

Summary

In this episode of Aging For All, hosts Jen Yanez Pryor and Andrea Price welcome Dr. Fayron Epps, an expert in caregiver research and the founder of the ALTER program. Dr. Epps discusses her work in creating dementia-friendly congregations, particularly within the Black community, and emphasizes the importance of caregiver support, community engagement, and the challenges faced in changing the culture of faith communities. The conversation highlights the need for awareness, education, and action to improve the quality of life for families affected by dementia.

Takeaways

Dr. Epps is dedicated to improving the quality of life for families affected by dementia.
The ALTER program focuses on creating dementia-friendly congregations in the Black community.
Caregiving can be both challenging and rewarding.
Faith communities play a crucial role in supporting caregivers.
Many caregivers feel isolated and need community support.
Dementia-friendly environments are essential for engagement and support.
Education and awareness are key to changing perceptions about dementia.
Building relationships with faith leaders is vital for program success.
Community feedback is essential for developing effective programs.
The ALTER Dementia Summit aims to bring together faith communities for education and collaboration.

Jen Yanez Pryor (00:01)

Hello and welcome to Aging For All. We're your hosts. I'm Jen Yanez-Pryor.

Aging For All (00:05)

And I'm Andrea Price. Thank you all so much for joining us today.

Jen Yanez Pryor (00:10)

Today, our special guest is Dr. Feiron Epps. Dr. Epps was recently named the inaugural Karen and Ron Herman Endowed Chair in Caregiver Research within the School of Nursing at the University of Texas, San Antonio. Dr. Epps is an accomplished nurse scholar, brings a wealth of expertise and experience in caregiving, strongly focusing on improving the quality of life for families affected by dementia.

She earned her doctoral degree in nursing from Southern University and A College and completed her postdoctoral fellowship with the National Hartford Center of Gerontological Nursing Excellence, showcasing her dedication to academic excellence. Dr. Epps also holds a master's of science degree in nursing, specializing in healthcare systems management from Loyola University, New Orleans, and earned her bachelor of science degree in nursing from Tuskegee University.

Her primary career goal as a nurse scholar is to enhance the quality of life for families affected by dementia through a combination of research, education, and service. Dr. Epps specializes in evidence-based practices that promote higher quality of life for African Americans with dementia and

their family caregivers. Her research is particularly focused on exploring how religious activities and spiritual connectedness can foster meaningful engagement among persons with dementia.

She is the founder of the only nurse-led dementia-friendly congregation program, ALTER. Through this program, Dr. Epps and her interdisciplinary team collaborate with African American faith communities, equipping them with the necessary tools and resources to support families facing dementia.

Aging For All (01:54)

Hello and welcome

Dr. Epps.

Fayron Epps (01:56)

Thank you. Thank you. I was like, where did you get that bio from? Oh, wait, and all where I got the degrees from and everything, Jen, but thank you.

Jen Yanez Pryor (02:00)

Ha ha!

You're

welcome. It's very impressive. I loved reading about it.

Aging For All (02:10)

Yes, and I love being a part of the Alter family. Our team and family at VCU is a part of the Alter team and family, and it has been an honor to work with Alter and with you, Dr. Epps. So tell us a little bit about Alter, a little bit more in detail and why this work is so important for America and hopefully globally soon.

Jen Yanez Pryor (02:31)

Thank you.

Fayron Epps (02:32)

Yes, yes,

well, kind of already globally, but this work, y'all, is, it is, I just don't know what to say about it, right? It's life-changing, not just life-changing for the communities and families we work with, but life-changing for me. And I think members of our team too, this journey has been wonderful. It hasn't been easy, very challenging at times, but just having that impact and seeing growth.

among your team members, myself, and also the community. And so for those that's, okay, she's still not saying what ALTER is. ALTER is a program where we partner with predominantly Black congregations to coach them on creating dementia-friendly congregations, right? So that's our whole goal is to have more dementia-friendly congregations in the community, particularly in the Black community, because of

the history of not having resources there, many families not being able to access supportive services. And so this is coming where, okay, let's build a capacity of these faith communities that are really strong in these communities to be able to fill in that gap and serve these families. And y'all, came about, you know, I started off when I moved to Atlanta in 2016,

I started off with just educating me and some team members, just educating the community because I didn't know as a nurse how dementia was disproportionately impacting certain communities of color. Had no clue. If I didn't know, imagine how many other people that did not know. And see, we started off with the education, but it took one bishop.

to stop me in the four year after education, he asked me, am I supposed to do with this? And I didn't have an answer for him. And that really kind of sparked me to, oh, you know what? We need to go beyond education and really create a full fledged program. We started off with an algorithm, but then it led to, as I was talking to more colleagues, us pulling into a full fledged program. that's how all...

