

Agitation in Alzheimer's Disease: Reflections of a Care Partner

Applications from the [GSA KAER Toolkit for Primary Care Teams](#)

GSA Momentum Discussions Podcast from The Gerontological Society of America

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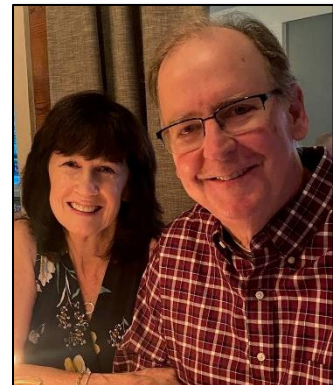
Laura Medders, LCSW

Administrative Director of the Emory Integrated Memory Care Clinic



Maureen Morrison

Care partner to her husband, Angus, who lives with Alzheimer's disease.



Jen Pettis:

Welcome to this GSA Momentum Discussion Podcast episode titled, *Agitation in Alzheimer's Disease: Reflections of a Care Partner*. Momentum Discussions highlight topics experiencing great momentum in the field of gerontology. We are grateful to Otsuka for their support of the new publication, *Insights and Implications in Gerontology: Understanding Agitation in Alzheimer's Disease*, and today's podcast episode. My name is Jen Pettis, and I'm the Director of Strategic Alliances at the Gerontological Society of America (GSA). I am pleased to serve as the host for today's Momentum Discussion, and I'm delighted to be joined by two guests for this podcast episode. Laura Medders is a licensed clinical social worker and the Administrative Director of Emory Integrated Memory Care. She is also a member of the Expert Advisory Panel for the new Insights and Implications publication, as well as for the GSA KAER Toolkit for Primary Care Teams. Laura and I are joined by Maureen Morrison, who is a care partner. Maureen's husband, Angus has Alzheimer's disease, and she's here to share with us her incredible story as well as insights and advice for us about this important topic. Laura and Maureen, thank you so much for taking time out of your busy day to talk to me about this important issue.

Laura Medders:

Thank you so much for having us.

Jen Pettis:

Laura, let's start by talking about agitation in Alzheimer's in general. What is it and how common is agitation for people with dementia due to Alzheimer's disease?

Laura Medders:

Agitation is a symptom that is very common for people who are living with Alzheimer's and other types of dementia. What agitation looks like can really vary depending on the individual experience, their stage in the disease process, and can also vary for the families and the providers who are interpreting what is happening. It is unique for every person and everybody's experience with how agitation can manifest will be different. Agitation may start off with more irritability. People may recognize that a person just has a much shorter temper than they used to. As dementia impacts a person's brain, there is typically a lowered stress threshold. Situations that previously had no impact may now become a cause of stress or create a stressful environment. When dementia is impacting a person's thinking, people may respond more aggressively to something that would otherwise be deemed as rather inconsequential.

It's difficult for family members to navigate that. It can sometimes be difficult for family members not to take it personally when that individual is experiencing that lowered stress threshold. Sometimes the agitation can be caused by things that are rather simple, like frustration when you can't button shirts anymore or when you forget somebody's name. It could just be a little bit of extra irritability in your day. But as the disease progresses and as your brain is changing, sometimes these symptoms become more pronounced than just a little bit of somebody feeling cranky. Sometimes agitation may be demonstrated through a person's behaviors in the way of being more fidgeting, or more exit seeking, or there's tapping or rummaging throughout the day. Those can be more difficult and more demonstrative in somebody's agitated behaviors.

In the late stage, you're looking at somebody who is clenching their fists or clenching their jaw where you can tell that they are not happy, but they may not be able to communicate with the people who are living around them. Agitation may look different for different people in different stages of the disease process.

It can sometimes be a very difficult symptom to manage, especially if that agitation turns more towards an aggressive side. If people cannot express themselves and they are upset about something that is happening around them or that they perceive to be happening around them, and not be able to communicate the severity of what they are feeling, sometimes people will have a very physical reaction or use curse words. They're raising their voice at a time where most family members would say, "this is very out of character for them." They've never responded this way before. The disease has changed the way their brain is processing things, and thus you're getting a very different reaction than you may have typically seen.

Also, some people have said, "well, he's just been mean and cranky his whole life." That may be the case, but dementia sometimes makes it much more difficult to manage these behaviors. It is much more difficult for the person to self-regulate their behaviors as well, allowing it to manifest itself in different ways. If you are a person who is living with the disease or a family member who is living with someone who is experiencing this agitation, it's important to share those concerns with family members, or share those concerns with providers so that they can help you figure out how to manage those situations and can potentially recommend changes in medications, which would be helpful as well.

