Opening on dementia caregiving strain

Well, think of the strain we put on families who are living with someone who is living dementia. In so many of these families, they have children, jobs, their loved one who's living in dementia, it's a huge struggle.

And we as a nation, as society, offer them no help whatsoever. that it's a burden, that why bother? I mean, I've had people say to me, my brother-in-law died, it just as well he had dementia, to die as a relief.

That we offer people, and I firmly believe this, we as society will not begin to provide the support that people living with dementia need to live with happiness and to thrive, unless we believe that their lives are worth living.

We just reject it. And so the strain we put on family caregivers is enormous. I personally think they should be paid. Welcome back to the Think Well, Age Well podcast.

I'm your host, Dr. Heather Sandison. Today's guest brings a perspective on dementia that is both deeply personal and quietly revolutionary. Marilyn Raeckel grew up in the shadow of Alzheimer's disease.

Nearly everyone in her father's family and many people in mother's families developed it. Her mother once told her, when we get Alzheimer's, walk away.

Marilyn Raeckelu2019s family history and early assumptions

There's nothing you'll be able to do. But Marilyn didn't walk. Instead, she leaned in. And what she discovered transformed not only her relationship with her parents, but her entire understanding of what it means to live with dementia.

She has a background in the performing arts and a master's from Harvard's Kennedy School. Marilyn went on to found the art of Alzheimer's, inspired by her mother's unexpected creative awakening.

Today she serves as executive director of Maud's Awards for Innovation in Alzheimer Care and is the author of Don't Walk Away, A Care Partner's Journey.

Her work is challenging one of the most deeply held assumptions about this disease, that there's nothing left. Instead, she invites us all to see what is still possible.

Marilyn, thank you for being here today. Oh, Thank you. It's very nice to be here. You grew up surrounded by this disease. Before you became a caregiver yourself, I'm wondering, you know, what were some of the experiences you had, so the thoughts and ideas that formed how you thought about the disease, how do you approach this?

Well, mom was very clear, and there are five kids in our family, she was clear to all of us from the time we were young that when we get Alzheimer's, I want you to walk away.

And we all thought, okay, that makes sense. In fact, as teenagers, we used to invent ways to kill my father when he developed Alzheimer. Very ghoulish family.

It was considered like a death, actually like, a fate worse than death because you were still here. And so I had no intention ever of becoming a care partner for mom.

It happened only because when I came back from graduate school, it was during the recession and there were no jobs. So my family said, okay, we're going to pool our resources, and we are going keep you afloat and you're gonna be the family care part.

Well, number one, I had no desire to do that. I really, really didn't, and I didn t know anything. And I also have to say, right at the get go, that I was never a family caregiver.

These people have the toughest job on the planet. I, mom and dad, lived in a really good continuing care facility. And it was, so I was more or less there to keep them occupied, to make sure they go to doctor's appointments.

But the place where they lived, Horizon House, took care of most of their care. So I had it easy, but I didn't want to be there. Whenever I got there, which was only once a week, or maybe often, more often.

Mom's words were always in the back of my mind, walk away, and so this went on for about a year and a half. And I was not good. I there reluctantly and I looked at the clock and it was gradual that I started to slow down and listen to them.

After all, remind myself, yes, these are my parents, I do love them, even though that word was never spoken in our childhood, never. Mom wanted the best for Dad because Dad was developing Parkinson's.

And Dad wanted best from Mom and I wanted for both of them. So it was shared goals that brought us together. But I was still not a good caregiver. It was only, only after Dad died.

Dad at 89 died and my brother and sister and I were in the room with dad and mom. Mom was asleep and we thought, should we wake her up? Because she's not going to remember.

And I got to tell her this over and over again, but they'd been together for 72 years. So we woke her but I've never seen tears like that from mom, there were rules in our family.

When someone died, no tears. It was a family that was informed largely by Scottish Calvinism, which regarded emotions as an indulgence, and especially around matters of death.

Discovering her motheru2019s creativity

because they all knew they were going to heaven. And so when dad died and mom started crying, we've got her calmed down. The next morning I got there early just to make sure she was okay.

She remembered and we talked about dad and what a wonderful life they had. Next morning, I get there earlier and she remembered. We talked to that dad, what wonderful man he was.

On the third morning. I and she was lying on her bed crying. And she said, I just want to be with your father. Without thinking about it, some of the mother of my youth and I said well mom, you should have thought of that before you started taking so good care of yourself.

