

# Alter - Empowering African American Churches to Support Members with Dementia and Their Families

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

Momentum Discussions Podcast from the Gerontological Society of America

Recorded March 14, 2024

---

**Guest:**

**Fayron Epps, Ph.D., RN, FGSA, FAAN**

Associate Professor, Tenured  
Director of Community & Research Engagement  
Alter



**Host:**

**Jennifer Pettis, MS, RN, CNE**

Director, Strategic Alliances  
Gerontological Society of America



---

**Announcer:**

The Gerontological Society of America, meaningful lives as we age.

**Jen Pettis:**

Welcome to this GSA Momentum Discussions podcast episode titled "Alter - Empowering African American Churches to Support Members with Dementia and Their Families." [Momentum Discussions](#) highlight topics experiencing great momentum in the field of gerontology. We're grateful to Genentech, Eisai, Lilly, and Otsuka for their support of the [GSA KAER Toolkit for Primary Care Teams](#) and today's podcast. My name is Jen Pettis and I'm the Director of Strategic Alliances at the [Gerontological Society of America](#) (GSA).

**Jen Pettis:**

I'm pleased to serve as the host for today's Momentum Discussion. I'm honored to be joined by Dr. Fayron Epps for this podcast episode. Dr. Epps is a professor and the inaugural Karen and Ronald Herrmann Distinguished Chair in Caregiving Research within The University of Texas Health Science Center San Antonio School of Nursing. She's a GSA member and serves on the GSA Board of Directors, and she's the Founder of Alter, a program that equips faith communities to serve and enrich the lives of all members, including those with dementia and their families. Dr. Epps, I'm so glad you could join me today.

**Dr. Fayron Epps:**

Thank you, Jen, for the invite. I am glad to be here.

**Jen Pettis:**

I'd like to ask you if you'd discuss a bit about the Alter program in general. Please give us a high-level overview of it.

**Dr. Fayron Epps:**

[Alter](#) is a program where we partner with predominantly Black congregations and Black faith communities across the country to equip them with the resources and tools that they need so they can better support their parishioners and the community at large that they serve. Many times, in my work in the community, I found that a lot of people depended on their faith community, their church. However, when I spoke with the leaders of the church, they were unaware of dementia, or they didn't have the tools to properly respond to the needs of their parishioners.

**Jen Pettis:**

I understand that this year you're celebrating 10 years of working in the community, in creating a faith network committed to developing dementia-friendly congregations. What inspired you to start this work and how did the work that you started become Alter?

**Dr. Fayron Epps:**

I would first like to drill down and give credit to my mentor at that time who started it. As I finished my Ph.D. and was writing for my postdoctoral, all my research in my Ph.D., graduate, and undergraduate programs had been related to family caregiving. She challenged me to narrow it down to the type of family caregiving. Who are these individuals caring for or supporting? What is the chronic disease or illness that they have? I was always interested in groups that had been historically put at a disadvantage. I wanted to know what is impacting the Latinx and Black communities. When I picked up some literature and I started reading, I ran across the facts and figures from the Alzheimer's Association, and I saw alarming numbers. I was shocked. This was back in 2012 -2013.

That's when I started drilling down and thinking that I wanted to find out more about dementia and find out how I can help these caregivers who are caring for someone with dementia. That's when I started the journey of meeting families that were on this journey and learning from them. I started in Louisiana, and it continued even when I moved to Atlanta seven and a half years ago. When I moved to Texas, it continued. It's all about meeting families and learning from them; learning what they're doing, how they're managing, and going through their day, as well as learning what they need to continue to navigate their journey or their caregiving journey.

**Jen Pettis:**

Dr. Epps, how does Alter support a congregation to become dementia-friendly? How do you help them sustain their Alter program once it's established?

**Dr. Fayron Epps:**

We support our programs by developing a framework, a model that we introduce to our faith communities. We have liaisons that will work with our programs to hold them accountable to the components of the model and then implement those in the model. We give them additional resources for them to continue to do the work. That's where sustainability comes in.

