Mary Ellen’s Legacy: Courage, Love, and the Right to Choose Transcript

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Introduction to Mary Ellenu2019s Story

That's how she wanted to live her life, and that's why she wants to be remembered. She thrived in her own life. During the protocol. And she thrives at her death.

She went in with such courage, such fortitude, Such I know what's best. 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 is means die well with dignity, autonomy, compassion.

These aren't just words, they are deeply personal values that shape how we live and how 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.

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 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.

Who Mary Ellen Was

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 so you much joining me today. Thanks for inviting me. It's my pleasure to be here. First, I want to just honor MaryEllen. 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 indicative of who Mary Ellen was and she would always say safety is no accident.

She was cautious, she was reserved, and a bit timorous at times and always had this let's be careful. And so she was, we lived that way, she lived 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 um oh penmanship was no accident she had beautiful beautiful penman ship she was a bookkeeper she 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 accidentally. A healthy lifestyle is not accident, friendship is a no-accident, love is an accident and of course I added, a husband is So she lived a life of intention.

She planned her future. she was generous. He planned every aspect of her life. And what I learned early on is she planning for her death as well. Long before she showed signs of dementia.

I could just see what she is 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.

That 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.

Early Signs of Dementia and Diagnosis

But as it proved to be that she had this thought that this could happen, of course, based on her family history, her grandmother, uncle, 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 a 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, memory care, 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, and the disguising. 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. She would have people over for games, card games board games dominoes. And she really good. and She was the one to beat.

Then all of a sudden I realized, She didn't win that hand. And, oh well, you know, then you just kind of move on. 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 our home for her office. 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,

usually computer related.

And so I was sitting by her helping her with certain things that normally she wouldn't be able to achieve on her own. 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'd 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?

She doesn't seem to be quite on top of it like she used to. And she was in her 50s at this point? Yes, 55 is when she 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 says, well, let's read the book.

And this is before she's diagnosed and we read it and, and were so hopeful. We go, wow, there's a way out. So at that point, having we both read 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. It takes about an hour. A few days later, we get the diagnosis.

and no surprise. Mary was not surprised. I was no surprised, it was like okay. But we have this other method and in Mary's mind she only had one option and that was to end her life 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 is a tremendous, uplifting piece of information. Mary was always in complete control of her life.

And here she had the opportunity to take control this. The neurologists, they just kind of say, I'm sorry. You know, you're kind on your own. 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 know I wanted a functional MD. So I found one.

He was very much aware of the protocol. And so it was like, great, we have a team now. 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 that we have this expertise to help us through this. But Mary is very realistic.

She said, okay, there's two approaches. And she never lost sight that the protocol is where we're at, what we are going to work on, we going devote everything we can to it.

But don't forget, she would say, I don' want to go to memory care. I've seen 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, this is in the back of my 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. I witnessed one test that she took and I could see that, wow, there we are.

Hope Through the Bredesen Protocol

And for people listening, the MOCA score is the Montreal Cognitive Assessment. So this is a 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 square of 11. 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, more involved, requires more resources, time, effort, and the odds aren't as good. 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' know as much as we know now in 2020 and in 2015, right? So there's no fault for anyone who didn get that help right out of the gate.

I think the narrative has been for so long, there is 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 could. If you know you have genetic risk, get started before you had 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 accomplished, that was deeply intelligent, in control, and was going to decide her fate.

and that whatever she was doing in the protocol with her diet, with exercise, figuring out what the mold was coming from, she had this amazing cognitive reserve.

read a lot, experienced a lots, 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 honest with her condition. She never denied it, never fought it. And I think the protocol allowed her to remain positive.

The protocol was hope. 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. Marius, I hoped 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. I watched her three times a day at the kitchen counter, counting out the countless pills that 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. 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, seen 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 and is what gets us out of bed. And if you don't achieve that, well, that's not false. Hope, you just didn't achieved it. That was the gift of the protocol.

The other gift to the protocols, 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 do we're more doing than watching TV.

What we are going to do is we kind of are gonna 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 plan 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 lots of plans that just couldn't carry out. That's why she deserves 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 deepens our love, deepen 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 you do, they're complex.

There are supplements involved and behaviors involved, but you could 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 an important topic of conversation. Is it worth it to go down a path where there is 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 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's having difficultly dressing. she was have difficulty cooking, everything.

But she were 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 to pull this complex system off and devoted to it. And there's far more than the supplements. It was the diet. My goodness, she so adamant about the diets.

We ate that way. I was a cook. Well, 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.