She laughed and said that's life. From then on she started to rejoin the world. The first thing I did was that she so bored. that I took her to this painting class for people living with memory loss.

And I didn't expect anything. She didn' t expect any thing. In fact, she thought painting was stupid. So her painting is fabulous. I was stunned. she didn t care because she claimed she couldn't do it.

For years it was up.. I couldn t do that. Okay. so I kept going every week on Tuesdays. her painting class. I took her to the painting classes, I would take the paintings from the previous week, otherwise she'd throw it away, and she would paint again.

And her paintings were just incredible. These brilliant paintings. At first when she saw a flower, she painted a flowers. Then she started to transform things.

A zucchini became a dragon. It's just really, really interesting. So that was when I started to go, I see she's still here. She's living with wit and invention.

And I still wasn't totally there. I wasn' a care partner yet. And that's when I started the Art of All Centers because whenever anybody saw the art, their first words were always the same.

I had no idea that the artwork effortlessly got people past their fear and resistance and enabled them to think and feel. So that was the beginning of my journey with mom.

I'm curious about before that. So your mom and dad both shared this idea that Alzheimer's is a fate worse than death. Just walk away. Don't torture yourself.

just walk. Where did that come from? I know that there was lots of other dementia in your family. Had your parents been caregivers for their parents or siblings or where did this trauma come?

Well, Mom was the caregiver for her mother, and she was again living in this really good place, but Mom didn't want to be a burden the way she felt her Mother was.

And with all of the other aunts and uncles on my father's side, we would all just wait and watch and who got it next. And again, if the fact that we were thinking about killing my father when he got Alzheimer's shows you how we felt about it, that it was death.

And so it a dark vision. We did not, like so many people in this country, we did believe that people living with dementia had value, had lives worth living.

That we just walked away. But it really came from mom and her experience with her mother. I mean we used to make fun of grandma when the minister would come by to call grandma would say, I'm not that kind of woman.

So we used to make fun, but it was never anything that we experienced because mom kept us far away from it. I see. It just kind came through your mom's experience, that there was this rejection of people with Alzheimer's.

Once they had that, yeah, there is no value. And I think that's all too common. Yeah, absolutely. Right. And it's also, I guess I'm a little bit curious about not only not no value, but the burden, right?

It's actually really negative. There's financial burden. there's emotional burden there is physical burden and you mentioned it when you were first going and acting as the family liaison at the care home that every time you're there, you are watching the clock.

You're like, when is my shift over? When can I go home? when can i go back to my life? And so, there is this not only an absence of value, but really an impingement.

It's a liability. Well, think of the strain we put on families who are living with someone who's living dementia. In so many of these families, they have children, the have jobs, their loved one who is living in dementia, it's huge struggle.

And we as a nation, as society, offer them no help whatsoever. Infact, we only offer that it's a burden, that why bother? I mean, I've had people say to me, my brother-in-law died, it just as well he had dementia, to die as a relief.

That we offer people, and I firmly believe this, we as society will not begin to provide the support that people living with dementia need to live with happiness and to thrive unless we believe that their lives are worth living.

We just reject it. And so the strain we put on family caregivers is enormous. I personally think they should be paid. Yeah, without a doubt. You know, there's a lot of nuance here because I've had, I was actually having this conversation with a dear friend of mine.

Her mom has Alzheimer's and her mom had gotten to a stage where she's quite combative and she is miserable and making everyone around her miserable. And so there was this very nuanced conversation about like, well, she was on these blood thinners.

Should we stop the blood thinner? And maybe she like could potentially have a stroke a little sooner. and that wouldn't be the worst thing in the world.

And to say that kind of thing out loud is terrifying, right? It is so, there's so much judgment coming from every direction, you're supposed to keep them alive as long as possible, do everything you can to intervene.

From rejection to care partnership

If you have the DNR, like there is a little bit of the do not resuscitate, but there was a bit judgment. But if you jump all the way to like, well, should we put her in, what about everybody else who's becoming a martyr to this?

There's just very nuanced conversation to be had here that I think is a struggle to have in families. Society does not really respect that conversation or make space for that.

And my opinion at this stage is that there's not one right answer. that each family will have to navigate it with the nuances and dynamics and resources that they have.

I'm curious your insights there. Well, I would say that, yes, it's true that sometimes it is a very, very difficult situation. But I do also think that how we react and relate to people who are living with dementia makes a huge difference.

