of the most important things you can do to improve your sleep health.

Then there's standard things like not exercising late at night. limiting alcohol or more and more we're saying virtually no alcohol is the best for our system.

Limiting your fluids in the evening concentrates your fluid early in day as we take water there because then you're not going to need to get up as much in a night to empty your bladder.

If you are having that problem. talk to your doctor about medications and get, you know, maybe get your bladder checked out because we can have changes in the bladder and there are treatments for that outside of medication.

So lots of different things, but I tell people to, most important is to focus on having a regular schedule. Yeah, getting to bed within this 30-minute window.

If your bedtime is 930, then you're in bed by 915 or 945 and really trying to make that window as small, as tight as possible. We see that people, their efficiency really shifts when they can commit to one bed bedtime.

It's almost like jet lag, right? If you are going to be at 830 one night and 1130 the next night, and 8 30 and then 2 AM, it's like a jetlag. Your brain's very confused.

I'm curious, after spending your career caring for patients with dementia and witnessing your mother's journey, do you know your own genetic risk? And how do think about communicating with your family about that risk or what you would want if you were ever diagnosed?

I cover that in my book because I think that's really important. As a culture, we don't generally like to talk about death. It was even uncomfortable for me to ask you that question.

Yeah, I know. I've had my kids say to me, Mom, not everybody's as comfortable talking about Death over the dinner table as you are. And I had been known at the Dinner Table to bring out a card game called Go Wish.

which is a fabulous card game produced by a nonprofit called the Coda Alliance, which was over in Berkeley. It's a deck of cards which put out things that one may or may not want if they're at the end of life or they are very close to the life.

And it's from having my family with me to being at home versus being in a hospital. And you sort through the cards into what is the most important to you, what's kind of in the middle and what to discard.

And. You have different sets of cards. So each person does that. and then you compare the Most Important Pile and it's a great conversation starter and extremely valuable.

so that's one thing that I have done in my home that, I recommend to people a lot. I then also am a big advocate for writing a dementia-specific directive.

When I would ask people, do you have your advanced health care directive in place? And the automatic answer is yes. And then I'd follow up with, Do you know what it specifies and where it is?

It's somewhere. So we need to update those. I actually put together a Dementia specific directive, combining several sources, but I made mine very, very short and sweet.

I was also influenced by an immersion experience at the Hokevac in the Netherlands, which is their dementia community, where moderate to severe dementia patients live and they're given free room around the community.

Their physical health improves. They approach life very differently. In the Netherlands, there were trip hazards everywhere. We were stunned, you know, fountains and, stairs and things like that.

And we said, we would point them out. The directors there would say, literally, things happen. So that's kind of what I have in my dementia specific direct, in that if I ever come down with a dementia where I'm no longer able to control my life and make my own decisions.

I don't want my lifelong prolonged. And for everything we do, for all of the strategies we implement, we might still end up in that sort of a state. So I've said very clearly to my family that if I am impaired and I I not living independently, I don't want any diagnostic medical tests or treatment that would prolong my living or my dying.

I want comfort care only. don't ever coax or cajole me to eat, even if there's risks with that. Joking or aspirating. The risks are aspiration.

Sleep, Daily Habits, and Practical Brain Health Strategies

But I've seen too many cases where people develop severe cognitive impairment and ended up in a non-ambulatory bed bound state with someone feeding them baiting them in bed and changing them and the family members would be standing around saying she never wanted this.

But she ended up there because we're all well-meaning and we think that we are helping someone by When they get a pneumonia and they have severe cognitive impairment, of course we want to get in chest x-ray.

Of course, we wanna start them on antibiotics. And our middle daughter, We have three daughters. Our middle is the first one for making healthcare decisions.

She's in that point because the entire family agrees she'd be the one to pull the plug. Every now and then she'll ask me, Mom, do you really mean that?

