Introduction to Mary Ellenu2019s Story

That's how she wanted to live her life, and that's how she wanted to be remembered. She thrived in her life, she thrived during the protocol, and she thrived at her death.

She went in with such courage, such fortitude, such I know what's best. This is Doctor Talks. Real talk from real doctors on the issues that matter to you most.

Today's conversation is deeply personal and profoundly important. I'm joined today by Keith, whose beloved wife, Mary Ellen, made the incredibly difficult decision to end her life through medically assisted dying in Switzerland last year, following her journey with dementia.

This is not a light conversation, and it's one that we enter into with deep care and deep respect. Mary Ellen's story brings up strong emotions and for many, very firm beliefs.

You may agree or disagree with the choices that she made, but I invite you to listen today with an open and compassionate heart. I want to be clear from the start that I am not recommending or endorsing this path.

As someone deeply committed to improving cognitive health and helping people find hope even in the face of a dementia diagnosis, there are other options to start with first.

As we explore what it means to age well on this podcast, however, we must also be willing to have the hard conversations about what it means to die well, with dignity, autonomy, compassion.

These aren't just words, they are deeply personal values that shape how we live and how we face the end of life. There's a saying that I aim to live by, that you can't judge anyone until you've walked a mile in their shoes.

And that couldn't be more true here. Keith is sharing the story not to spark a debate, but to honor Mary Ellen's life and the deep, profound love that they shared.

And also to invite a fuller and more nuanced conversation about what choice, peace, and presence can look like even in our final days. In my clinical practice, for some, just knowing that they have Xanax in the medicine cabinet can bring a little bit of relief and comfort, even if they never use it.

And my hope today is that learning about the option that Mary Ellen took at the end of her life can bring a little bit of comfort to some of you. That a sense of agency can actually open us up to more joy, to more connection, and to living with the time that we do have rather than in fear or feeling out of control.

I thank you so much for joining us today in this very tender, brave, courageous space. I hope that you will find, as I did, that Keith's story about Mary Ellen, about their life together, and how she chose to end it is really much more about living a full life.

Thank you. Keith, thank you so much for joining me today. Thank you for inviting me. It's my pleasure to be here. I first want to just honor Mary Ellen.

Can you tell us about who she is? Mary Ellen was, is, and remains to be an extraordinary person. She lived an understated life. She did not toot her own horns.

She really lived by example from the moment I met her to our last words together. She was strong, committed, resourceful, and extremely dynamic. She was someone that I admired from the moment I met her and continue to admire her throughout our life together until the very, very end.

She lived life. I had the privilege of watching the eulogy that you did for her in the backyard celebration of her life. And there was a theme of intentionality that she really did things on purpose.

Can you give some examples of that? Oh, absolutely. We had a joke amongst ourselves and amongst all our friends, and it was just such an indicative of who Mary Ellen was.

And she would always say, safety is no accident. She was cautious. She was reserved. She was a bit timorous at times, and she always had this let's be careful.

Mary Ellenu2019s Intentional Life and Early Signs of Dementia

And so she was, we lived that way, she lived that way. And it was not the way I was living my life. So I adjusted to her life. And so in the eulogy, I brought that up.

And then I added many other flavors to her sayings and such as, oh, penmanship was no accident. She had beautiful, beautiful penmanship. She was a bookkeeper.

She was always careful about the things that she said. Her Picture taking was no accident. Whenever I would take pictures, she would have to review them all.

So a good picture is no accident. A healthy lifestyle is no accident. Friendship is no accident. Love is no accident. And of course, I added a good husband is no accident.

So she lived a life of intention. She planned her future. She was generous. She planned every aspect of her life. And what I learned early on is she was planning for her death as well.

Long before she showed signs of dementia, I could just see what she was reading, who she donated to groups such as Compassion and Choices. And I just thought she was just being generous.

I didn't realize that there was a backstory. I watched her practice things to improve cognitive health long before she needed to. She would eat with her non-dominant hand.

She would do games. She loved games. Just things like that. And she was always talking about, you know, this is good for your brain. So again, you mentioned intention.

And back then I just said, oh, it's just Mary being Mary Ellen. But as it proved to be that she had this thought that this could happen, of course, based on her family history, her grandmother, her uncle, her mother all died of dementia.

And she witnessed all of their deaths and knew that if this were to happen, that that was not how she wanted to finish her life. Did she serve as a caregiver for her family members?

She was a wonderful daughter, but no, she was never frontline caregiver. But pretty involved in watching their demise. Absolutely, and helping them through.

moving them from the family home to a smaller home, to assisted living, to memory care, to funeral preparation. She was a beautiful daughter. So she started to notice cognitive impairment.

Can you walk us through a little bit of the timeline up until when we met? Yes. As you know, a patient with dementia is aware of it before most others.

And there's the workarounds, the hiding, the disguising. And I'm really not quite sure how long that went on. But of course, I could see that there was a change.

We loved to play games, and she was so good at games. We'd have people over for games, card games, board

games, dominoes, and she was really good. And she was the one to beat.

And then all of a sudden I realized, wow, She didn't win that hand. And, oh well, you know, then you just kind of move on. And I guess that was, in retrospect, when I first thought, that's unusual.

She was still working. The pandemic started. She had to move to her, our home. for her office and so all of a sudden I'm a little more involved in her day-to-day work life and she would call me in and say oh I need a little help with this you know usually computer related and so I was sitting by her helping her with certain things that normally she would be able to achieve on her own and then other signs as I mentioned earlier penmanship she had this style that, as I had mentioned before, anyone would be so envious of this perfect, perfect penmanship.