It proved to be inevitable. diet was, you know, easy to move towards the keto diet. Her exercise program was easy and take it up a notch. her dental hygiene was EASY to take up and 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.

Balancing Treatment and Future Planning

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, was occurring, but her alertness to the protocol was the last to go.

It was really the least to do. 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's sooner or later.

That's kind of how she went into this. My understanding of some of her decision, her decisions 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-hours a day, 7 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 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. It was apparent, your respect for her, admiration of her. The humor in your relationship, how healthy your dynamic was.

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 the primary full-time. She allowed me leave for extended periods because she could still take care of herself.

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

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 any period of time, you will have go to memory care.

and she would respond with, well, nothing's going to happen to you. And I go, Well, I know, but, and at this point, she was having more trouble with the protocol.

I could see she 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 am ready, 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. Like the author Amy Bloom in the book In Love, It was tasked on me like it was task 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 though.

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 you forgive yourself. How to love your spouse no matter what.

Find a way out. Do you mind if I set the stage a little bit legally? In the United States, it's illegal to help someone in their life. 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 there is physician assisted suicide as an option there.

With a caveat, you have to have a six month prognosis. And with dementia, with a 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, 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 hand full of States where this is an option.

There are no States in U. S. 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.

Is that dignity, right? To have to do it 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 conversion around how we want 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 your 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, and 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. What was her hesitation in sharing with other people? Shame, embarrassment, lack of dignity.

This is a, And it was too bad because you can't keep this a secret.

Choosing Switzerland and Pegasus

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 my need.

Once she announced it, I could say it's 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 kind of was 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 is gonna 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 announce her diagnosis? Her diagnosis, yes. This is 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 am 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, you know, or you can fix it. And I can see it was an easier story to tell and it's a much easier 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, 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 into memory care. It was our code word for it was Switzerland. So whenever the topic came up, it just Switzerland, she knew what that meant.

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 he 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 flip it. You know, just take out me back and I could see that, 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 wanna 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 your not able to express your wish in a way that's legally binding anymore.

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

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 would you have to do, and that must be a really, really impossible situation to 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. In Amy Bloom's book, she was exploring all kinds of options, all dead ends, until she learned Dignitas.

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 it was up to me to figure it out. Mary's on the protocol and I'm on protocol as well, but I am 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. 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.

She's losing control, and now I'm in control. So that went on for a year, 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 view within that criteria. And in Switzerland, they have different criteria, but this threading of the needle of sorts, because particularly with dementia, You need to able to the one as the person going through this process, You need to be the one who is making the decision that needs to clear to multiple medical professionals.

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

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

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 am cheering you. 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 did'nt know her own birth date.

Traveling for the Final Trip

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, a month or two months.

There's a lot of paperwork. I had to provide birth certificates for both of us, marriage certificates, for us both. It's funny, I have to have these certificates.

I would contact the different states. They take weeks. You have send all this to Switzerland and then they expire. And we were postponing this as long as we could.

OK, it's all there. Now they would say, just pick a date. That was up to us. Pick a day. And it wasn't something that we we're looking forward to do. Because Mary, still Mary.

She's still walking. she's Still entertaining friends. It's she 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. 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 staff before. And 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 did I ask her? She's just that way. 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 twenty-seventh? 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 the timing. I suppose some families wait too long. the patient is unable to defend themselves, to express their desire.

Mary was able to expression her desire to the very end. And those last questions are asked at the end, and if she faltered, they would say, sorry, or goodbye, 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 and 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 light-hearted. Um, 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, and that was our plan to do a But traveling with an Alzheimer's patient, it's not easy. We did it in the best style we possibly could.

Um, we moved to the front of the airplane. And Amy Bloom talks about doing this as well. Absolutely. And it was Mary's money and she knew it's her money.

She said, hey, this is my money, let's go big. It was our last trip together and we loved Switzerland. We'd been there before. 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 plain. It's not available to everyone.

No, it certainly isn't. And it is expensive. In the scheme of things, Memory care is also extremely expensive. Tell us how expensive that is. Memory Care starts in many places at six to eight thousand dollars and goes up to twenty thousand 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, right?

And so the financial, 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 is. But financially, It's, a bargain. You know, 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, but 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 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.

That was really a wonderful day, we all enjoyed it. Mary Ellen was as Mary-Ellen as can be. She was wonderful, she was curious, was attentive. It was a good idea to go early.

We had this throwback to where it once was.