If we don't know how to speak to them, if we do not know to listen to, them if it's all about rejection, then how do you expect that they're going to react?

That combative response can possibly be lessened. So I'm not going project on anybody's experience, but just in all my, when I began to accept this, and I started to visit mom all the time because of the art, I kept learning every single day how to better react to her.

Now with mom, it was easy because mom was incredibly funny. I've always said mom is distilled to our essence. She was funny, she was competitive, and she is basically the mother I always knew.

Different, but always new. But what was interesting is that when I began seeing her more often. And I just assumed, I was assuming a lot of things. Of course, Mother's going to be excited to see me because I'm her daughter.

But then I realized she was far more interested in the people with whom she lived, that they were her new family. And fortunately me, they are willing to accept me as a member of their family, so it was when I started, at first I One big change is that I let go of the mother I thought she used to be.

I stopped asking these questions like, do you remember, or don't you, remember that are meant to reassure you that she's still there when in fact she is not.

She's let it go and accept the person who's living with you in the moment. Don't fight it. don t test it, makes her unhappy makes you unhappy. And that I let go and I began to embrace the woman who was with me in the moment.

That makes a huge difference because you're not fighting them. You're trying to make them be something that they can be otherwise. Imagine if we did that with all of our relationships.

Yeah. Well, that was a thing that is so amazing. Because I was with mom as her care partner, caregiver for like 10 years. And that after all those years, and I learned so many things about how to live with people living with dementia, I realized that everything that makes them happier and enables them to thrive, works the same for everybody, everywhere.

You're listening to them, you're asking questions, You are giving value to what they're saying. It's a skill. So, with

mom it was easy, but it's not always easy.

But there are ways you can relate to people that lessen that stress. And so with mom, all these people with whom she lived, All my new mothers, adopted mothers and assisted living, I never, only once did I encounter somebody who was so angry, who were so rejectful that I didn't know how to deal with it.

And I asked the staff, and I said, "I don't how deal this. You're going to have that with me." But with everybody else, i was treating them as human beings.

I was treated them people of value. and it makes a difference so that it exists, yes, you see the difference, but if you fight the differences, it's gonna make it even worse.

Yeah, there's this window of opportunity to connect at a different level, right? And like you said, distilled to her essence, we all can be distiled to our essence.

And there is some parallels in communicating with children, and even animals. There are these basics of just being present and coming with sincerity, approaching the conversation and the connection, the communication with the sincerity.

You get different outcomes, right? If the goal is to put someone into that rest, digest, heal, comfortable space, there's more room for connection. But if our interaction with them puts them on the defensive, makes them feel attacked, then, of course, they're going to be in a fight-flight-free state, and we're not going have the capacity to connect.

And it's creative, like certainly in your mom's scenario. So, and that's true no matter what living organism we're engaging with, right? We want to get into that rest, digest, heal state so that there can be more connection.

And you really have this incredible story around how profound flipping that switch can I want to get into kind of, yeah, like the nuts and bolts of this.

And I think that part of the reason I brought up my girlfriend and her experience right now is because where I don't want it goes into judgment around others' experiences, right?

Each family is unique. You have this incredible, it sounds like you have all these siblings who are very supportive and wanted you to be there. Even though you didn't wanna be here, but there was a dynamic that allowed you there and kind be that liaison for your family responsible for you mom's care.

And for some people, they're stuck in it themselves. They don't have siblings. they don' have other people. Or they are arguing with their siblings and fighting over the power dynamics, right?

So I just want to give voice a little bit to the range of experiences that can be had here. And then now I want you to just tell us, like, how did this profound transformation take care of you?

Well, part of it was when I saw her art. It was like I had no idea. Like everybody else, I have no ideas. And because I had to be there, I have to continue to there.

And what was interesting is that I was still seeing her. I mean, at that point, because of the art of Alzheimer's, must admit I will confess that was more interested in mom's art than I wasn't mom.

Every week I'd get there, I grab a photo, and I go back to start amplifying its impact. It took me a year. That changed. I had my sort of aha moment. So once I was looking at her art, before that she was doing all these incredible transformations.

She made this butternut squash look like this jaunty little creature with a face that looked exactly like a Blue Meanie from Yellow Submarine. They were always amazing, but that started to deteriorate.

Painting started to me look like she was losing interest, seeing colors, same scratchy lines. I thought, hmm, so I got there early to painting class and we did everything she liked to do.