Alter was truly birth, what was that way. And it has been amazing journey to be able to help faith communities. And y'all, I see this as my ministry, right? Because I may not be directly touching these families, but I am helping and equipping our leaders, our faith leaders in the community to better support them. I received so many phone calls like, what to do, where to go.

You know, like they want to help, but sometimes they just don't know what to do. And that's what Altar is here to show them. Hey, these are the things that you can do. This is how you can better support. And we also focus on early detection, brain health as well. So it's not always about just who is on this journey. We also want to do risk reduction and making sure people get the help.

One of the things I want to share with you all, my goodness, it just slipped my mind. I wanted to make sure I get this out as I was talking. I was like, wait, wait, I got to make sure I share this piece, but it'll come back. So I'm going turn it over back to you.

Jen Yanez Pryor (06:05)

I'm sure it definitely will come back. I think this is really important work that you're doing. And I think that the space that you're working in, just being an educational gerontologist, I hear a lot of people asking for help with understanding dementia. What do we do? How do we help engage folks? And for our listeners who may not be familiar with the term dementia friendly, could you tell us what that looks like?

Fayron Epps (06:33)

Thank you, Jen. That's actually what I wanted to talk about. I wanted to talk about like the origin of the dementia friendly piece, right? And so I received some funding early on from the Alzheimer's Association to create these dementia friendly faith village worship services. This is how it all started, right? Like my research piece. And in order to make a worship service dementia friendly, I needed to back up and see

Jen Yanez Pryor (06:35)

great!

Aging For All (06:36)

you

Fayron Epps (07:02)

what the community is expecting, particularly the Black community. So Dementia Friendly America, of course, they have their organization, their broad definition of what dementia friendly is. And I don't know it word for word, but basically it is having a welcoming and supportive environment that families that are on this journey can engage in.

and still receive support services, things like that. And so there's a lot of dementia friendly communities where businesses are relooking at their environment, relooking at the hours that they're open, the things that they have available to support these families. But for this work, I actually took a pause and say, let me go to the black community and ask them what do they need?

And the things that came out were kind of very similar to what we have with Dementia from the America. And one of the things they said, they wanted a welcoming environment from their church. Surprise, right? Because I was like, church is supposed to be welcoming. But for those who grew up in church, know, every church is not too welcoming. They get in their little ways and, you very judgmental. So they wanted a welcoming environment. They wanted a church that would provide

Jen Yanez Pryor (08:22)

you

Fayron Epps (08:24)

resources.

Also a place that was really concerned about the personal well-being, especially of that caregiver and that person living with dementia.

So welcoming resources, I don't know the other two y'all, I'm about to pull up the article. But it's basically just having that church that is open, welcoming, non-judgmental, have the resources that are there for families so they can continue to have a good quality of life while on this journey.

Aging For All (09:03)

Yes, and I think that's what is really encouraging about the work that I'm able to do with ALTAR. I often tell the congregations, we don't know who's going to walk into the doors of our church, and we don't know what conditions we might find ourselves in. So we want to make sure this place is dementia friendly and ready and inclusive. I think this work is about having an inclusive environment, and that's the beauty of ALTAR for me. You mentioned briefly caregivers. So share with us a little bit about

Fayron Epps (09:24)

Yes.

Aging For All (09:32)

the caregivers role in the work we do through ALSER and why this matters also.

Fayron Epps (09:37)

Yeah, think, you know, caregiving is challenging. That's, I mean, that's really spread throughout the literature, the great literature, all on the website. They talk about how challenging caregiving is, but I do want to make sure caregiving can be also rewarding. And in this space, we just want to make sure that we have the resources for caregivers, because many caregivers feel that they own this journey alone.

