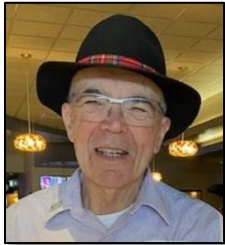


**Perspectives on Caregiving:
One Couple's Unwelcome Journey with Alzheimer's Disease**

Applications from [The GSA KAER Toolkit for Brain Health](#)
Momentum Discussions Podcast from the Gerontological Society of America
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Announcer:

Welcome to the Gerontological Society of America's Momentum Discussion, where we explore groundbreaking topics in the field of aging.

Jen Pettis:

Welcome to this GSA Momentum Discussions podcast episode titled, **Perspectives on Caregiving: One Couple's Unwelcome Journey with Alzheimer's Disease**. Momentum Discussions highlight topics experiencing great momentum in the field of gerontology. We're grateful to Genentech, Lilly, Eisai, and Otsuka for their support of The GSA KAER Toolkit for Brain Health and today's podcast. My name is Jen Pettis, and I'm the Director of Strategic Alliances at the Gerontological Society of America (GSA). I'm pleased to serve as the host for today's Momentum Discussion. I am honored to be joined today by Jim Mangi, who is a Vietnam veteran, author, retired business owner, and environmental scientist with a PhD in ecology. None of these experiences in any way prepared Jim for the most difficult and the most important job of his life, which was serving as the loving and selfless caregiver for his wife, Kathleen, whose 17-year journey with younger-onset Alzheimer's disease ended in December 2024. Inspired by his wife's grace during her journey with Alzheimer's disease, Jim has dedicated himself to dementia activism efforts.

Jim, I appreciate it so much that you accepted my invitation to talk about your and Kathleen's journey and to share a bit of your volunteer accomplishments aimed at helping people with dementia live in their community with less difficulty and more dignity. Welcome, Jim.

Jim Mangi:

Hello, Jen, and thank you so much for your interest in this important topic around dementia and caregiving.

Jen Pettis:

Thank you, Jim. In preparing for our discussion today, I read several pieces that you were either interviewed in or different presentations that you had been sharing your experiences, and you referred to Kathleen's unwelcome journey with early onset Alzheimer's disease. That phrase to describe living with Alzheimer's disease really struck me. How did that unwelcome journey begin?

Jim Mangi:

With uncertainty, surprise, fear, and a whole bunch of other reactions. About 2008 or so, Kathleen, my wife, began showing some memory problems with her short-term memory, as in what just happened. She started showing some confusion. She started having new sorts of mood swings. She couldn't complete tasks like setting the table or putting the groceries away, and she was misplacing things. And, at the time, I did not recognize this list of activities as being among the 10 classic warning signs of dementia. I didn't know about that. I thought at the time that it was something like a post-traumatic stress disorder from some event back in her childhood or something like that. Or maybe it was clinical depression. There was no one day when these things started; it was all gradual. And when we went to a counselor and the counselor suggested, maybe this is Alzheimer's, I said, How could that be? Kathleen was 57 years old at the time, and certainly Kathleen, my sweetheart, didn't recognize she was having any of these problems at all. What we were both doing was swimming in the Egyptian River, "Denial."

We were off to a kind of shaky start on a journey that was starting even before we had had a chance to really embrace anything called retirement.

Jen Pettis:

Jim, at that time, as you're searching for this answer of 'what's going on with my wife,' what help did you get from the medical community or other sources that maybe were available at this time of searching for a diagnosis, and then when you received that diagnosis?

Jim Mangi:

There was a lot more help available than was provided. Our general practitioner at the time just shrugged off the reports I gave him of Kathleen's difficulties. He interviewed her for maybe 30 or 40 seconds, and he instantly said, "Oh, she's just getting old." It took us a while to get to a specialist in a memory clinic. We did find one and we got a more thorough examination, and the results of that examination was a diagnosis of younger onset Alzheimer's disease, but it was "diagnose and adios." It's in my memory that the doctor delivered that diagnosis and instantly beamed up out of the room as if she was going back to the Starship Enterprise. She was gone as if this diagnosis of Alzheimer's disease was too shameful even for the medical people to talk about. And this is perpetuated. This practice continues, perpetuating the stigma that is still associated with having Alzheimer's or any of the other dementia diseases. As you can tell, after 17 years, I'm still annoyed about that.

Jen Pettis:

I know a lot of your work focuses on making sure that folks are part of a community and not outside of that community, and we're certainly going to talk a lot about that in just a bit. I read a quote from you in an interview where you referred to the first few years of the dementia journey as "a clueless caregiver," which were rough for you and for Kathleen. At some point, you went from what you describe as "a clueless caregiver" to someone confident and competent enough to share your story to inspire others. What happened along the way to allow you to gain that confidence and competence?