We looked at the sky. She played the piano, we sang, We played Scrabble, which we did every day. And then I took her to the painting class and her painting completely changed.

All of a sudden these warm animal images started to occur. That's when I realized, I see I have a role to play in this. We're partners. So from then on, for the next nine years we worked together to build the best possible life for both of us.

and that went for me as well as mom. Mom was always light years ahead of me and living with dementia, but I was still fighting it. But once this happened, I wasn't fighting at any.

It was, we're working together. We're partners, care partner. So that's for the next nine years. That's how I left. I wrote down every single thing mom and I did for nine year.

It's fascinating. And every day, and by this time I was seeing her every, then it wasn't something that I had to do. Something I needed to be there. Every day I learned something new.

Learned something about living. So wonderful, and the women with whom she lived were all so wonderful. So that one of the things I started doing is I starting giving everybody shoulder massages.

I'd get there and I would ask everybody if they wanted one and they wouldn't necessarily know what I was talking about, but they'd see the person next to them swooning with pleasure and then they would want one.

Living with dementia through connection and joy

So even the staff wanted them at a certain point. I got the best compliment of my entire life from Gloria, one of adopted mothers. She came up to me and she said, do you tuck your wings in a handkerchief when you're not here?

I mean, just so every day was happy. Every day, was this effortless ability to express and receive love, which is not how I was raised. I was raised to win and to not listen to other people and just to when.

But now I listening to the people. I would ask mother questions, something I hadn't done before. She used to say, what do you think Seattle's going to be like in 50 years or 500 years?

It didn't matter. And at the beginning I would make up these stories, and then I'd change the subject because I found it boring. And then one day I asked her what she thought it would be.

She said, well, I'm not going to be here, so you're going have to come up and tell me what it's like. I said but what do you think it will be like? Do you thing it'll be underwater?

And we had finished ourselves swimming through Seattle. Then she said well I think women will wear skirts again. We had fun. And she didn't always know who I was, but she always knew she was happy to see me.

So it was and every, she still didn, She still would not acknowledge painting. I don't know where that came from, But I would compliment her on her art.

She'd go, I didn' do that. He said, it's really pretty. and she said I must have gotten that from her father's side of the family. wonderful, wonderful experience.

It changed me more than it changed mom. Made mom happy. But it change me incredible. I am a much nicer person now than I used to be. Do you have a sense of like, was that creative aspect of your mom always in there, but sort of rejected through that buttoned up sort, you mentioned the Scottish cultural rejection of emotion and it

sounds like potentially even creativity and artistic expression.

Do think that that was always her or do you think something changed in her brain that allowed it to? I don't know. I mean, everybody in our family was involved in the arts.

My grandfather wrote poetry. Mom played the piano every single day of her life from the time she was like six. Her sister Louise, she played piano. People played instruments, but for some reason, art.

No. I asked her sister, Louise once, I said, did you ever paint? She said no. once she started to do it. What was interesting is that it was there, but it wasn't the painting that attracted her.

It was the chance to be at the table with all these people. He was a part of this community. In fact, sometimes she was really fast, so she'd paint. and then she'd get up and leave.

And then, she walk around the halls, and she would see this group of people sitting at a table. She'd say, may I join you? And they would say why yes, so she could paint again.

So it was just, I don't know, it had something to do with painting, but the piano, It was interesting that Mother, when she lost ability to read sheet music, And so she developed her own special medley and have videos of it because I found it so fascinating.

And she began with Silent Night and at exactly the same time, every single time it would morph into Polly Wolly Doodle all day. And her skills on the piano were brilliant.

And so there was something there. It was always there, and we used to sing all the time. We had one favorite song, Winter Wonderland. Mom didn't know the words, so we'd just sing the melody.

When you finish, we go walking in a winter wonderland and mom would go bump, bump. So we had fun together. There are a couple of things I want to say about that.

It's not about you. It is not whether you might get dementia and how you feel, which scares people. I want to see the woman I used to know back. And I met this man once and he was telling me about his wife who lived in a nursing home.

He said, when I see her, she kisses me and she tells me she loves me. When I look in her eyes, there's nothing there and I leave in tears. And I thought, why is it that he couldn't see what I most likely would have, which as a woman was something to say.

And, I think that if your entire framework is nothing but sorrow and loss, that's all you can see. Happiness together, or if you could watch her experience happiness, then you see that person you thought was gone emerge because you're seeing this person enjoying themselves.