The Last Day and Mary Ellenu2019s Death

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, 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 trains, or make a reservation at a restaurant, just to get us home or get 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 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 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, but it wasn't there. Once we landed in San Francisco, and 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. I didn't see it because Mary, she could walk, but front of the line. stopped everybody from getting on the buses, everybody getting from 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? You have any advice? It sounds like this is a great takeaway, right? Just get the wheelchair service, check the disabilities box and take the service so that it can make it a little less stressful, a bit easier.

Do you have 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 the end. Are you open to sharing about that last day, April 27th? Yes, for sure. powerful emotional day. You know, we're there for four days and we all, everybody knows why they're, why, they are there.

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

It's tragic. Its 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 know, you sort of have this vision of Switzerland, and it's a true vision. It's beautiful place, it is picturesque. 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 is not a practice freely embraced even in Switzerland. They are not in downtown. There not next to the hospital. Their 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. They explain it to you. I go 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.

Um, so… They give Mary another round of tests. Mary passes. And they just say, you know, take your time. We sit around a table, we're telling stories, telling where we are from, it's congenial.

Then they show us the room. 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, 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, you know, we have our, our last talk. And I said, hey, Mary, I mean, i can take care of you.

You know? Let's, let's get out of here. I can care for 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 would cry. I said, okay. Okay, I get it, and I got it. It was a, it was my Hail Mary. Let's do something else.

So I said, okay, are you ready? And she says, I'm ready. And, and the people from Pegasus and our dear friend come, come in and, you know, It's goodbye and are ready and she bumps and nods 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. It was so quick and she was gone. Something had…

I never…… I never imagined that I could witness.

Aftermath, Grief, and Sharing the Story

I kinda… Freed out…. I had to leave. Couldn't… 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 world. She did it. She got her wish. I was there to honor her. 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 thrives during the protocol and she's thriped at her death.

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

Even though at the time I go, no, this is not what's best for me. I can care for you. If you're alive, I don't miss you." When you are gone, one of the things that she said on her bed was, Keith, don t worry about you, she knew that I would survive.

She knew that i would thrive and I'd 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 know this book was gonna tell my story. And I'm glad I read it afterwards.

I didn't need to read at first. We had our method. I didn' have to do all the homework that Amy did. I knew what we were going to d. So I've 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 am so thankful that you wanted this story told. I avoided you until your office reached out to me and here I love the idea that you and I are here.

When we were going through your programs, Mary-Ellen and 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. And I, felt like I understood her and I thought I want to grow up to be like you guys.

It is 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 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 can have a team and community around you makes a 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 practiced in 15 or 16 states, is not an option. She wanted to have a choice, to just have it in their back pocket. And that was all she wanted, just to 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.

She went to Switzerland. No, that's not the lead. And the journalist says, oh, you want to bury the lede? I go, yes. Pardon the pun. We want a bury of the laide.

But we want it mentioned. So it was put at the very back of The Obituary. we wanted Mary's life to be told, not her death. That will come later. 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 more. Um, 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 then selfishness that 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 their thoughts soften and their respect for Mary grow.

I mean, their beliefs are the same and we honor those, or we honored 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. 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 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 blessed me with her life and bless me 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 live like we had been living with it. Looks good, maybe deep down good will catch up to me. And I have to, because I've to honor Mary. fall off the deep end, you know, that is…

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

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've been a But then again, you know, if there was not the support, it would have just been that much harder.

Closing Reflections on Love and Choice

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 any easier. Yeah.

I got a joke for you. Let's hear it. So there's this couple standing in front of two dear friends, and they say, you know, after a lot 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 Eulogie is tough for a spouse. Uh, really tough because you don't know if you can pull it off. Cause you cry so much. So much cried so.

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

So I miss the crying. I can cry, but it's just not as often. 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 eulogy. I go, if I can't do this, would you please read it? But I guess I like a crowd.

And I'm going, this is, I, can do it. But, i realized that I gotta make sure I could 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 I was while my friends are handymen they do it themselves I kind of go well if you're going to be a hand man you got to do 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 to kick when I was successful, and she felt sorry for me when wasn't. But to kind of ease whatever ego blow I had when couldn't do it, she said, Keith, you know, I love the idea that you can fix things and want to fix thing.

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, so gratifying.

That's what she really likes. Well, she is remembered. I hope that she's 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 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 for showing up here. You've flown all the way down to San Diego to share this story. And I feel confident, I felt certain that there will be many people out there who will get some peace, that we will reduce some suffering for people who are navigating something similar to your and Mary's story, but thank, you thank for being here to show it with us, Keith.

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