Jim Mangi:

Necessity. I didn't get very much help at all from the medical community, but Kathleen was having increasing difficulties. I had to go find some information. I had to dig it up myself. Of course, I did what anybody does in the modern world - you go to the internet, and I found that the internet is a lot like the salt water in the ocean. There's a lot of it, but it is not fit for human consumption. I did find, with some effort, some good, reliable, evidence-based information about the disease, about Alzheimer's, about younger-onset Alzheimer's, and information about caregiving. One of the things that I did that really helped me was go to a support group. Now, this one was sponsored by the Alzheimer's Association, a great outfit, but they're not the only ones that have support groups. I went to a support group, and there was an older gentleman there, and he knew I was a newcomer, and he was talking to the rest of the group about the years that he had spent taking care of his wife, who was at that point homebound, bedridden, and without words.

He was going on talking about his years of grueling effort, and I think he heard my jaw drop at hearing all this. And he turned to me, and he said, "You will be amazed at all that you can do and how well you can do it." And he was right. The information is there; the support is there. It is a matter of connecting caregivers with the information and the support that they need.

Jen Pettis:

Jim, how did you care for yourself along Kathleen's journey with Alzheimer's disease?

Jim Mangi:

Not nearly well enough. The reason I say that is that early on in the caregiving journey, I embraced it because I had to. Kathleen and I were living just by ourselves, empty nesters, and all that. I realized I've got to do this so well, I read up and attended support groups, and I took on the role of being her caregiver. Her condition was getting worse, as of course it always does. But I was keeping pace and taking care of her. One night I had had a difficult day, and I finally got Kathleen settled into bed with clean linens and clean bed clothes, and finally got her settled down, and I collapsed, boom, out on the floor.

And I remember looking up from the floor, and Kathleen, my sweetheart, was in bed. She was saying, "What are you doing down on the floor, Daddy?" I somehow managed to summon 911. And it was in the ambulance with Kathleen with me on the gurney that made me realize I really couldn't do this caregiving, this solo caregiving, this macho solo caregiving. Now, I couldn't do it alone. I reported to my daughter about the incident, and, basically, as adult children are wanting to do with parents, she said something like, "Dad, I told you so." She was very sweet. She said, "Dad, you have to realize you can't do any good taking care of mom from six feet under." To which I said, "Don't sugarcoat it, sweetheart."

My daughter was exactly right. I had failed in one of the absolute cardinal rules of taking care of someone with dementia: you must take care of yourself. Fortunately, my ambulance ride on the gurney had a good outcome, turned out to be a quasi-false alarm, but it was a clear signal to me that I had to make sure that I not only took care of myself, but got help in that caregiving journey, which is a discovery that almost every caregiver makes the need to get help. Unfortunately, too many caregivers do not make that discovery until they themselves pass away before the person with dementia. I think it is extremely important for caregivers to make sure that they are prioritizing their own care, also.

Jen Pettis:

You mentioned support groups, certainly the connection with fellow caregivers, how important that is. I see you do a lot of that in your work. You are an award-winning Alzheimer's Association volunteer. Congratulations. You are also the driving force behind Dementia Friendly Saline, which is now called Dementia Friendly Services. What motivates you to do this work, and why did the name change?

Jim Mangi:

My motivation is having cared for my sweetheart, my best friend of 49 years, it has been a terrible journey. It has also been a beautiful journey. I wanted to reach back because I know there are so many other caregivers out there, and, oh my goodness, the number of people with dementia, the number of caregivers is increasing substantially. I know there are so many other people in this situation that I was in years ago, and I just felt it was the right thing to try to reach back and help other people along the journey. I set up, at the time, an organization called Dementia Friendly Saline, because that's the small town in Michigan where I lived. The initial objective was to get that small town, of 9,000 people or so, to be a member of the Dementia-Friendly Community Network.

There are several hundred dementia-friendly communities around the country, and I worked with a small group of people to get Saline recognized as a Dementia-Friendly Community. From there, we have continued the effort to make more organizations, businesses, municipalities, churches, any kind of organization to get them to learn how to be dementia friendly. And then beyond that, beyond educating communities, we also wanted to reach out and do things for people living with dementia and their care partners. We also began offering social events like memory cafes.

We didn't invent this idea either. There are many memory cafes around the country, and they are social events for persons living with dementia and their caregivers to come together with other caregivers and other persons with dementia in an embarrassment-free zone to connect with one another, have some fun visit, meet new friends, listen to some music, play some games, learn a few things, and basically be themselves. We started a memory cafe in Saline several years ago. We recently encountered the difficulty of having to change venues because we outgrew the original space. We started in the wonderful church that hosted us, and their social hall just couldn't be expanded any bigger. We went to another church and used their larger social hall, because we now get about 70 people twice a month coming to our memory cafes.