I meet people who are having a hard time. I say, OK, try this. Just try. This take five minutes. Pick one thing that your mother enjoys doing or your father or that the both of you do.

And just do it together for five. It could be singing. It could be looking at the view. Could be anything. But just do that briefly, and you'll see that person that you thought was gone having fun.

And it can change your perspective. You might want to do it again. That's what happened to me. If you can get rid of that sorrow and loss, overwhelming like there's nothing there.

if that's how you start, how difficult this is going to be for you to see anything else. Yeah, it's that attachment, letting go and acceptance. right?

Which is sometimes easier said than done, but also an invitation, right, to go in that direction. You also mentioned

the transformation you went through yourself.

I want to touch on that because this role as care partner can be deeply transformative for both people. And I think that's sometimes left out, right? I hear over and over again from people who have served as carers partners, there's a spectrum of experience, but most people wouldn't give it up for anything.

They feel very grateful they got to do it. But there were moments that were torturous. I'm curious, you mentioned that you're a kinder, it sounds like you feel like a better version of yourself having gone through it, can you talk about that?

Well, raised in this family where emotions were never spoken of, where I was the fourth of five kids and my job was to win. My two older sisters were on the marriage track.

I liked grades and I didn't like boys that much, so I wasn't on that career track, So for me, everything was about winning and not about listening and about working together.

It was just all about me and winning, and I felt alone. With this experience, it was the first time I've felt where I wasn't in a competition, that I was enjoying myself.

The thing about when I would tell people that, I'd go to assisted living to visit mom, to relax, they would just look at me like I'm crazy. And it's because there were no deadlines, there are no rules.

It's just the peaceful moment. Yeah, it sounds like if there was a challenge, It wasn't to prove something or to win something, or compete with anyone, check a box.

It was to connect. To connect and express love. Because when I would give shoulder massages once, Harry, who was at the men's table, he wanted one. So I went over to the Men's Table to give them the massage, and Harry was interesting because he was eating lunch and I started to give him a massage and all of a sudden these chirps started appear.

And then the chirps slowed down and it became a song and Harry began to sing. And I kept massaging him and the song got better and bigger. At a certain point, I realized that everyone's food was getting cold because everybody was just wrapped with the tension.

When I stopped massaged and he stopped, the entire lunchroom burst into applause. It was this communal, thing. Living with dementia so often lose is the need to be of value.

They never lose the needs to value, but they lose opportunities. And this was simple. But I once asked the kitchen crew, I said, all those napkins you put out on everybody's places, could you just bring all of them to me in a big lump and toss them on the table?

And they did. And I said to Mom, look at all those napkins, Mom. Would you help me fold them? She just started folding them up and put them neatly in everyone's places.

I say, oh, thank you, mom. You're now the folder in chief. Then sometimes when she wasn't looking, I grabbed them all up again and I threw them and she'd do it again.

Just that simple little thing of being of value, of having someone say thank We forget how rare that is. All these things that were so abundant in their lives.

And so with my experience, and I started to slow down and started listen and asked questions and enjoyed the moment. I shared joy with people. Imagine having never really done that in your life and all of a sudden you're doing it and it's becoming part of your pattern.

I mean I have to remind myself even now, when I get an email, instead of starting it with telling them all about me,

what I'm doing, I stop and I say, don't do that.

And I ask them how they're doing first. I ask questions and I listen and respond as if to acknowledge what they have told me and that how I'm feeling comes second, that it's not about me.

All these simple little things I could have learned years ago, but I didn't. And when mom, mom taught me one thing that was interesting, because she was always teaching me things.

You know how you heard that thing about mom became the daughter and became a parent? Mom was my mother. She was teaching something. And she taught me this one really important thing.

Creativity, personhood, and the Art of Alzheimer's

Mom began every conversation at Horizon House where she lived with a smile and a compliment. Compliments were really difficult in our family because to accept a complement meant you thought you deserved it.

So in out family growing up, if someone gave you a component, it was best to change the subject, preferably to something depressing. And we all got out of the habit because it sort of depressing, And so all of a sudden, mother was giving compliments to people.

And when I tried it, it was like, oh my goodness, what a nice way to begin a conversation. Again, I learned that from mom. Simple things that I, you know, years ago, and this is really interesting.

Years and years before mom developed dementia, she was living in Horizon House in an independent living. I lived in this big house, not far. And she came by one day and she come into the house, because it was sort of open, and came up to my room and I was taking a nap, that she laid down next to me and told me she loved me.