You know, y'all, going to speak, you a lot of my work is focused on the Black community. So I'm going to speak to their stories and their experiences, but it does not, I don't want to say, hey, they're the only group that experiences this. I want to be very clear. But based on my work in the community, many Black characters feel their ownness journey alone. And even if they're going to church, they still feel like they're on this journey alone because this is not talked about.

No one in church is really saying who's a caregiver, especially for someone living with dementia, or they keep that to themselves because that stigma that's related to dementia. So of course they're going to feel like they own this journey alone, that nobody's there. And that's what we're trying to change. We want to see that, them to see that they are not alone. And actually the church is part of their care team. And that's what we're trying to build up. So now they can feel comfortable.

calling on their church family to support them on this journey. I just had a caregiver this week. They don't go to church as often and she was just in tears. She was like, I am the only, I'm the only one. I'm doing this, the only child, here I am, nothing's there. And then when I was sharing with her about the faith communities that we're working with, she could not believe it.

She was like, well, I'm going to that church, you know? And I was like, yeah, they're on this journey now. I'm not going to say everything was perfect, but they're working toward it. And just hearing about the additional resources that we're offering. And with us working with churches, we provide research opportunities. That's one thing. We are exposing them to the different research opportunities that can also help the community.

help the caregivers. And so one of those research opportunities that we promote through our churches is caregiving while Black. And again, this is just another way, it's a safe space for caregivers to learn and to emotionally share what's going on. Get this basic foundation and then they're able to receive more information from others.

And so those are the things that in our altar churches that we are doing to kind of support caregivers. So I think back to your question, what role do they have? They really don't, their role in the altar program is just to be there receive, use the services that the faith communities are putting in place.

Jen Yanez Pryor (12:50)

I love this. You have me thinking, with your intersection of education and research and service, I'm thinking of all kinds of questions to ask you, but I'm curious if you could talk a little bit about what are some of the challenges that you've seen? We're talking about changing the culture of a faith community, right? And so what are some of the challenges that you've seen?

Fayron Epps (13:12)
I'm gonna go to bed.

Jen Yanez Pryor (13:18)
struggle with a little bit, but then maybe reflect a little bit on what are those outcomes once you get over that challenge? What are some of those outcomes that you're seeing?

Fayron Epps (13:27)
Yeah, so one of the biggest challenges is when the faith leaders do not recognize the urgency of this or that this is really a crisis, a public health crisis. And so when you're sharing what's going on, it's still, it's not high on their agenda. And that's very challenging because you know, I mean, we all know we're in this space and we're like, we have to act now. We need to act like yesterday, you know, yesterday.

But we have to respect that, you know, it's going to, it's a learning curve for them. And if they do not have a personal experience with this, they truly do not know. And so, you know, that has been, especially when I started off, that has been one of my biggest challenges. People like they listen, but they don't take action because they don't, they didn't see the urgency of it. And what I learned was that I needed to stay persistent.

And so don't get discouraged, you know, and don't get upset because they truly don't know. And you have to just keep showing up, putting the information in their face, not in a way that you're nagging them, right? Where they ban you from coming in, but in a manner where it is still welcoming, you're not overbearing.

with, y'all need to do this program. And it takes time. Many people in the community think, this should happen overnight. And it does not, right? It does not happen overnight. It really takes time because you're sharing this information. You also have to build these relationships. And even though I identify as Black and African-American and I'm working with Black churches, many people

from afar was like, well, that's easy to do. And that's not easy. I'm still having to build a relationship. I'm working with several denominations. So I'm not just focused on Baptist or A and E. Currently we are in 13 Christian denominations. We're trying to expand to all denominations and faith beliefs. And that takes time. That takes time. And as a researcher,

Jen Yanez Pryor (15:40)
you

Fayron Epps (15:52)
you also have to take the time to learn. So it's not just learning a culture you're learning this faith and not like it's a lot that you go in to try to understand their doctrine, their practices, their beliefs. So when you are trying to share these statistics and the urgency of this, you can align it. And so they can be able to better receive it. And I will tell you all, when I first started off, I didn't have that down pat.