And I'm like, yes, sweetheart. I really do, because I saw my own mother go through that. It was terrible. A very close friend of mine lost her dad this past week, and they went through the process with physician-assisted end-of-life.

And he had had pancreatic cancer and was in a huge amount of pain. It was really this eye-opening journey they were on because it was so different from what most people choose.

And when he decided that he was ready to drink the drink that would end his life, he, you know, got this burst of

energy and he able to talk to his wife and talk the kids and the grandkids and they, decided who he wanted in the room.

And it was very intentional. His granddaughter was reading her book and his grandson whose five was doing a puzzle and it really normalized and created this kind of ceremony and they had you know, there were flowers of course and and all of these well wishes and It was a spiritual process.

But I think I saw the pictures after and there's pictures, right? there are pictures of this process and All these people were present for it and radically different from what I think most people experience was like this, you can choose something else.

And that might not be the right thing for everyone, of course, but dying in a hospital with all of the bells and whistles ringing and tubes. Yeah, that isn't the thing right for anyone either.

So to have this ability to intentionally choose is really kind of this radical notion. Well, we have to have a conversation first. Yes, you've got to talk about it.

We've gotta talk it, and in our society, We have write things down. So I've also seen families where they had the conversation, but they never wrote anything down, And then there are disagreements among family members about what the right thing to do.

And so for family member, making tough decisions is made easier if you write down what you want your family to do. And what you're talking about there, the death with dignity, they specifically excluded anybody with cognitive impairment.

They had quite a bit of difficulty in the state of California getting that law over the finish line in first place. There were too many people who felt that if they included anything with Cognitive Impairment, that was a slippery slope.

So I have known people that have gone to Switzerland. where you can either get in it, you take a potion or you get an injection. But it's interesting, and you have to be very careful in doing that, in that you to have a psychiatric evaluation over there, to determine that have the capacity to make that decision to take your life.

So if someone waits too late, then they may not have that option. This is a really heavy talk we're having here, Heather. It's hard and every situation is unique.

Yeah, and there's another episode for anybody who's interested in this. We have another with Keith where his wife decided to go to Switzerland and take that.

path through what that looks like. Because as you're mentioning logistically, it's a lot, you know, he was talking through, she was at a stage where he couldn't let her go into the women's restroom and the international airport by herself because she wouldn't be able to find her way back to him.

So she that far along. And so he had a female friend come with them. And then, yeah, even just the experience of international travel, she was much more disoriented.

And so the psychiatrist might not have allowed her to go through with it because of the disorientation just associated with jet lag. So they needed to have enough time for her, to get settled, regroup, get on the time zone, and then they went and met with them.

But she very, very clear that that was the option she wanted, right? And it's not for everyone. And I do think it is worth everyone knowing that it exists.

Yes, there is not a state in the US where the death with dignity is a possibility for someone with cognitive impairment. You have to have that six-month prognosis.

So understanding that and knowing it may need to be navigated, these timelines, they lengthen and shorten outside of our control. What I talk with families about is, and I talked with patients about this, is that as we age and we accumulate medical conditions, because that simply tends to be part of aging, life does become more difficult.

If we're at that point where life is difficult, we might look upon something like a pneumonia, as an opportunity to make a graceful exit.

Advance Care Planning, Dementia Directives, and End-of-Life Choices

So that's kind of how I phrase it. And for the people, not many people want to choose to take their life. That is uncommon. It's nice that it's out there.

I'll be surprised if we see it in the United States. But anyways, I look at it as there are other opportunities which do present themselves. and I've been with families where someone is really very impaired.

and they get something like a urinary tract infection, I will say, well, we could give antibiotics, or we call in hospice support here. And they may even be on hospices, and I'll say we can ask hospiced to focus on comfort care.

The family will be like, no, not ready for that yet. That's fine. Because oftentimes something else comes along, then the next time they are ready. It's a process.

It's a process and there's not one right decision. There's different dynamics in every family. Correct. So many considerations and understanding the options and that you're not trapped.

