

NINA MOINI: June is Alzheimer's and Brain Awareness Month, so we wanted to highlight work happening in the state to support Minnesotans affected by dementia. That's the general term for the loss of memory and other cognitive abilities. Alzheimer's disease is the most common cause of dementia. According to the Alzheimer's Association, more than 100,000 adults aged 65 or older in Minnesota live with Alzheimer's. We're joined now by a University of Minnesota professor who's trying to visit all 87 Minnesota counties to give information and learn more about innovations in dementia care. Joseph Gaugler joins me now. Thanks for being here, Joseph.

JOSEPH Well, thank you for having me. Appreciate it.

GAUGLER:

NINA MOINI: Well, I'm glad we were able to set the scene a little bit of just how many people are impacted by Alzheimer's, because I think if you don't directly know someone, you might not realize it's as common as it is. So I understand you did your first visits in 2018. How many counties have you been to, and what made you want to do this?

JOSEPH Yeah, so my last county visit was actually just last week in Isanti County. So that made 46 counties so far of the 87 in Minnesota. So I have some ways to go. My motivation for doing this really began with-- I think for two reasons. One, first and foremost, I felt it was important, given the mission of the University of Minnesota and the work we do where community outreach and engagement has always been very important to it, is to share with Minnesotans what have been some of the most up-to-date findings of how we've come to understand Alzheimer's disease, how we identify it, and perhaps most importantly, is there anything we can do about it, either personally or in terms of emerging therapies and treatments?

Secondly, as a researcher, I think it's been incredibly beneficial to our work in-- when we hear the shared lived experiences of people living with dementia in our audiences or those who care for them, it's really helped us identify questions and a program of research that we hope is as most impactful and beneficial as possible.

NINA MOINI: Can you give an example of that? I just wonder what you're hearing from everyday people about their experiences. And what would help them? And what are the types of innovations that can come from those kinds of human interactions?

JOSEPH Well, I think one thing we hear a lot from families are really the importance of key transition points throughout the course of a loved one's dementia, the diagnostic transition, the transition of maybe having to make that decision to move a relative into a 24-hour residential care facility, whether it's a nursing home or maybe an assisted living, having to give up driving, as another example, which can be very impactful to the sense of independence of the person living with dementia, but also is stressful for the family too. How do you deal with this? How do you help the person living with dementia navigate the challenges of that, but also helping them to remain safe, for example?

And so some of our most recent work has really attempted to craft support programs to help families navigate these different transitions. We have a recently completed study that provided support to caregivers of people living with dementia who have a loved one in residential long-term care and what kind of support we could provide to them. We've just completed a preliminary study for those who are navigating families and people living with dementia, navigating driving cessation called CarFreeMe.

A third project we've just finished has to do with a very, I think, interesting subgroup of people, but that's growing are people living with dementia who don't have a care partner available. Either they're not living near one or they don't have one at all. Those are individuals as well that have significant challenges and needs. And a lot of the questions and the inspiration for these questions have come out of the engagement we've had with people living in communities across Minnesota.

NINA MOINI: It makes you think about just the aging population overall here in the state of Minnesota. And what are you seeing as you're looking down the road of how this state is going to be impacted by this? And it was striking to me to think about the people who don't have caregivers. That's probably a lot of people.

JOSEPH GAUGLER: It's potentially a lot of people. The estimates range in terms of the number of people who don't have an available care partner. I've seen it roughly from 10% to 20%. But some have even seen in clinic populations as close to 30%. So, I mean, those numbers vary. I don't know if we have a good idea of that. But I think it really alludes to some of your introductory comments where you talked about all of us probably have maybe a loved one who has been living with dementia. Perhaps we ourselves might be having issues with our memory and thinking. And I do think that's very much a function of the overall aging of the state of Minnesota.

Again, an unfortunate non-modifiable risk factor for Alzheimer's-- now, again, it's not causal, it's a risk factor-- is age. So roughly 13% of people over the age of 65 are thought to have Alzheimer's or related dementia. That percentage jumps up to 32% for those over the age of 85. When you look at the demographics of the state, there are now more people over the age of 65 than there are 18 and under. So that in and of itself gives you an idea of the scope of simply the prevalence or potential prevalence of dementia in Minnesota.