I didn't, you know, I was just going in there with my, with how I was trained, but you know, I would say five, six years, I guess I'm six years into this. don't know, but many years into this, I can say, you know, I have that down pat and I'm now trying to train others to, get to that point. And now that I have a down pat and many members of my team, we're seeing an influx.

a faith community is interested now. Because now, you know, you have one faith leader, hey, we doing this and, you know, and they can vouch for you for the next faith community. And it's a lot. Because it is. And so and that's what we're seeing. We're seeing all of this interest now from our faith communities, but also just from community members, members of the Black community, like

Aging For All (17:07)

We did.

Jen Yanez Pryor (17:07)

you

Fayron Epps (17:21)

now they're seeing this. They want to be involved. They want to help. They're super excited. Everybody, know, the Pew Research Center put a lot of statistics out and we know there is a trend where less people are attending church. But that's for many reasons. And I think with our work, we're trying to kind of change that.

as well. I, you know, I've had pastors say, well, so-and-so is coming back to church. I've had caregivers say, well, you know what? I'm coming to church this Sunday. You say this is what they doing? I'm gonna bring my husband and we come in. And to me, that's that's that impact, right? When families say, I feel good. I can share what's going on because the pastor talked about this on the pulpit. That's

That's the impact.

Aging For All (18:20)

Absolutely. I think another beauty about altar is kind of the ancillary impact. Some churches I've met with don't necessarily, or they're not ready yet to become altar churches, but they do want me to come and provide some education about dementia. And so that's also a beautiful part of this too. I didn't expect that, but I have been invited over and over again to spaces just to talk about dementia because they heard about altar.

Fayron Epps (18:32)

Mm-hmm.

Jen Yanez Pryor (18:33)

Thank you.

Aging For All (18:49)

And so hopefully they'll come on and know we've had to pump the brakes. But the interest in just learning about dementia has grown, I believe, because of what altar is to the community.

Fayron Epps (18:57)

Yes.

Yeah, and that is a good point. You know, I think more awareness is out there now and people are willing to talk about it. You know, one of the good things is, know, y'all, feel maybe about two, two, three years ago, we, we really overcame, I'm not going to call it a barrier, but

many times and researchers don't think like, yeah, worship service Sunday or if it's Sabbath day, seven day event is, you know, is that sacred? You know, we can't do nothing on that day. We cannot provide education. And it actually was a seventh day of vintage church was the first church that invited me to speak on their Sabbath. And I was like, whoa, what?

I say, well, you're going to preach, right? Nope. You're going to deliver the message. And at that point I was like, whoa, we, have arrived. So it's not as like for them, they're taking it that serious where they going to take their Sabbath and dedicated to providing education. And that was the first that followed by many. And now that's the normal thing.

to just invite me, because now they're like, well, everybody here on a Sunday or here for worship, let's just give you the mic. And I would have never dreamed of that when I just started this off. I was like, no, no one's going to even let me speak during the worship. But now it could be 10 minutes or me delivering the key message during a worship. And to me, that is the biggest win, even if they don't become partners.

Just getting that education to me, that's like the first step. So now they can start having conversations at home, at the barbershop, at the beauty shop, at work, based on what they learn during worship.

Jen Yanez Pryor (21:06)

Wow, I love, you know, I, I haven't heard your spiel, right? I haven't been to the services and, I can see connections between what you could be talking about and just spirituality and religious duty, right? We're taking care of one another. And so I could see that from the perspective of you're not here to sell us something. You're here to help us grow in our faith and community and

I think that's a beautiful thing. When you take a step back and you recognize that we're not caring for all of the members of our congregation, of our community in the ways that they need us to care for them. And Dr. Epps is gonna help us understand how we can do that better. I love that, I love it.

Fayron Epps (21:52)

That's right. That's right.

That's right. And I love what you used the word about. I love that phrase, religious duty as well, because that is the thing that I, y'all, you know, a lot of faith communities, you know, they talk about love. A lot of stuff is based off of love, but love is action. Y'all, it is our duty to take care of our fellow parishioners, you know, and that's the message that I put out. And for those that are listening, you know,

Jen Yanez Pryor (22:12)

Mm-hmm.