Jen Pettis:

Thank you for that great overview. I would like to turn now to Maureen, and I'd love to learn a little bit from you about your husband Angus's journey so far with Alzheimer's disease. Can you tell me about Angus's initial diagnosis when he was diagnosed with Alzheimer's, and what signs and symptoms led to that diagnosis?

Maureen Morrison:

My husband was diagnosed approximately eight years ago. However, before his diagnosis, he began to see things in himself, and I saw things in him that weren't normal or weren't right. The first thing that I remember is that he lost his sense of direction. My husband was one of those men who didn't need a map. He could get in the car, and he could get from point A to point B regardless of the detours. He was losing that. I could tell by the way he drove, by his reaction to things, that it was leaving him and that worried him a lot. My husband is a brilliant man. He has his master's and his CPA. He was formally the CFO of a public company.

He found himself with the inability to do some of the simple things that were previously easy for him, such as balancing a checkbook, writing checks, dealing with some financial things that had become second nature to him. He couldn't perform those tasks anymore. We would agree to meet at a location at a certain time, and he wouldn't show up because he didn't remember that we were supposed to meet. These types of incidents led him to tell his general practitioner (GP) that something was wrong. The GP was very surprised because he was still in his late fifties at that time and said, "Angus, I don't think it's anything to worry about." Eventually he was sent to a neurologist where tests were done. To everyone's surprise, including the neurologist's, it came back, after he had a spinal tap, that it was very likely that he had early onset Alzheimer's.

We began to try and prepare ourselves for what was to come. I began to familiarize myself with available research on Alzheimer's disease. I had never known anybody that had Alzheimer's and I didn't know anything about this disease. I did a ton of research and reading but the research doesn't prepare you for the personality change that can occur with someone with Alzheimer's.

Before Alzheimer's my husband was the nicest, calmest, most laid-back individual you'd ever meet. He was a consensus builder. He was the man people would go to in the company or in the neighborhood when they wanted to get people together and get everybody on the same page because he was the least offensive person you'd ever meet. He grew up a Southern boy in a Southern town and just had those kinds of skills. You could see him "work a room" in a large social event. He would walk around and make everybody feel at ease. As the disease progressed Angus disappeared in so many ways. Our family was shocked as we watched him not only lose some of those skills, but those personality traits were replaced with someone who was short-tempered, belligerent, and sometimes downright mean. That was difficult to handle and heartbreaking in so many ways. I wasn't prepared for that. When you watch a movie about someone with Alzheimer's, they show calm, older people with a smile on their face that just don't remember things. That's as far from the truth of our experience as you'll ever be. Calm was never a word used to describe Angus's journey, Unfortunately, it has been one where agitation was pronounced daily.

I'll give you a few examples of the early stage. Angus was a very sociable person, and we previously had an active life. I found that when we would go to social events, the noise level would agitate him, noisy restaurants would agitate him, conversations between multiple people as you would have in a cocktail party, agitated him. It got to the point where he would say, to my surprise, "let's go," and I wouldn't understand why. I soon came to realize that he couldn't follow the conversations. He could not handle multiple conversations. He couldn't hear over the noise or process what he was hearing. As a result, our lives began to shrink. Socially, we were down to our very good friends that stuck with us, but the range of what we used to do started shrinking.

Another example of this is that my husband was a fabulous golfer, which was his hobby. However, it got to the point where golf was too much for him. He could still hit the ball, but the frantic nature of a golf course with people running around in a cart, and the active process of hitting a ball, finding the ball, and keeping the pace of play became too much for him. He would get frustrated and he himself walked away from what was, other than his family, his favorite thing to do. Those were symptoms of his dementia in the early stages.

The biggest manifestation of agitation that Angus has is when he wakes up in the morning and he constantly moves. He doesn't sit down, he grazes over food, he wanders in our home from window to door to window to door looking out, and never sits down, which makes it very difficult to care for him. Some of the things that we tried to entertain him with were to suggest he sit down and watch a movie, a golf match, or college football, which was his other passion. He couldn't focus on that anymore, so he wouldn't sit down.