NINA MOINI: Yeah. And I wonder, too, about the future of helping families and caregivers. And you mentioned how a lot of the resources that you offer go to the caregivers and the families. And I wonder if you want to talk a little bit about some of the ways that that experience has been turned into a more common experience or support groups like where do they meet? I'm seeing here that Winona has an effort underway to make the entire city dementia-friendly. I wonder what that looks like.

JOSEPH GAUGLER: Yeah, in terms of the dementia-friendly movement, it's really under the aegis of what's called dementia-friendly America, which is really done in concert with all the Area Agencies on Aging across the US, US Aging is the organization that kind of is the national coordinating entity for that. But really, the dementia-friendly movement started in Minnesota with something that was called Act on Alzheimer's. And this was, I want to say, around 10 years ago or so.

A number of communities across Minnesota decided to try to make their communities dementia-friendly, meaning that what is it like to live with dementia? How can health care systems, the local hospitals and whatnot, identify someone potentially living with dementia? But going even beyond that, how can law enforcement be more dementia-friendly? How can the local library be more dementia-friendly? How can businesses be more dementia-friendly?

And so these communities came together, put together pretty large roundtables of different key organizations in their communities like Winona has done, layered on top of that, our regular community education events that again, I think has really identified, first and foremost at its core, to reduce the stigma of living with dementia, which is a really, really consistent problem. This is something, certainly, we hear over and over again when talking with people living with dementia, their families.

And then also understanding that in order to best address the needs of someone living with dementia, we have to approach it from a contextual standpoint. Because Alzheimer's, I really do believe, is a disease of context. It first and foremost affects the person with dementia, of course. But then family caregivers are very much-- or care partners are very much potentially adversely impacted from a loved one's dementia, as are the local health system, businesses, vis a vis workforce productivity, for example, for caregivers. And the list goes on and on. So once we understand those ripple effects, I would argue we can better address them as communities.

NINA MOINI: And with that in mind, you're talking about some of these community-level impactful moves that are being made. But what else would you like to see at the federal level or the state level, or continued on the local level that you think would help make places more dementia-friendly?

JOSEPH GAUGLER: I personally think there have been a number of significant milestones that have occurred in Alzheimer's disease in terms of research and our clinical understanding of the disease, really motivated by the National Alzheimer's Project Act, which was launched in 2012. And one of them was done at the behest of the Centers for Medicare and Medicaid Services, CMS. They launched a national demonstration project called the GUIDE model, Guiding and Improved Dementia Experience for people living with dementia based on a series of successful trials that have occurred across the country, emphasizing that in order to provide optimal care to someone living with dementia, number one, a care partner must be identified and included in the care planning process. And two, that if that care partner is identified and they have needs-- for example, for respite, like adult day program or home health or other types of support, that that care partner should have that support provided to them and it should be covered under Medicare.

So the GUIDE model was launched in 2024 amongst roughly 300 to 350 provider sites across the US. It's going to be done over an eight-year period. And I'm very, very number one supportive of the model and two, hopeful that the model will show significant enough benefit, just like the trials did, to suggest that this should really be the model of care for people living with dementia.

Now, as far as that relates to communities in Minnesota, what I would like to have seen and what I hope to see, is that more health care providers can deliver the GUIDE model once it hopefully becomes routine care. Now, there are roughly three to four physical GUIDE provider sites in the state. And there are several-- a handful of others-- that are providing the GUIDE model vis a vis remote delivery. So they're not actually located in Minnesota. They're located elsewhere.

I think it's very hard for communities to even know about the GUIDE model, for families to even know how I can get these things. And these are the types of barriers I would like to see change so people can get this type of care that we believe is most helpful.

NINA MOINI: Joseph, thanks so much for your perspective and telling us more about this. Really appreciate it.

JOSEPH Thank you for having me.

GAUGLER:

NINA MOINI: Joseph Gaugler is a professor at the University of Minnesota School of Public Health.