And I remember crying because I'd never heard that before. Then she said, I guess I should have said that more often. Again, we didn't talk about it because, after all, our life together as care partners unlocked all that love that had been waiting so long to express itself.

And so it was just this from hands, from fists clenched to hands open. That's how I describe it. People have asked me, they said, well, don't you sort of resent your brothers and sisters for not spending time with your mother?

I said I wish they had that opportunity. I wished they could have. They'd be so much happier today. except for one of my sisters who spent years in therapy, so she got there first.

And if you listen, every single day, they're telling you something that's worthwhile. It sounds like there was almost a path of unlearning. Yeah. Letting go, letting go.

But then it just, once you start listening, it becomes a habit. Once when mom and I walked out of her apartment and there were no one in sight. There was no in the hallway.

And she turned to me and she said, do you know what this means? I said no. She said we're the most beautiful women in site. Just to have fun. that mother was having fun.

And once I started to absorb her outlook, everything changed for me. You founded the art of Alzheimer's, and this really highlights creativity in people living with dementia, which I think doesn't even cross a lot of people's minds.

Yeah. Why do you think it is that creativity remains so accessible, even as our memory and for a Well, number one, I think that nobody gets, nobody abandons their need for accomplishment.

That to be able to paint or to do anything, to sing, dance, that you take pride in your accomplishments. It is, and it's fun. We forget when we think of people as these poor, sad creatures who just need to We forget their need to be creative, their needs to have fun, they need for accomplishment, the need of pride.

They're just like us. This is what I call enduring personhood. That there are certain things that we as human beings never ever let go. And these are all things they needed to laugh and the needs have friends, that need have accomplishment.

The need be of value, to need love and to belive. These are things we share and always will to the day we die. As I was reading about you preparing for this conversation, I couldn't help but be extremely curious about your mom's art.

Where can people see it? If they go, well, we have a website called the art of all, let's see, the books website is don't walk away.net so they can see If they order it on Amazon, they can scroll down and see some of the art.

But it's not widely available everywhere, but it is fabulous. And I have every painting except for a couple that I gave away. The only painting that she never transformed were strawberries.

And I think it's because we went strawberry picking as kids every summer and would pick tons of strawberries, and so when Mother saw strawberries she painted a strawberry, which was funny.

But, but it, it just, The ability to see that the creativity is still there and the ability share the joy of that is wonderful. One of the things that she said to me really late, she was probably 95 when we were playing Scrabble, by that time Because mom was so competitive.

When she couldn't make a word, we would just add up the scores. She had more scores on their tiles. But once she had these tiles and she was trying to figure out a work, she said, is dog a bird?

And then she stopped and thought and looked at me and said you know, sometimes your brain just gets in the way. And she made Jewel on the triple. Again, she was always surprising.

Always surprising me. And if you're open to that, it's so wonderful. In fact, and this is funny, this was when mom died, about three days after that I went back to assisted living because I wanted to be around all my mothers.

Ruby, this wonderful woman from Atlanta with this fabulous accent. And she and Evelyn, who was 104, they were talking about mom. Ruby held up this red plastic flower and she said, I think about Jean every time I see this.

You want to know why? I said why. She said because she tried to eat it. And there I was, I back where I could be happy. Surprised and laughing and playing.

And just enjoying them. If you're open to it. I once was being interviewed by somebody and I telling stories about mom and how happy it made me. When I finished she said, yes, but isn't awful." And I said, well, you would think so.

But then I would tell some worse stories. And then at the end of that, she said yes, but isn't it horrible. I thought, if you're deeply committed to the fact that this is awful, I'm not going to be able to change your mind.

Well, you make this really powerful distinction in your book about living with versus suffering from dementia. And I think that's the concept you're getting at here.

So maybe unpack that. I've talked about elements of it, but you have a list of when you distinguish between them of what living-with versus-suffering-from looks like.

Well, I think it's pretty simple. I mean, it is how we live. We are, instead of spending every day, ugh, hate my life, sadness and sorrow, you're just living.

You're encountering every aspect of your life the same way we are. and you're not spending all your time suffering. And that it's more for us that they're living with.

So just know that this is about us being able to understand that these are people who are alive, human beings who our alive. not sad creatures who are suffering, and that's all they are.

It's really for us. We have some agency in how we show up, right? I think that is a big part of your message and also some responsibility, how do we walk into the room?