Jen Pettis:

Maureen, you've shared a lot of his behaviors and you mentioned that he's frustrated, how are these things making the two of you feel dealing with those behaviors and those symptoms? You mentioned that Angus was frustrated with things, but did he communicate other feelings with you about how these behaviors were impacting him overall? You mentioned your social circle started shrinking and no longer being able to attend social events with Angus and dealing with his agitation and restlessness. How did it feel finding yourself having to navigate all these experiences?

Maureen Morrison:

It made me feel like I did not know what was coming next because these changes happened so quickly. It felt like I couldn't communicate at the same level or degree with the man that I have been married to for 36 years. I couldn't get a response from "Honey, what's wrong?" or "How can I help you?" Not only was I trying to help him physically, but I was trying to help him get comfortable. My goal all along has been to have him comfortable in his own skin. He is going through the most awful thing you could ever go through. To watch him be uncomfortable and to lose all the things that used to give him joy caused me to cry myself to sleep more nights than I care to remember.

He would get frustrated and then he would get angry. Unfortunately, he'd get angry at me most of all because he tended to relax the most around me and let his guard down. When his guard was down, he let his anger show. We brought in some caregivers during the day to help him and give me a bit of a breather. I also took him to adult daycare three days a week. During the mid stage of Angus's Alzheimer's journey, both of those strategies worked reasonably well for a period. My husband really liked the one-on-one caregiver, he tended to be on his best behavior around her. He did well when I brought him down to adult daycare.

It was good for him to get out of the house. It was good for him to interact with other people. The people at the adult daycare know what they're doing, so they could do the sorts of things you're supposed to do when somebody gets agitated. They could redirect him, keep him calm, let him wander around the facility, because he did the same things down there that he did at home. Those were some things that helped us deal with Angus in terms of the agitation. But even those didn't work after a while. As the disease progressed, he had about a five-hour window and after five hours of being at adult day care, he would start to lose it. He would get angry, aggressive, and he literally sometimes got physical.

They worked with me by asking if I could pick him up at two o'clock. Anything past two o'clock, he would tend to melt down. I would be at the door at two o'clock and pick him up. That worked for a period. The agitation changes and you must be prepared to deal with those changes. After a while, I would pick him up, but he wouldn't get in my car. I would walk with him, and he would be so agitated by that time that he refused to get in the car. He would argue with me about getting into the car, and it took everything I could to calm him down to get him in the car. We'd be driving down Georgia 400 and he'd be unbuckling his seatbelt and he'd be trying to open the door. One time he reached out and grabbed the steering wheel. It ultimately got to the point where it wasn't safe to get him out of the house to attend adult day care. That was another way the agitation impacted him. It took away something that worked for us for about a year of this journey. It took from me the ability to get that breather in the day of having someone else take care of him for five or six hours a day.

Jen Pettis:

After that period when that strategy wasn't working anymore, what were you able to employ to help you keep him and you safe regarding his behavior?

Maureen Morrison:

There were different strategies that worked at different times. The biggest thing for me was to realize that I had to accept his reality. I spent a lot of time during this disease telling him that he really didn't see something, or he didn't have to worry about this. He hallucinated and he had delusions, and he saw things that weren't there. For too long I would try and talk him out of that. Then I realized that I had to accept his reality. Instead of saying, "no, you don't see the people in the house," I would say to him, "are they upsetting you, honey? Because if they are, I'll ask them to leave." he would say, "oh, okay." then I would say, "you sit, and I will go talk to them and ask them to leave."

In the meantime, I would bring the dogs to him because he was very good with our animals. I'd walk out of the room, and I'd come back and say, "alright, I think they're gone now." he would say, "oh, okay, good. Thank you." He had a delusion, for example, that the people across the street were trying to hurt us. They were a nice, new, young couple. We barely knew them. He was convinced they were trying to hurt us. The gentleman drove a black pickup truck. My husband became obsessed with black pickup trucks. Do you know how many black pickup trucks there are in Georgia? Every other car is a black pickup truck. When driving my husband down the road, he would see all these black pickup trucks and he would say, "see, there he is" and the agitation would build. I eventually told him that I was going to go talk to this gentleman and make sure everything was okay. I had to convince my husband that for whatever reason it was okay. Rather than tell Angus, there's nothing wrong, I had to tell him that I would fix it. I felt like I was giving into that disease by acknowledging his reality. However, at that stage of the disease, what it took to make it work was to accept his reality.

Jen Pettis:

Maureen, you talk about how you could alleviate Angus's concerns and help to calm him. In addition to not having that behavior or symptom, when that agitation is avoided or treated well, how does that benefit you and Angus together? How does that allow you more joy together?