As part of our partnership with our programs during the initial two years, we learn from them, and they learn from us. We provide a lot of education to them and introduce them to new opportunities that they can then apply for additional funding. We encourage them to establish partnerships on their own that can help sustain programs. We have collaborated with one of the managed care companies in the Atlanta area who were then able to support some of our faith communities after two years. They can continue to do activities, such as a food pantry or serving the older adults in these families who are affected by dementia. We have had a lot of opportunities to do that.

One of the things we're doing to build capacity at Alter is creating dementia-friendly congregations, but overall, we are building capacity within our faith communities. I want to make sure that when I walk away they will still be able to continue these initiatives, continue to serve their parishioners, and continue to serve the community. Many times, we don't think about that in the beginning, but it's very important. We can have that strategically placed throughout the partnership so they can learn about how they can sustain this on their own. Now they don't want to let us go, Jen.

**Jen Pettis:**

I bet they don't. You work with them for two years and then really build that program alongside them and give them the tools to continue it on their own, is that right?

**Dr. Fayron Epps:**

In response to their not wanting to let us go, we're developing a legacy program. At that two-year mark, if they want to continue, they can still be a legacy partner; they just get less support.

**Jen Pettis:**

When you're training in the churches, are you training just the church leaders or are you training others that will volunteer to support part of the program? Who do you train?

**Dr. Fayron Epps:**

Each faith community identifies ambassadors. Those ambassadors could be current ministry leaders, or it could be someone that they want to appoint to work with us. Those are the individuals that we work with and coach. We train them to be able to deliver education. We also come in and deliver education, but they can now reach out to others. We teach them how to do those things and implement programs like respite programs and things like that within their community.

**Jen Pettis:**

You've mentioned some education, respite, and other programs like the food pantry. What are some of the key program activities? Can you shed some light on what led you to develop those activities as part of the Alter program and maybe even how they've evolved?

**Dr. Fayron Epps:**

A lot of the activities that we asked our churches to implement are informed by the evidence that's already out there. There are not too many activities that we developed ourselves, rather we pull from the literature, pull from great programs that already exist, and share those with our faith community. They can now choose if they want to implement this or that. One of our common activities, which surprised me, is that many of our faith communities select to do [Memory Cafes](#).

I was very shocked some of our Black faith communities implemented Memory Cafes once we explained what it was. We do have a few of our communities who learned what respite was and took that initiative as well and are creative in how they do that.

Education is very popular. The virtual dementia tour is another popular program as well. Then we have some of our faith communities who have decided to supply closets for families. In response to the economic crisis and knowing that a lot of these supplies that family caregivers need, they may be unable to afford, many of our faith communities have started supply closets. I know we're talking a lot about education and support, but one pillar that sets the Alter program apart is that we don't forget this spirituality piece, that religion piece. We also work with our congregations and communities on how to modify worship experiences.

That has been well received, surprisingly. To tell a faith leader to switch up and change their format or their service can be challenging or intimidating to some. We have been able to do that by giving the rationale and they've been very open.

**Jen Pettis:**

Well, that's terrific. I know you and your colleagues have studied the outcomes of Alter. What have you learned?

**Dr. Fayron Epps:**

What we've learned is, "Build it and they will come." That is the biggest thing, especially in the Black community. We know this. This is in the literature. There are so many people out here on this journey who are not speaking about it. I think years ago, people called it the silent epidemic. It still is a silent epidemic, especially in the Black community. We've seen if our faith communities build resources, build support programs, they will see members in their congregation who have been there for 10 years who previously said nothing are now speaking up. Build it and they will come. I've heard we have a lot of qualitative results where we've heard from families themselves. Family caregivers say that their clients used to just sit in a corner and not say anything. But now seeing them being involved in Alter, they feel empowered.

Now they feel comfortable speaking up and sharing the diagnosis of their husband and how they may need help from our faith leaders as well. You can see a big difference because now they're excited. Jen, they called me and said, "Hey, I had a family join the church today. They told us about their mom, and I told them what they need to do and how they can still be welcome." They're grateful because they said before this being introduced to the Alter program, they wouldn't have known how to respond at all. We are in the process of developing a Dementia Friendly Community Assessment Tool. I would love to come back and give you those results. We surveyed a little over 1,300 Black parishioners in the State of Georgia as it relates to their assessment of their faith and the community at large as it relates to dementia friendliness.