Fayron Epps (22:22)

We use love a lot, but it is truly an action word. And we have to think about ways that we can support each other. So even if you're not faced with dementia right now, what is it that you can do for your neighbor or a family member or a fellow parishioner that may be? And it's just kind of thinking about that. I will share also for the listeners,

I speak a lot about this being in a Black faith community, but a lot of these principles can be brought into many communities as well, right? And can work. And I am totally open. We're working with other groups to share. So this is not like, just for Black churches. No, we're open to sharing, to being able to see how other groups may can apply some of these principles, because it's about all of us.

getting help. It's just for right now, I want to be clear that the primary focus for the ALTER program is for the Black community, because we're trying to curve those statistics, y'all. So y'all bring me back on a podcast in 10 years, so we're going to see. And we have a change, you know, but that's what I'm trying to, that is my goal, you know. So by 2035, some of those statistics will look different because we've been out there educating, creating these supportive programs in the community.

So these families can benefit from it. We are also, y'all, while I'm doing this work, it's so important for others that are doing the work in the community to listen to your community. What is it that they need? They may not need an altar. They may need something else. So I think it's very important that you listen. And when you truly respond to their needs, you're to see an uptake of your program.

Cause they told you what they needed. You built it. You're bringing it to them. And now they're going to be there to use it. And they're going to appreciate that. And they're going to be your, your number one supporter throughout the process. And I bring that up because as I was even working with the churches, y'all, I, they were telling me they wanted a big gathering and I was just ignoring them. That was intentional. Cause I was like, that sounds like a lot of work, but

You know, eventually I said, you know what, they keep bringing this up. I have to listen. I have to be able to respond. And I want to put a plug in for our Ulcer Dementia Summit that is held annually in Atlanta for right now. We have our next one, April the 10th through the 12th in Atlanta at Impact Church. And this is where we bring everybody together.

So all of our faith community partners, but even those that like we mentioned early, they're not ready to partner, but they still want resources. They want some practical tips that they can bring back, right? And align with their faith practices to be able to help these families. We're bringing everybody together so we can learn from each other. We can also find solutions that would better work.

for the black community. Learn about research so we don't have to wait 17 years or so to get findings and then make something happen. No, learn directly from researchers and ask your questions so you can know, okay, this is my takeaway. This is the stuff I need to start doing now. So

those are the things. I just wanna put that plug in for the summit. If you are listening, please, you can go to alterdementia.com and alter is A-L-T-E-R.

Dementia.com and you can learn more about our summit and to register pass the word We're just super excited and y'all this is the this is not me. This is the community Taking action. I just helped pull that together I'm hardly on the stage at the summit Because it's the community that is pulling this together and they're gonna move this this movement forward

Aging For All (26:40)

Absolutely. And one other thing I do want to bring up are the national partnerships.

are the national partnerships with ALTER. And I think that also has helped it grow and get the word out even more. So thank you, Dr. Epps. You are a change agent. And I am just honored, honestly, to be a part of ALTER and the ALTER family. And I'm grateful for VCU seeing the vision and understanding this is important for our citizens here in the state of Virginia. So thank you.

Jen Yanez Pryor (26:52)

Thank

Fayron Epps (27:10)

Thank you. And you know, when you brought up partnerships, even partnering with VCU and the other organizations and universities, mean, it it means so much to me. So it's not just what I'm doing in the community. When I have these organizational partnerships means so much, because that means people, they see the vision and they want to have impact and they understand how it's important to partner so we can have help.

their communities in their respective geographic regions. So we partner with a lot of universities, service providers, Alzheimer's disease research centers, public health agencies. We partner with everybody. If you are on board and really wanna have impact and like it was mentioned, be a change agent alongside me as we, you you wanna come in, let's trailblaze these.

these waters together, I am here for it. So please do feel free to reach out. And I thank you all for having me.

Jen Yanez Pryor (28:17)

Yes, yeah, we want to thank you so much, Dr. S, for joining us today. It is, I've learned so much. It's been such a pleasure to learn about the ALTER program and the impact you have in the community. And I also want to thank our listeners, as always, for tuning in.

Aging For All (28:32)

And please join us next time for another episode of Aging For All.