And then it was just slowly going away to the point where It was scribbled block letters going almost vertical. And so we would talk about it and we would say, what's wrong here?

And then one summer, maybe four, five years ago, we just had a heart to heart and We both agreed, well, we have to explore this. But prior to that, we were having visitors, friends over, and they would corner me and say, you know, what's with Mary Ellen?

You know, she doesn't seem to be quite like on top of it, like she used to be. And she was in her 50s at this point? Yes, 55 is when she was officially diagnosed with Alzheimer's.

So, in discussion with a friend, she had said, I just read this book. It was by Dr. Dale Bredesen. And I shared that with Mary Ellen, and Mary Ellen says, well, let's read the book.

And this was before she's diagnosed. And we read it, and we're so hopeful. We go, wow, there's a way out. And so at that point, having we both read the book, I knew It was time to get professional help, so then we arranged to see a neurologist.

But she goes through the standard tests in the neurology office, you know, it takes about an hour. you know, a few days later, we get the diagnosis. And no surprise.

Mary was not surprised. I was not surprised. It was like, OK. But we have this other method. And in Mary's mind, she only had one option. And that was to end her life.

when she felt it was the right time. But now, but now we had another option. Here was this blueprint of what we can do. And it was a tremendous uplifting piece of information.

Mary was always in complete control of her life, and here she had the opportunity to take control of this. The neurologists, they just kind of say, I'm sorry, you know, you're kind of on your own.

Diagnosis, Hope, and the Bredesen Protocol

And we would have been on our own without this blueprint of maybe a way out. So we embraced it. We jumped into it. I knew I needed help to work within this complicated protocol.

And I knew I wanted a functional MD. And so I found one. And He was very much aware of the protocol. And so it was like, great, we have a team now. And from there, we found you.

Just searching there, you popped up and you offered an in-home program. We just signed up for it and we were so thrilled that our team was enlarged and we have this expertise to help us through this.

But Mary's very realistic. She said, okay, there's two approaches and she never lost sight that The protocol is where we're at, what we're going to work on, we're going to devote everything we can to it.

But don't forget, she would say, I don't want to go to memory care. I've seen it. I don't want to do it. So she referred

to it, as you have said, Xanax, she would say, I want this in my back pocket.

And every time we would move in that direction. It was, yeah, I want this in my back pocket. So I was working two paths. helping Mary with the protocol, and then knowing that this is a long shot.

Mary was diagnosed with a MOCA score of 11. We came to learn that that was low, and I witnessed one test that she took, and I could see that, well, there we are.

And for people listening, the MOCA score is the Montreal Cognitive Assessment. So this is the way that we put a number on how severe someone's cognitive decline is.

And 26 and above is normal. It's a score out of 30. And Mary Ellen had a score of 11. And what we see is just like in cancer treatment, right? When you're diagnosed at stage one and you can initiate treatment, you have much higher confidence.

When you're diagnosed at stage four, it's harder, it's more involved, it requires more resources, more time, more effort, and the odds aren't as good.

And so, really, part of the conversation here at ThinkWell EdgeWell is about getting early intervention, about measuring and testing of those first signs.

Now, we didn't have the research. We didn't know as much as we know now in 2020 and in 2015, right? So there's no fault for anyone who didn't get that help right out of the gate.

I think the narrative has been for so long, there's nothing you can do. The neurologist has a few medications and they don't help that much. And so for people now who are listening, please initiate treatment, start the Bredesen Protocol as early as you can.

If you know you have genetic risk, get started before you have symptoms by all means. But for Mary Ellen, unfortunately, by the time you were learning about the Bredesen Protocol, she was already in that relatively late-stage dementia.

My experience of her, even with a relatively low MOCA score, was that she was accomplished, that she was deeply intelligent, that she was in control, that she was going to decide her fate.

And that whatever she was doing in the protocol, with her diet, with exercise, with figuring out what the mold was coming from, with any of these pieces, she was all in.

She was intentional and she was fully present and she was all in. And she had this amazing cognitive reserve, is what we call it. She had clearly read a lot, experienced a lot, had been very sharp throughout her life.

And to see her change, I'm sure, was really hard on you. and her. Oh, clearly. It's a tragic story. And to witness it is very difficult. To live it for her was extremely difficult.

But I've always said she made it as easy on me as possible. Her compassion for me, her patience with me, was remarkable. And I'm trying to practice all of that too, compassion and patience and care and intention.

And she's doing the same thing. She realizes that it's just not hard on her. She was so committed. She was so honest with her condition. She never denied it.

She never fought it. She always remained positive. And I think the protocol allowed her to remain positive. The protocol was hope. And hope is such a wonderful thing.

Hope is how we grow. Hope is what we aspire to. We all wish, we all hope for an outcome. And some of those outcomes are possibly not achievable, even in our everyday life.

I hope I make the light. It just might not happen. Mary is, I hope that this is going to work. But we both knew it would be a miracle. We called it a Hail Mary.

And she never became lost in that this was going to work. However, she tackled the protocol like it was going to work. I watched her three times a day at the kitchen counter, counting out the countless pills, the tinctures, all of the steps for two years.

And she would shake a bottle and go, Keith, I think we're low on this. That was my job. I was the procurement agent. And then we'd go upstairs where we had our inventory of pills and look at them and the list and she'd be right over my shoulder and she would be so thankful that I was there ordering and counting and making sure she always had something.