If we are stuck in this idea that they're suffering from, that we have so much loss, they aren't the person they used to be, then that shifts how the person with dementia is going to respond to us and whether or not they're combative, whether they are engaged, creative, that creativity can be expressed, laughing and enjoying life.

There's agency and responsibility. How do you think through that? Well, this goes to one of the first things I learned, is that I was talking to mom and I telling her about my job at that point, which was not fun.

And I started telling about it and then I realized I could just feel her pulling away. She was absorbing my stress. she was observing my unhappiness. I recognized it, I immediately stopped and changed the conversation to the food we were going to have for dinner that night.

It was the last time I cried because I wasn't being able to confide with mom anymore about my sadness, but she's going to pick up on all those emotions.

How we present ourselves, they're going absorb. If we think of them as sad creatures, how do you think it makes them feel?

Hope, respite, and support for caregivers

Yeah, we're projecting that onto them. You also distinguish between care partner and caregiver. Yeah. Talk me through the language there. Well, and I don't mean to in any way impugn every caregiver out there, but for so many caregivers, they are taking care of a person who is conceivably sad, a personal who's in need of help, not as an equal human being, as opposed to a care partner.

then together, together we're working together and together were building a life. Yeah, it's one direction rather than collaborative. And it was for me really important because I hadn't been seeing her as an equal human being, but we were and that she was as joyous and happy and competitive and funny as she always was.

Potentially more so it sounds like. Yeah, she was teaching me at this point. And she, was she just funny. I mean, it's just really simple things. Then it goes to listening.

One day she said, you know, when you're ever feeling kind of blah, like life isn't worth living, look at, and she held up this tattered old copy of Better Homes and Gardens.

She said it was just wonderful. Mother was finding happiness and joy in places I wasn't even considering. And that's when I thought, okay, I'm going to calm down.

I will relax. That mom's got my back. Mom was just, every single day there was something like that. Just listening to her, just being with her. It was fabulous.

And I know, and I have a friend who was a caregiver, care partner with her husband for years. And it was really hard because she had kids, she got a job, And she said, what I like about your book is the word hope.

I had a harder time with joy. She said there wasn't as much joy in my life as you had. But the world hope is really important. We can change our understanding of dementia from despair to hope, to help that they're still here.

To hope that that can live happy lives. So hope they can thrive. Hope that we as a society can understand that the deserve and need our support and their care partners.

You, as a caregiver transforming into a care partner, experience those feelings of overwhelm and isolation and even resentment at times. What would you say to someone who's at that stage, who is just beginning this journey maybe and having some of those emotions come up?

Well, I think, number one, they need, and I always say this, that they to look at their community, their local senior centers for the activities that exist, for activities for their loved one and also for themselves.

That they needs respite. They need respites. More caregivers are in danger of dying early because they're exhausting themselves and then not giving themselves support.

And I think that we're lucky in Seattle because there are so many things. There are memory cafes, and they're increasing everywhere. Memory cafes and senior centers and all sorts of programs.

They're dance classes. We even have one program called Momentia that has a daily newsletter that tells you all the activities that are happening that is free in your neighborhood.

and that it is important for caregivers to let go, to not ask those horrible questions like, do you remember or don't you? But also to give themselves opportunity to relax and to rest.

And I know they're busy, but even if you can take five minutes every so often, relax, my niece was starting to encounter that. She wanted to become the principal caregiver for her father who's developing dementia.

And her Father lives in Squim, Washington, way over here, and she lives In New York, so it would be exceedingly difficult. I said, you have to take care of yourself, because she was becoming exhausted.

You have take of care yourself and ask for help. Ask for guidance, ask For help, but ask And that's where senior centers can be very valuable, is that there are people there who can help You wrote the book, Don't Walk Away, and this was a really personal act.

What compelled you to share your story and what do you most hope readers get when they get a copy of it? Well, the main reason because the art was having such a powerful impact on people.

So this is a story, it's an invitation to take a walk with me and Ma and experience a life Full of hope and creativity. A person living. Yeah. But also just a life, a people, someone living adventure, tools, laughter, the experience of laughter of, hope, but also there are all sorts of lessons that it can be life-changing, that can also be incredibly challenging.

The art is fabulous. It's all these things that I wrote down in my nine years with mom, all the stories of me and mom. But they're all illuminated by her artwork.

And so it's just a book of hope. I hope that people how people will take heart from it to realize that they and their loved one can live with connection to their communities active.