The name change that you asked about is kind of illustrated by that. Our memory cafe has grown, including other programs, such as workshops on how to be dementia friendly. Our other programs, like our dementia-friendly movies, have expanded so much beyond Saline that we wanted to make the point to other people that we're interested in helping other communities, helping people with dementia and their caregivers wherever we can. We changed the name to Dementia Friendly Services. We continue to offer lots of different services, but not just in Saline.

Jen Pettis:

Jim, you mentioned your movies. When I learned of that program, I just thought it was terrific. Tell us about a movie screening with your organization.

Jim Mangi:

This is something that we pioneered in this country as far as I can tell. No one else in the United States at the time we started our program two years ago was doing regular dementia-friendly screenings. Here's what we do. We are in partnership with a local commercial movie chain, Imagine Entertainment. They are a corporate partner from heaven. Once a month, we screen a classic movie, usually a musical like *Singing in the Rain* or any of the Fred Astaire and Ginger Rogers movies, or more up-to-date, *Grease* or *Mamma Mia!* It's a great choice for a movie, but we watch it with the lights on. We soften the sound a little bit. The idea is to let everybody be comfortable.

And then we tell our audience with a slide on the screen. We also have a live MC who tells people, "Go ahead and forget the rules." If you want to talk during the movie, get up and move around. Go on down to the snack table down front and grab some food. If you want to clap to the music, sing along, get up and dance, go ahead and do it. And Jen, they do all those things. At the Saline Theater we get upwards of a hundred people, people living with dementia and their caregivers and some family and some friends all coming together in another embarrassment free zone where everybody is free to be who they are and just have a great time watching a movie, singing along, dancing, and sometimes participating in the costume contest. Think of *Grease*, a great opportunity for costumes. Think of *Singing in the Rain* or *Pajama Game*. Oh, we have good times with costume contests, and we give out door prizes to the best costume or to the person who has traveled the furthest to come to our movies. The movies are a great success. Measured not just by the number of people who come to our theater in Saline, but the fact that we started the program two years ago, and, as of today, there are at least a dozen other cities in seven states from New Jersey to California who are doing dementia-friendly movies because we started it.

Jen Pettis:

That's terrific, Jim, and *Grease* is my all-time favorite movie. I'd be there singing with you.

Jim Mangi:

I agree with you about *Grease*, but *Mamma Mia!* just got everybody clapping, singing, and literally dancing in the aisles to *Dancing Queen*. It was a sight.

Jen Pettis:

I bet it was. That's just terrific. Wonderful. Jim, I read an article in which you were quoted as saying that dementia is a disease, not a disgrace. Tell me more about that phrase, and you've certainly touched on that as we've had a conversation here, but talk about that a little more.

Jim Mangi:

The reason I talk about Alzheimer's as a disease, not a disgrace, is because of my experience getting thrown out of the house by my wife. I've said that I have learned over the years how to be a better-informed caregiver, but at the beginning, oh, I didn't know what I was doing at all. There was one evening when Kathleen, my wife, had been particularly annoying to me; frustrating to me because she was asking the same question over and over, and because she was messing things up. She was misplacing everything. It was a frustrating day. After dinner, just on a spur of the moment, I said, "Sweetheart, you need to go to a doctor to get your memory issues checked out."

That's the night that I spent in a hotel, because after 30 years of happy, faithful marriage, she said, "Get out of here. You are accusing me of being senile. I want a divorce." Well, the divorce didn't happen, but the hotel did. And her reaction of fear, of anger, stayed with me, making the point that this concept of having dementia (her term was senile, which we don't even use anymore), but her reaction at the potential to be disgraced stayed with me. And that's why I use that phrase to really just make the point to everybody that, whether it's Alzheimer's brain disease or one of the other brain diseases like Lewy body dementia or frontotemporal or one of the other conditions like vascular dementia, these are conditions, they're diseases. They don't reflect bad moral choices. They reflect bad chemicals, bad proteins in the brain, for goodness sake. And when a person is forgetting things, they're doing the best they can with damaged equipment; we can't yet cure these diseases, but we have to understand that they are diseases. They are no more shameful than having kidney disease.

Jen Pettis:

Absolutely. Jim, I have one final question for you. If you could only give one piece of advice to another caregiver, what would that one piece of advice be?

Jim Mangi:

Realize that you are not alone and you don't have to do this journey alone. There is help out there, there are organizations, there are people that will help. Don't try to do it alone. Nobody can successfully navigate this entire journey without help, and there's no shame in asking for help.

Jen Pettis:

Jim, I want to thank you so much for taking time out of your busy schedule to join me for this podcast episode. And most of all, thank you for all your wonderful volunteer work to support people living with dementia and their caregivers. I also want to thank those who listen to this episode of the GSA Momentum Discussions podcast. We hope you find it informative and enjoyable. Thank you again, Jim.

Jim Mangi:

Well, thank you very much, Jen, and thank you for casting light on this important subject.

Announcer:

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