But she was smart enough to shake the bottle. She'd never brought an empty bottle to me. So seeing her resolve, seeing her commitment made me Follow the same path.

The commitment to resolve. The hope. I don't really… buy into the notion of false hope. As I said, hope is hope. It is what gets us out of bed. And if you don't achieve that, well, that's not false hope.

You just didn't achieve it. And that was the gift of the protocol. The other gift of the protocol is it gave the two of us a focus. We're working on this together.

We're doing more than just walking around the block or doing more than just watching TV. What we're going to do is we're going to beat this. We so wanted to beat it because she deserved to live a full life.

She deserved to live the life that we had planned, that she had planned from the day she took a job right out of college. and worked at for 30 years. She was diagnosed the year she retired.

So there was a lot of dreams, a lot of plans that we just couldn't carry out. So that's why she deserved to win this one. And there's also, we both thought we're gonna show those neurologists.

They warned us, don't go down this path. We could both see that this was the right path. It deepened our commitment, it deepened our love, it deepened our goal achieving.

We wanted to continue this great life that we had together. So I want to just double click on this, this idea of hope and false hope versus false hopelessness, right?

To hear from the neurologist, there's nothing you can do. And then to hear through the Bredesen Protocol, through my work that, hey, there are these things you can do.

They're complex and there are supplements involved and behaviors involved, but you can do them together. And there is this kind of guiding light. Although there's not guaranteed outcomes, right?

So this is nuanced and I think that this is an important topic of conversation. Is it worth it to go down a path where there's hope, but not a guaranteed outcome?

And in Mary Ellen's case, we didn't achieve that outcome. Her MOCA score did not improve. Her condition did not get better. And it was heartbreaking for everyone who knew her.

And yet, it sounds to me like maybe what you're saying is there was still value in going down the path. Absolutely. As I've said before, we had something to do.

Mary couldn't read. She certainly couldn't drive. She was having difficulty walking. I mean, she was having difficulty dressing. She was having difficulty cooking.

Everything. But she was still able to perform the requirements of this protocol. Cognitive reserve is something that

you mentioned and that was so well exemplified in what she was able to do.

She was able to pull this complex system off and devote it to it and there's far more than the supplements. It was the diet. My goodness, she was so adamant about the diet.

And we ate that way. I was the cook. We ate well.

Caregiving, Planning, and the Decision for Switzerland

We ate often. and with enjoyment. And that was this keto diet. But Mary, as I mentioned earlier, she was always preparing for this inevitable disease, which proved to be inevitable.

And so her diet was easy to move towards the keto diet. Her exercise program was easy to take it up a notch. Her dental hygiene was easy to take it up a notch because it was just who she was.

We were lucky. We were not changing lifestyles 180 degrees, we were just pushing them a little farther down this protocol path. So it made it that much easier.

And if I slipped something onto her plate that maybe she was suspect of too many carbs or sugars, she'd say no. It's so funny when eventually we brought in more help.

The year Mary died, she had 60 hours of paid help a week. The year before, she had six hours. So the progression was occurring, but her alertness to the protocol was the last to go.

It was really the last to go. So one time, so I had a cook come in and she was providing wonderful keto meals and then Mary would say to me, she'd say, hey, Keith, you gotta pick up your game here.

You got to take a few of these recipes that I've been enjoying. So she always brought humor and I tried to reciprocate with humor. She knew she had a good life and she knew that it was going to come to an end and whether it was sooner or later.

So that's kind of how she went into this. My understanding of some of her decision, her decision was entirely hers and I want to get into that, but part of what I understand about how she made it was in large part because she didn't want you to be a caregiver to her.

And at some point, also, caregiving is not a one person job. This isn't a 40 hour a week job. It is a 24 hour a day, seven days a week, 365 days a year job when someone has severe Alzheimer's.

And you guys were starting to face that with these 60 hours a week, or excuse me, 60 hours of care that year. I'm curious about your experience as a caregiver.

Now, I've seen the deep love firsthand, how deeply you loved Mary Ellen. I could see that it was apparent, your respect for her, your admiration of her, the humor in your relationship, how healthy your dynamic was.

And The burden of caregiving even in the healthiest relationship is real. Can you speak to that? Oh, yes. My admiration for caregivers has no bounds. I never had to reach that level of care because Mary didn't want it.

She wasn't going to let it go that far to witness. There's such deterioration in a person's behavior. And then to be their caregiver, it is very difficult.

We were fortunate that I could bring help in. Mary was fortunate in that she didn't want me to be the primary full-time. She allowed me to leave for extended periods because she could still take care of herself.

But, you know, she needed help driving. She needed someone to entertain her by taking her, you know, to the park, things like that. So she always let me do what I had normally been able to do until I couldn't.

You know, the moment that she realized that she was going to have to reach into her back pocket is when I said to her, I go, Mary Ellen, if something happens to me, it's not being hit by a train, but I could just break a leg or end up in the hospital for a period of time.

You will have to go to memory care. And she would respond with, well, nothing's going to happen to you. And I go, well, I know, I know. But, and at this point, she was having more trouble with the protocol.

I could see she was confused with the Countless bottles in front of her, all of a sudden they all look the same, her ability to dress. I mean, she knew the progression was no longer in our control.

And that's why I brought it up. So a couple days later, she said, okay. I'm ready. And I knew what she meant when she said, I'm ready. And just to back up a bit, so we're deeply committed to the protocol, but she's also expressed throughout this journey that I don't want to go to memory care.