Sometimes you are. But that there are things to consider along this path. I think it's hopefully it gives people more agency. I'm curious the lessons that you've learned about aging and resilience and purpose and meaning from your patients over the years.

I've learnt a lot from the patients who I found were grateful for what they had. Basically looked at who concentrated on counting their blessings. I always learned a lot from those individuals because I think if we go through life and we look at the raw deals that we got, I that negative perspective has negative consequences on our health and well-being.

So, i always grow with individuals who I surround myself who share mutual positive energy. It's synergistic. And so I've grown from a lot of patients and their families, and I feel really good when they can understand what I'm trying to teach them about anasognosia, about planning, approaching decisions.

that helps me feel better grounded that I'm doing good work. That's beautiful. For someone who's facing a diagnosis or even high genetic risk and feeling overwhelmed about that, what would you most want them to know?

That there are strategies they can implement in their life right now to alter that trajectory. And with altering that projectory in the near future, I think we will have more medications that they can then add to those treatments.

So it is indeed getting brighter. In the fairly near future, I mean, is that gonna be three years, five years? I think that's quite realistic. That's a very hopeful message.

On this podcast, we talked about living well and not just living longer. And I thank you are certainly a model for that, not for your patients, for everyone that you touch.

With everything you've learned as a neurologist, a daughter, mother, an author, wife, and a caregiver, the many roles, What brings you the most joy in your life at this stage?

That's an interesting question because I can't say I would ever pin it on any one thing. I think it's almost like a field of flowers. So I mean, how can you pick out the one which is the prettiest?

And so I look at life like that. And I have to say though, at the stage in my life, grandkids are the biggest joy. That's fun. Good stuff. Dr. Madison, thank you for sharing both your professional expertise and your personal wisdom and journey with us today.

It's really a privilege. One of the things I appreciate most about your work is your ability to have hard conversations and bring both clarity and compassion to topics that feel so overwhelming and challenging.

Dementia affects memory, but it affects those relationships as well. Identity, the way that we think about the future, and even think of that graceful exit.

And so your insights are just this wonderful reminder that, we can't control everything, with understanding, with clear preparation, and with humanity.

I want people to know where they can find your book. And it's called Navigating Memory Loss, Essential Questions and Answers on Alzheimer's and Dementia.

So again, tell them where you can buy that, Dr. Madison. It's available anywhere online. Where books are sold. I mean, locally at Book Passages, but it's available online, it is available digitally.

Lessons on Aging, Purpose, and Where to Find Dr. Madisonu2019s Book

And I really enjoy the feedback I get on it. people appreciating the way it's organized in a question answer format. So it simple. And as you said, I tried to take the difficult questions over the years where I found that the answers were the most valuable and put them together into a short read that you can get through in an afternoon.

It's wonderful. What a fantastic guidebook and resource. Where can people find out more about you? Do you have a website? Are you still taking patients?

Kind of, no. Taking patients, yeah. I work with seniors at home, and as you mentioned earlier, I'm the medical director at Rhoda Goldman Plaza. So again, as we talked about, working in a group and a community helps you support yourself.

And so I am working with a wonderful group of people and I consult on the patients that are in that organization. Wonderful. But otherwise, I've really tried to dial down the wide exposure in my life.

I went through many years where too many people wanted a piece of me. Yeah. And that was too draining. Dr. Madison, it is an absolute pleasure to have you here.

Thank you so much for your time, your expertise and all of the work you do to care for our community. It's been a pleasure and until next time, for all of you out there, please share this if you have found it valuable with friends and family alike.

And until then, think well and age well. Thank you so much for listening to the Think Well, Age Well podcast. If you enjoyed today's conversation, please take a moment to subscribe, leave a review, and share this episode with someone you care about.

It's one of the best ways to help others discover tools and inspiration for aging well. To stay connected, get bonus resources and never miss an episode, head over to drheathersanderson.com and join my email list.

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