**Jen Pettis:**

I can't wait to learn about the results of that. We'll have to talk about that and what people are hearing on the streets, in their community. I'm also interested to learn a bit about the study that you and your colleagues conducted in which you examined the perceptions and attitudes of African American congregants toward dementia before and after attending a dementia-focused workshop. Would you share a bit about what you learned?

**Dr. Fayron Epps:**

This was early on when we were offering education before the program became an official program. We did a workshop called, Dementia Friendly Workshop for Church Leaders. One of the goals of that workshop was to see if we can alter the perception of how people in the Black community think and how they act towards someone living with dementia. We used a free word association exercise at the beginning of the workshop in which we gave them the word dementia or Alzheimer's disease, and they will write the first couple of words that come to their mind, and then we'll talk through that. We'll post it, draw trees and they'll put it on leaves, and we'll talk about that. They share their experiences.

After the four-hour workshop, we would repeat the exercise, give them leads again, and have them write these phrases or words that come to mind, and then we'll post them up so they can see the difference. Throughout the workshops we've done, we saw, in the beginning, that the word correlations were very negative. Gloom, death, hopelessness, anger, and loss were some of the words. In the end, the words included love, hope, partnership, and helpful. That just really made our hearts smile, being able to see that, but then also sharing, showing it instantly to the attendees how their thinking changed in just a matter of four hours.

**Jen Pettis:**

This was a great discussion and some of the things that I heard stuck out with me. We talked about the silent epidemic and often this is especially early in dementia, it's a condition we don't see. It's not a visible disability for folks. Giving people the opportunity to feel welcome and included by empowering the churches to meet their needs and create an inclusive environment is just so powerful. I loved it when you said, "Build it, and they will come." If you make these things available for the parishioners, they'll feel welcome, and they will have that support. What are a couple of key things you want to leave our listeners with?

**Dr. Fayron Epps:**

I know we'll have all different types of folks listening in, and I just want to encourage everyone, if you have a program in your heart, something that you see that can help the community, I will say move forward with it and do it. I know there are so many people out here with great ideas on how they can support their faith community or community organizations, but they don't do it because they think of all the barriers. I will tell you to build it and they will come as well. It's so important. I say that Jen, because I don't want to be the only person out here doing this. We need everyone. It takes a village for us to meet the needs of these families, and to change outcomes.

It takes a village. I just want to encourage anyone who has even a small idea because that's where this one started. It was just me coming up with something just outside of the box. It used to be called Dementia Friendly Faith Village Community. It was this whole long name. It just took one or two people to believe in me and say, "We will volunteer our time."

**Dr. Fayron Epps:**

We'll sacrifice to see because we want to serve, and we want to be able to help. That's where it started, especially with the work specific to the churches. I just want to encourage everyone. If any families are listening, I want to ask you to share your experiences and share your testimonies. Families can no longer be silent on this journey. We need to speak up, advocate, and make sure that we get the resources that we need. That's advocating at all levels, advocating within your family, within your care team, and that includes your healthcare providers.

As you learn and become educated; advocate, speak up. There's no reason for you to be on this journey alone. When you speak up, you're helping yourself. I firmly believe you're helping yourself, but you're also helping the next caregiver, the next family that is on this journey.

**Jen Pettis:**

Absolutely. Well, I think that's a pretty great way to end. Dr. Epps, thanks so much for joining me and for sharing your insights and your passion for this wonderful program. Thanks to everyone who's listening to this episode of the GSA Momentum Discussions podcast. We hope you found it informative and enjoyable. Thanks again, Dr. Epps.

**Dr. Fayron Epps:**

Thank you.

**Announcer:**

The Gerontological Society of America was founded in 1945 to cultivate excellence in interdisciplinary aging research and education to advance innovations in practice and policy. For more information about GSA, visit [geron.org](http://geron.org).