And so like the author Amy Bloom in the book In Love, It was tasked on me like it was tasked on Amy to figure it out. Okay, you're not going to memory care.

We know what that means. How do you do it? Amy's book is such a wonderful work that describes what she and her husband went through and what Mary Ellen and I went through.

It's kind of a how-to. But it's a how to follow your loved one's wishes, even when they're so difficult. It's how to forgive yourself. It's how to love your spouse no matter what.

It's how to, well, find a way out. Do you mind if I set the stage a little bit kind of legally? All right. So in the United States, it's illegal to help someone in their life.

And my mom will say, if you ever start to notice me going downhill, if I'm going to need memory care, take me out back and shoot me. You can't do that.

It's not an option, but it's an expressed wish to not need this sort of care, to not lose the capacity to care for yourself. And so, to your point, what does that mean?

What do you figure out? And you live in the state of Oregon, so you and Mary Ellen lived in Oregon, and physician-assisted suicide is an option there.

With a caveat, you have to have a six-month prognosis. And with dementia, with the dementia diagnosis, people can live for decades with dementia. So unlike cancer diagnoses or ALS, Lou Gehrig's disease, some of the other neurodegenerative diseases, where you end up with the six month prognosis, you can use the state, you know, the legal, it's legal in a handful of states.

I have a friend whose mother was diagnosed with ALS and they were able to use this option in the state of Hawaii. And there are a handful of states where this is an option.

There are no states in the US where physician assisted suicide or dying is available to those suffering with dementia. And so not only are you tasked with figuring this out, it's not available by law where you live.

And I think that there's a bigger conversation around this in terms of, you know, what is death with dignity? And there are people who procure things so that they can do this independently.

And is that dignity, right, to have to do this alone and hiding and fear? There's a wonderful conversation, another book that I want to offer as a resource to listeners is The Inevitable by Katie Engelhardt, which provides a conversation around less of a how-to manual, but really a conversation around how we want to end our lives, particularly when faced with a diagnosis like dementia.

So you ended up with this option in Switzerland at Pegasus, right? That's correct. And can you take us through how

you found that resource and then how you navigated that with Mary Ellen?

I was fortunate that I had dialogue with friends, limited friends, because for a long time Mary did not want it to be known that she had Alzheimer's. The two of us lived with this knowledge for well over a year.

before we presented it. But a dear friend who I could talk to, unbeknownst to Mary until she caught me. Oh, she laid into me. But a couple of days later, she apologized and said, I get it, Keith.

You know, this is your life too. You have to do what you need to do. What was her hesitation in sharing with other people? shame, embarrassment, lack of dignity.

And it was too bad because you can't keep this a secret. You display it all day long to anybody who's close. And that's what she was trying to protect.

But eventually she could see that. I think she said we will because of my urging, because of my need. Once she announced it, I could see it was a great relief.

It was a relief. Do you think that part of her wish is that she had maybe shared that with people earlier? No, I don't think so. It was kind of her timing.

Well, and I also think maybe the protocol is going to turn this around. This could be our secret case. I'm working on it. Maybe no one's going to know.

Everything needs to know. That could have been it. But then sharing it, it gave you community to share that burden with and then allowed her to drop some of the sort of hiding, right, to have more acceptance.

Absolutely. So, to get back to your question. How did I learn of the option? But before I say that, I want to back up just a step about when she announced it to our families.

And this was another… When she announced her diagnosis? Her diagnosis, yes. This was another feature of the protocol that has a dividend. She could bring this horrible news to the family and family members probably have heard this before with other friends or acquaintances or family.

So it's just this bombshell. But what Mary could say is, I know this is bad, but I'm following this path. There's this protocol. I'm really hopeful. And we're going to do it.

And I could just sense the relief that the family members got from that. It was like, oh, wow, I didn't know that. Way to go. Oh, you can fix it. And I could see it was an easier story to tell and it was a much easier story to hear.

So. I'm sure especially coming from someone like Mary Ellen, who was so, I think, convincing, but also had that ability, this innate ability to execute.

Absolutely. Yes. So that was an unknown feature or positive note about the protocol. But back to going to Switzerland and Mary Ellen and I referred to this option.

There was a protocol and then there was this other option, not going to memory care.

Applying to Pegasus and Preparing for the Trip

It was our code word for it was Switzerland. So whenever the topic came up, it was just Switzerland. She knew what that meant. So I was able to talked with a friend and I said, Mary's always said that she would not want to live with this disease.

And he went home and this started going on the internet and said to me, texted me and said, Hey, look at this. And that was Pegasus. So I had, an option, doing it at home, no way.

I hear all the time, take me out back. And when people say that to me, I go, I get it, you don't want to live your life that way, but what are you doing about it?

Who have you told? And it's almost flippant, you know, just take me out back. And I could see that, no, that's not really how this works, because I witnessed Mary living this out for maybe 20 years.

She was not just saying, take me out back. She was fully aware that this is a process. And during the process is what we're doing together as a couple.

estate trusts, wills, contact telling friends. We don't have any children to tell, but anything that she could do, telling lawyers, getting it written.

She didn't really know at the time how it was going to be done, but she just kept it moving along. I mean, I knew early on in our relationship that this was something that was needed to be explored.

So that's what I tell people who say, oh, just take me out back. I go, what are you doing about it? And if you're not doing anything, then your wishes might not be fulfilled, right?

If we want to age well and we want to die well, then having those hard conversations and seeing them through is important. Otherwise, there may be a point where you're not the one in control, where you're not able to express your wishes in a way that's legally binding anymore.