Maureen Morrison:

It took the tension out of the room. It took the elephant out of the room. When he relaxed, when he could smile, I was able to communicate with him more. I was able to reconnect with the man I was married to and have been married to for all these years. It allowed me to be able to say, "all right, Hun, what would you like for dinner?" I was trying to hold on to a little bit of normal for both of us.

Alzheimer's chips away from you bit by bit. It takes away the normal. It takes away your social life. It takes away the little things that give you joy. The thing that we had had together for so many years was dinner. I'm not the best cook in the world, but I would always cook dinner for us, especially since the onset of his disease.

We gave up going to restaurants, so having dinner together was our thing. When it got to the point that he wouldn't even sit down for dinner, I realized that that was taken from us as well. One of the hardest parts of this disease was knowing that an important communication point that we'd had together for so many years was gone because he couldn't sit still to have a sit-down dinner with me. It chips away at what you're trying to hold onto. It's hard. It's heartbreaking for him, but so heartbreaking for me and for my children as well.

Jen Pettis:

Maureen, in a moment, I'm going to turn back to ask Laura another question or two, but I wondered if you could perhaps offer advice for other care partners who might be just beginning a journey with a loved one who has Alzheimer's. What would you suggest to them?

Maureen Morrison:

First, dedicate yourself to learning as much as you can about this disease. The medical profession is still learning. Social services are still learning, and there's new information being discovered all the time. Even more important than reading and looking on the internet is developing a network of people through adult daycare. I connected with other spouses and children of people with Alzheimer's. The tips we were able to give each other, and the emotional support was a godsend. Along this terrible journey were moments of incredible joy. Much of that joy came from strangers. The thing that makes me cry the most is the unexpected kindness of strangers. People who are on their own journey with Alzheimer's are the most giving and wonderful people. To be willing to open yourself to that and to be willing to share yourself is what helps this journey be at all survivable.

Jen Pettis:

Maureen, what a gift you have given us and our listeners to share your story with us. I'm so grateful for that. I want to turn to you, Laura, to talk about the great work that you and your colleagues do at Emory Integrated Memory Care. How do you help individuals with agitation in Alzheimer's disease and their families address the condition? Can you discuss what the interdisciplinary team recommends for their approaches to care, including non-pharmacological and pharmacological interventions?

Laura Medders:

The first step in figuring out how to treat agitation in someone living with dementia is really including all the members in your care team. That includes the family members and the care partners who are living with the person who is exhibiting this agitation. Whenever possible, including the person who is experiencing this agitation and the treatment and asking what is wrong? It is about trying to help figure out what are the triggers for this agitation. What is causing this? Is it the noisy restaurants? Is it the black trucks that Maureen mentioned that are escalating some of this agitation and aggressive behaviors? The care partners and the other people on the care team need assistance in determining strategies to use when these triggers come up. They need strategies that will help them modify the environment so that it looks different, to remove the triggers.

While it's hard to remove those black trucks, other items that trigger reactions could be removed. If a person sees a purse or keys and that triggers the thought that it's time to leave the house, then putting those items out of sight in the home could prevent that association trigger. Working with the care team to try to figure out what's going on and what we can do without medication to help improve and reduce some of those experiences is beneficial. I think Maureen is exactly right that different strategies work at different times and sometimes strategies need to change within the span of a day or a week. What worked in the morning may not work in the afternoon. It's helpful for care team members and family members to understand that being flexible in that approach and understanding the importance of trying again is important.

When the individual has spoken with our registered nurses, and they've talked through some of these strategies with an occupational therapist or a social worker on our team, it could be time for medication to be added to the person's regimen to help reduce some of the distress that this agitation is causing and help take the edge off. Thus, it really is the whole team approach and not just the medical team's input that is valuable and critical for treating and managing some of these agitation symptoms.

Jen Pettis:

Maureen and Laura, I want to thank you both so much for joining me. Maureen, thank you so much for giving us a glimpse into your world and your valuable insights that you shared with us today. I'm sure that our listeners are going to find it extremely meaningful and learn a lot from your experiences. I want to thank everyone who listened to this episode and I'm sure you found it as meaningful and as I did to have the discussion. I just want to say thank you to both our guests for joining me.

Announcement:

To learn more about The Gerontological Society of America, visit geron.org. The Gerontological Society of America was founded in 1945 to promote the scientific study of aging, cultivate excellence in interdisciplinary aging research, and education to advance innovations in practice and policy. For more information about GSA, visit geron.org.