But I also hope that it can reach people to say, these are people who deserve our help, that it's not something to be afraid of. This is how my experience might not be yours, but this was my experienced.

Imagine if all these wonderful people, I had a sister once who said, mom left us years ago. And I said well, if mom, left who's there? And, and I would suggest it somebody well worth getting to know.

It was for me, It was just, it was life-changing for me. And I don't think it life changing for mom, but I know she had fun. She had time. Your mom you mentioned, she passed.

I'm curious about that transition out of that care partner role. It's hard. Well, first of all, mother, First of mother made me laugh on her deathbed, which is not easy to do.

she grew up in this banking family during the depression and they hated Franklin Delano Roosevelt. Every time she heard his name, she'd go, we didn't like him.

So her blood sugar had spiked to 600. She's in a coma. she's two days from death. And my brother and sister and I are standing around her.

Closing reflections, Maud's Awards, and joy in later life

We're singing to her, telling her we love her and i mentioned her dislike at the Roosevelt Hotel and mom flinched. Wow. And I knew she could hear me and I know she can understand me.

So for the next two days, I sat next to her and held her hand and talked. We had a memorial service, which again, in our family was like no funerals, no memorial services, and no tears.

Scottish Calvinists. When I got up to speak, the first thing I said because her younger sister Louise and her cousin Frank were in the audience. I said, I realize that this is showy, because Mother considered memorial services show-y.

And they laughed, and they both act like this. And then I realized I was about to cry. And I couldn't cry in front of them. I just couldn' t. There were no tears.

But with every ounce of my being, I pushed those tears away. Then two days later I went back to assisted living and I found another. Evelyn became my new mom.

She was 104. she was wonderful. We had a fabulous time. And she was at 105. She was in hospice. And I went up to her once and I knelt down next to and just said, I love you, Evelyn.

and she opened her eyes and said life is so wonderful. And that was the last I heard from Evelyn. And after that, I had to make the decision to reenter the world, which was really hard because it wasn't nearly as much fun, not nearly, as peaceful as my family and assisted living.

But that's when I was working hard on the art of Alzheimer's. Then I met this wonderful man named Richard Ferry who sent me an email and he said, all right, have this idea.

And it was about Mods Awards. And Mod's Awards is a program when his wife developed dementia in 2013, and he didn't know what to do. He had no idea, like so many people.

Then he thought, because he's a man of means, he said, well, perhaps if I do this award program. So every year we give away $100,000 for innovations in Alzheimer's care.

These are for individuals and organizations, for-profit, non- profit. Anybody who has enriched the lives of people who are living with dementia, it's not a grant, they can apply.

Applications are currently open. They go to modsawards.org. And in a simple, there are six questions. We're in our seventh year now. And so, this is a wonderful thing to be able to do.

So, Alzheimer's world became my new world, and Mauds Awards is the fabulous thing as one ages to able do good. To have an impact. What brings you joy at this stage of life?

Well, aside from my job, baking. And the reason it brings me joy is that it used to be really serious that growing up, I didn't like to shop, so I would make cookies for my brothers and sisters.

Then it started to grow as people started taste the cookies, because these are not average cookies. These are really difficult cookies Three years ago, I made 2,000 cookies using 80 pounds of butter, 47 different kinds of cookies.

But the thing that's fun about them, and I don't make as many now because that is absurd, but is giving the cookies to people. People are so happy to receive them.

So that makes me happy. In fact, now that I'm no longer making thousands of cookies, but even so I make cookies all the time and I give them to my neighbors and they're all really happy to receive them.

So, that make me be happy! Marilyn, do you walk around giving out cookies and massages? I mean, who wouldn't want to hang out with you? No massags anymore, cookies yes!

Man, and this conversation has been really powerful as a reminder to everyone I know that's out there that even in the face of something challenging and horrible and just one of the most difficult phases of life, like facing dementia, there is still so much opportunity for connection and creativity and yes, even so many joy and laughter.

and your work and really hearing your transformation, it invites all of us to shift from that fear and withdrawal into presence and an openness to the possibilities.

That is something I wish more people got a chance to hear. So thank you, thank thank today for not walking away, for your stubbornness. And for showing the rest of us just what becomes possible when we choose to walk with that person, with our loved one.

Thank you, thank you for your time and for everything that you're doing to have such a big impact on this space. I'm really grateful for the work you are doing.

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