Other people are making decisions on your behalf and there's no guarantee they're going to be making the ones that you want unless you've really put this into action.

You know, I noticed something interesting in what you shared around how your friend was the one who found Pegasus, and I'm curious about that dynamic you've pointed to of essentially assisting her, right?

Not with the last step, with ending her life, but with figuring out what those steps were going to be, what you would have to do, and that must be a really, really impossible situation to be in.

And so having a friend be the one to find the resource almost makes it a little bit easier. Oh, absolutely. Absolutely. It was a godsend. I mean, this was a compassionate, a dignified and legal way to do it.

This was the answer to just take me out back. No one's going to take you out back. And so here it was. And in Amy Bloom's book, she was exploring all kinds of options, all dead ends, until she learned Dignitas.

And so like her, I said, oh, here is a path. You have to be ahead of it. This is not something you can wait for too long with. So you're right, it was extremely difficult to go down that path.

And that was up to me to figure it out. Mary's on the protocol and I'm on the protocol as well, but I'm also going down this path. So I find Pegasus and then I apply.

Before that, I told Mary, look, Mary, this is an option. And again, okay, I want it in my back pocket. So she gave me permission to go down that path.

So when it was necessary to bring Mary in on that path, I was reluctant because I didn't want to express doubt in the protocol. She was working so hard, so dedicated to it.

I didn't want to do anything to undermine it, but I was forced to pursue this other path. But whenever I brought it up, she never rejected it. She never doubted my commitment.

She could say, okay, take it the next step. I want it in my back pocket. So I did. And You have to apply. I applied for her. I answered her questions, but I let her read it.

I had to, to not, well, then it's just like I'm, she's losing control. And now I'm in control. So that went on for a year, I bet, that we're working our way down two paths.

And this is really, when you talk about the application, there's a criteria that has to be met. Just like in the state of Oregon, you have to have a six-month prognosis to be within that criteria.

And in Switzerland, they have a different criteria. But this is a threading of the needle of sorts because, particularly with dementia, you need to be able to be the one as the person going through this process, You need to be the one who is making the decision that needs to be clear to multiple medical professionals.

And also you need to be correct me if I'm wrong, but can you describe the process? You need to be able to administer it yourself, drink the fluid. You cannot be dependent on someone else to physically help you through the process or to make the decision for you.

That's absolutely true. Each step, the patient has to be fully aware and the ability to communicate that to the doctors, the psychiatrists who evaluate.

And there's multiple times that that occurs. So once Mary said, all right, we're going down this path, I then would take the next step and Pegasus was attentive, they were responsive, you know, they were there.

Maybe not as quickly as you might want, maybe, because of course you just want to make sure that this is all moving smoothly and quickly, but it doesn't.

There's no fault there. It's complicated. And maybe by design, right? You don't want something like that to go too quickly because it's irreversible. This is the most final of final decisions.

So we started that psychiatric evaluation on Zoom. Mary Ellen and I would be side by side in front of our iPad and the psychiatrist would start asking questions, you know, like, what's the today's date?

How old are you? And these are questions that my new Mary might not be able to answer correctly. And I'd be sitting inside her wanting to give her the answer.

And that's a very unusual position to be in. I mean, I want her to get this right so that she could die. It was very Well, unusual. I'm your cheerleader here, but what am I cheering for?

All I could say is I'm cheering for you. I'm cheering for what you want as hard as this is for me. But Mary really didn't need my help. Maybe she didn't know the date.

Maybe she didn't know her own birth date. But she knew what she wanted. She knew what it was going to take to convince a psychiatrist. That, again, cognitive reserve.

She pulled it out. So this process went on for, I mean, I don't know, a month or two months. There's a lot of paperwork. I had to provide birth certificates for both of us, marriage certificates for both of us.

It's funny, I would, oh my God, I have to have these certificates. I would contact the different states. I would get them. It'd take weeks. And you have to send all this to Switzerland.

And then they expire. And we were postponing this as long as we could. Okay, it's all there. Now they would say, just pick a date. That was up to us. Pick a date.

And it wasn't something that we were looking forward to do. Because Mary, still Mary. She's still walking. She's still entertaining friends. She's still Mary Ellen.

And they're cautioning us. Don't wait too long. But this time elapsed to where the certificates were no longer valid because they had been issued a few months before.

So I had to do it all over again. And now I'm getting nervous because are we running out of time? So I scramble again and get them off to them. And just as a side note, when Mary's gone.

I'm back home, empty house, going through our papers, her stuff. I'd never gone through her stuff before. I look in her file cabinet and there's all those certificates.

Under B, birth certificates. Under M, marriage certificates. She had them all there. this. Why didn't I ask her? She's just that way. Of course she did.

Of course she did. Originals. And I was tearing my hair out trying to get all this stuff done. So you picked a date eventually in April of 2024. April 27th, yes.

Well, I might have said April 24th and they said, I'm sorry, that's not going to work. How's April 27th? We said, okay. So it was in motion. I learned that These organizations in Switzerland do not see an awful lot of Alzheimer's patients.

They do see some, but not the majority. It's a minority because of the difficulty, because of the timing. I suppose some families wait too long and the patient is unable to defend themselves to express their desire.

Mary was able to express her desire to the very end. And those last questions are asked at the very end. And if she faltered, they would say, sorry, or goodbye.

And you'd walk together, you would walk out the door. So they're very, adamant about this being the patient's decision. We could have gone the week after the diagnosis.

These organizations, their requirements are a lot different than ours. Medical aid in dying is, as you've mentioned, you're on your deathbed already. There is absolutely no hope.

And I don't really feel that that is a dignified way to go. Plus, they're required to do every step on their own. It's archaic. And especially when you witness another system, which is so compassionate.

They're so good at it. Loving, compassionate, lighthearted if you need to be lighthearted. They recognize the gravitas of this decision and greet you with that in mind.

So can you share what Switzerland was like when you got there? And Sarah came with you, a friend of yours also accompanied you. Mary Ellen and I, we traveled a lot.

We love to travel, we love, and that was our plan to do a lot more.

Switzerland, the Final Day, and Mary Ellenu2019s Passing

But traveling with an Alzheimer's patient, it's not easy. We did it in the best style we possibly could. We moved to the front of the airplane. We relied on limousines.

We relied on the finest hotel. And Amy Bloom talks about doing this as well. Absolutely. And it was Mary's money, and she knew it was her money. And she said, hey, this is my money.

Let's go big. And so it was our last trip together. And it just, we loved Switzerland. We'd been there before. And One thing that I would recommend is to do that to the best of your ability.

But if you can't, that back of the plane is okay. This is an expensive process, regardless of where you sit on the plane. It's not available to everyone.

No, it certainly isn't. And it is expensive. But in the scheme of things, Memory care is also extremely expensive. Tell us how expensive that is. Memory care starts in many places at $6,000 to $8,000 and goes up to $20,000 a month.

This is something I've had patients tell me and it breaks my heart every time I hear it, but I'll die when the money runs out. And I think it's another way of saying, take me out back.

But there's a very real financial component to this. Flying to Switzerland and then registering and using the services of Dignitas or Pegasus is not free.

No, it's not. But financially, it's a bargain. Two to four months of memory care. Two to four months of memory care. And Mary was so clear, I worked too hard.

I spent an entire career from college to retirement in the public health system. And by God, I'm not going to just let this money go. And she said, Keith, I don't want your money to go.

I'd rather you see it and live your life the way we have lived our lives. So the financial aspect is key to this, and it's easy to see. So you guys did it right though.

You had the ability to go and stay in the nicest hotels, be chauffeured around, sleep on the plane, and really enjoy the time that you had together. Yes, it's a funny word to use, enjoy, but we did the best we can and we decided to go over a couple days early because we love to travel.

We got there and I could see, I go, wow, maybe this is too difficult. Maybe we shouldn't have expanded the time together. Because it was so difficult moving Mary from just place to place.

It took two of us to make this happen. But then, oh, the sun came out and we took a train ride to Lucerne, a beautiful, city in Switzerland and we could see the mountains.

And that was reliving what we've enjoyed so much. And that was really a wonderful day and we all enjoyed it. And Mary Ellen was as Mary Ellen as can be.

She was wonderful. She was curious. She was attentive. And so it was like, oh, it was a good idea to go early. We had this throwback to where it once was.

The reason I suggest, if you can, to have someone accompany you is just the logistics. A man traveling with a female, with Alzheimer's. I mean, going through the airport, going to the restroom.

I mean, that's not… common. And I had to at that point, she needed an escort wherever she went. So having a companion, a dear friend was invaluable.

And then once you're there, you know, the stress on me having someone to look at the time schedules at the airports, at the trains, or make a reservation at a restaurant, or just to get us home or get us back to the hotel.

It's priceless. I have to imagine this is one of the more stressful events of your life, right? And by far, probably one of the most emotional. By far.

And so to have somebody there to double check that the arrangements are made, that you know where you're going, you know what time you need to be there, I can imagine is just priceless.

priceless. It's hard to imagine doing it alone. The other thing that I learned and our friend suggested is start with a wheelchair at the airport. In this time of reduced air airplane services, they're still really good about those requiring a wheelchair.

And of course, when I suggested it to Mary, it was, no, I don't need that. Well, okay. I said, but it was there. Once we landed in San Francisco, they were there with the chair.

And Mary looked at it and goes, if you insist. And wow, from there all the way, it was first class treatment, regardless of what class you were in the airplane.

It was a remarkable idea. And I didn't see it because I could, Mary, you know, she could walk, but front of the line. I mean, they stopped everybody from getting on the buses, everybody from getting on the airplane in order to get Mary Ellen through.

It was remarkable. So there's a simple free tip that we rely on. Traveling with some with Alzheimer's, this comes up often in my clinical practice and with coaching participants as well.

It's this rub between wanting to have these experiences, these shared experiences together and feeling like maybe we don't have that many more left. And yet, traveling with dementia, I mean, people with dementia can be disoriented day to day in very familiar places, let alone in a totally foreign environment with jet lag across time zones.

Traveling, being on a plane, the oxygen is lower, right? So you can feel the ramifications of all of this. You're exposed to germs that you might not be otherwise, and you could fall ill.

This can be a big stressor for people who have full cognitive capacity, let alone someone without. And so this rub between, you know, do we take that one last trip?

Do we have these last experiences? Do you have any advice? It sounds like this is a great takeaway, right? Just get the wheelchair service. Check the disabilities box and take that service so that it can make it a little less stressful, a little bit easier.

Do you have any other bits of advice for traveling with someone with dementia? It's just what every caretaker caregiver knows. Patience, slow it down.

Don't argue, don't correct. Mary and I think all patients who have the cognitive ability to take this trip is aware of what's going on. And they, at least in Mary's case, was willing, patient, knowing that any stress on her was worth it because of the goal we are achieving.

Any means was worth the end. Are you open to sharing about that last day, April 27th? Yes, for sure. It's such a powerful emotional day. We're there for four days and everybody knows why they're there.

And here we're trying to have a normal life, eating well, walking, window shopping, going to cafes. We could do all that and enjoy all that, but there's this end zone that you're so aware of and it's surreal.

It's tragic. It's tragic to Shakespearean proportion. There is no good outcome here. We know what we're doing. And as you get closer and closer to that, It just gets harder and harder.

You sort of have this vision of Switzerland, and it's a true vision. It's a beautiful place. It's picturesque. It's Heidiville. And we all have that concept of this country.

So you expect that this clinic on the hill It's going to be so inviting. Well, it's not really how it is. It's not a practice freely embraced even in Switzerland.

They're not in downtown. They're not next to the hospital. They're kind of off the beaten path. And as you drive in, you're being escorted by the professionals from Pegasus.

And you go, oh, this is it? It looks like a cross between an auto yard and a strip mall. It's like, whoa. And they explain it to you. I go, hey, why? We're not welcome in places around town.

We don't want to be known as the capital of this. So that's like, okay, get used to it. But once you're in, you've forgotten that, even though it's not a hospital-like setting or a salon.

It's just they've made the best of what they're given. So… They give Mary another round of tests. Mary passes. And they just say, take your time. And we sit around a table.

We're telling stories. We're telling where we're from. It's congenial. And then they show us the room. And it's a nice hospital-like setting. lay Mary down upright in a bed and they show her the mechanism.

And for some, it's just, you just flip a, you turn a valve and then the lethal dose enters the system. Mary didn't quite have that ability. But they have another one where all you have to do is just push a stick and that drops the drip.

But before that, it's just take your time. Everybody leaves the room except Mary, Ellen, and I. And that's where we have our last talk. And I said, hey, Mary, I mean, I can take care of you.

Let's get out of here. I can take care of you. And she says to me, No, Keith, it's my turn to take care of you. We did a lot of crying. And then we would find things to laugh about, and then we'd cry.

And I said, okay. Okay, I get it, I get it. And I got it. I mean, this wasn't. It was a, it was my Hail Mary. Let's do something else. So I said, okay, are you ready?

She says, I'm ready. And then the people from Pegasus and our dear friend come, come in and you know, it's goodbye. And are you ready? And she bumps the knot.

And just like they said, it's, she just. It looked like she just fell asleep, painless, quick, compassionate. But I knew she wasn't just falling asleep.

And to me, it was very, very difficult. I couldn't stay by her side. I mean, it was so quick and she was gone. And I witnessed Something had to… I never…

Aftermath, Family Reactions, and Keithu2019s Reflections

I never imagined that I could witness. I kinda… Freed out. I kinda had… I had to leave. I couldn't… I… I didn't see sleep, I saw death. It was, it was terror.

I saw it felt like terror. When I witnessed, I left the room. Eventually I could come back into the room. She did it. She got her wish. I was there to honor her wish.

She was such a strong, confident, accomplished, fun person. That's how she wanted to live her life, and that's how she wanted to be remembered. She thrived in her life, she thrived during the protocol, and she thrived at her death.

She went in with such courage, such fortitude, such I know what's best. This is by far what's best for Mary Ellen, what's best for her, and she knew what was best for me.

Even though at the time, I go, no, this is not what's best for me. I can care for you. I don't want to. If you're alive, I don't miss you. When you're gone, I miss you.

One of the things that she said on her bed was, Keith, I don't worry about you. She knew. that I would survive. She knew that I would thrive, and I would thrive better with this outcome than if she'd lived this out the conventional way.

She had another wish, I understand, which was to share this story. And that's part of why you're here today. It's true, referring back to Amy Bloom's book, the first page of her book.

And the only thing on that page is a quote from her husband, Brian. I want you to write about this. And when I read that page, I just knew But that's what I knew Mary Ellen wanted, that.

And I knew this book was going to tell my story. And I'm, I'm glad I read it afterwards. I didn't need to read it first. We had our method. I didn't have to do all the homework that Amy did.

I knew what we were going to do. So I read the book afterwards. However, I did listen to her podcast before we

both did. And when I read that, I knew that that's what Mary wanted.

And you're right. That's why I'm here. And I'm so thankful that you wanted this story told. I avoided you. until your office reached out to me. And here I am.

And Mary would love the idea that you and I are here. When we were going through your programs, Mary, Elle, and I would say, God, isn't she cool? Wouldn't it be great if we could be her friend?

That's how we thought of you. And here I am. I'm your friend. It's such a privilege. You know, I felt the same way. I relate to Mary a lot. I felt like I understood her.

And I thought, I want to grow up to be like you guys. And it's hard to lose her. I think that one of the things that really struck me was that you guys didn't feel like you could talk to me about this process.

And that was part of the goal in having you here today is to start to have these really hard conversations and make it a little bit more okay. to discuss these things because they feel impossible when you're in it.

I think when you can have a team and community around you, it makes the really, really hard stuff a little more bearable. Yeah, yeah. Mary didn't want to be an advocate of this, she just wanted people to know that there's a real choice.

Medical aid in dying as practice in 15 or 16 states is not an option. She wanted people just to know, to have a choice, to have it in their back pocket.

And that was all she wanted, just to know. And I didn't know how to do that. In Mary's obituary, it's mentioned. We had professional help with the obituary.

And as a journalist, the writer put the who, what, where, when, and how at the first paragraph. And we go, you know, she went to Switzerland and we go, No, that's not, that's not the lead.

And the journalist says, oh, you want to bury the lead? I go, yes, pardon the pun. We want to bury the lead, but we don't, we want it mentioned. So it was put at the very back of the obituary.

We wanted a, we wanted Mary's life to be told, not her death, that that will come later. And so Mary was clear. She wanted that. in her obituary. It's not like the phone rang off the hook, but for me to tell me more, tell me more, it didn't happen.

Friends, family were, you know, so supportive. And it's, I want to go that way, they would say. So, oh gosh, and even those who didn't know her very well were just in awe that This is how she would want to do it and the courage that it would take and the unselfishness that it would require.

You mentioned to me that you have family members who are deeply religious and that there was a little bit of tension in that. I wouldn't necessarily say tension hurt.

And Mary knew that it was going to affect some dear people in our lives, and she really felt. bad about that. She didn't want to cause this upheaval in their lives.

Here was somebody they respected and loved and to pull this was so contrary to their beliefs. But over time I've seen their Oh, their thoughts soften and their respect for Mary grow.

I mean, their beliefs are the same and we honor those or we honor those beliefs. But it was gratifying to see that they understood. They understood that this was her choice and they also understood what it meant for me that I didn't have to live this life of Alzheimer's for the next 10 to 15 years.

So that too softened their firmly held beliefs and came to accept it and to forgive. I've heard them say, I forgive. And

that was a missing piece for me to hear that they forgave.

Forgiving Mary is forgiving me. And this too is an unfinished piece that we're finishing, having this discussion with you. Now what's next for you, Keith?

Oh, Mary's right. She didn't have to worry about me. I have a very full, exciting, healthy life. But I carry this level of sadness with me. You know, it's kind of like this.

bird on my shoulder or you see two birds that fly in synchronicity or symbiotic relationship. I have a symbiotic relationship with suffer, with sorrow.

She's just right there. I'm just going through life like this and I just got this little piece, sometimes it's bigger, sometimes it's smaller, of this sorrow, this missing But along with that sorrow and sadness, there's this deep respect of this woman who showed such courage and Bless me with her life and bless me with her love.

So that is, I'm forever grateful for that. You know, I'm just trying to make my life look as good as it's always looked. Let's just make it look good.

Live my life like we had been living with it. Looks good. Maybe deep down good will catch up to me. I have to, because I have to honor Mary. If I fall off the deep end, you know, that is…

Then what was it for? What was it exactly? What was it for? I owe it to her to live the life that we could not live together, but I can live. I'm curious, I'm a parent, as you know.

Do you think that you might have navigated this differently if you had had children? Absolutely, it would have been different. And I think about it all the time.

What if a child said no? Well, Mary had the strength to say, I'm sorry. It would be different. I mean, it could also been such a wonderful thing that a family, as many families will do, would do this together.

You know, to have the support of children during this would have been a wonderful help. But then again, you know, if there was not the support, it would have just been that much harder.

It could have so alienated a family. But, yeah. Mary Ellen and I often said, boy, we're glad we don't have kids. This would not make it. I got a joke for you.

So there's this couple standing in front of two dear friends and they say, you know, after a lot of thought, we've decided not to have kids. And we're going to tell the kids tonight.

That was a joke that Mary Ellen and I loved. There's one more that you told during the eulogy, one of Mary's favorites, about how handy you were. Oh yeah.

You know, the eulogy is tough for a spouse. really tough because you don't know if you can pull it off because you cry so much. So much. I cried so much.

I cried so much that I miss it. The catharsis. It's such a reminder. It's such a lovely reminder of who you miss and how strongly you miss them. But for some reason, it changes over time.

So I miss the crying. But I can cry. It's just not as often. So in a eulogy, Now you're just asking for it. It's not the time you want to cry in front of a crowd.

So I didn't even know if I was going to do it. I had a dear friend. I handed him the eulogy. I go, if I can't do this, would you please read it? But I guess I like a crowd.

And I go, I can do it. But I realized that I gotta make sure I can get through this so I would add humor to it. Both

Mary Ellen and I loved each other's sense of humor.

Me loving hers more than she loved mine. So the story I told to the crowd was that I like pretending that I'm a handyman because my friends are handymen.

They do it themselves. I kind of go, well, if you're going to be a handyman, you got to do it yourself. So I would tackle the projects, do the best I can, sometimes with success, sometimes without success.

And Mary has got a kick at that, that I would try. And she really got a kick when I was successful, and she felt sorry for me when I wasn't. And so to kind of ease whatever ego blow I had when I couldn't do it, she said, Keith, you know, I love the idea that you can fix things and want to fix things.

And I really love that cute little carpenter belt you walk around in. But what really turns me on is when you call the plumber. It was so sweet, you know, so gratified.

That's what really she really likes. Well, she is remembered. I hope that she is honored by our conversation today. Is there anything else that you'd like to share about Mary Ellen or about your experience?

No, I think we covered a lot and I appreciate the opportunity and I appreciate your ability to get me to talk about something that's really hard to do.

I don't think anyone else could have done it quite as well as you did. Thank you. Thank you for your courage. Thank you for showing up here. You've flown all the way down to San Diego to share this story.

And I feel confident. I feel certain that there will be many people out there who will get some peace, that we will reduce some suffering for people out there who are navigating something similar to your and Mary's story.

Thank you. Thank you. Thank you for being here to share it with us, Keith. You bet. Mary thanks us too. Thank you for tuning in to Doctor Talks. We hope today's episode has enlightened and inspired you on your path to optimal health.

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