

The Brain Trust Podcast | Episode 4: Eco System of Alzheimer's and Dementia

Transcript

Speaker 1: Kate Rowland, MD

Welcome to the Brain Trust, A Physician's Guide to Diagnosing Alzheimer's Disease and Related Dementias. Brought to you from the Illinois Academy of Family Physicians. I'm Dr. Kate Rowland, family physician, member of the IAFP and faculty at Rush University. Funding for this podcast series was provided by a grant from the Illinois Department of Public Health. The goal of the Brain trust in this podcast series is to educate and empower the primary care clinician in the early detection, diagnosis and management of Alzheimer's disease and related dementias.

Clinical resources, Free CME and other educational materials are available online at the [BrainTrustProject.com](https://www.braintrustproject.com). CME Credit is available for each podcast. The Illinois Academy of Family Physicians is accredited by the Accreditation Council of Continuing Medical Education to provide continuing medical education for physicians. Information on how to receive credit can be found on the Brain Trust Project website.

Thank you for joining us as we empower each other and provide training on the early detection of Alzheimer's disease and related dementias. And now today's episode.

Speaker 2: Eukesh Ranjit, MD

Hello, everyone. My name is Eukesh Ranjit. I am assistant professor at Asus Center for Family Medicine, and I'm also the director of geriatrics here at ACI Center for Family Medicine. Today I am heading to the great city of Chicago, a city known for its lakes and its deep, this pizza. Today here I am meeting with Dr. Raj Shah, who is a geriatrician and a professor at Rush University, which is lots of leading universities here in the Midwest and the country crowd.

I will be talking with him about a few questions related to primary care and how it fits into the greater ecosystem when it comes to dementia management. Folks, we as primary care providers, we work in our clinic, we take care of our patients. However, we are a part of the broader ecosystem that has various key elements which are providing care to patients with dementia.

Today, we will be focusing on some of the aspects of dementia care, which do not necessarily pertain to our clinics, but which are helping us immensely in our clinics and taking care of patients with dementia. Without further ado, I'll just welcome our guest today, Dr. Raj Shah. Welcome.

Speaker 3: Raj Shah, MD

Oh, thanks to Eukesh. Thanks for making the trip down from spring up from Springfield to Chicago, here on the west side of the city. And hopefully that traffic on the Eisenhower wasn't too bad coming in and you were able to find parking in our ten-story parking lot. So, you made it. That's a great test of cognition.

So, thanks for being here.

Speaker 2: Eukesh Ranjit, MD

I made it and that's what matters. So, Raj, I would like to start our conversation today by just asking you a few questions. The first one that has been on my mind for a while is about the state of Illinois. What is the state of Illinois doing to build a dementia capable state at the moment?

Speaker 3: Raj Shah, MD

Oh, that's a great question. And it has a long history that I'm also been learning over the last 20 years by my engagement and civic activities with the state in my role at the Rush Alzheimer's Disease Center. So actually, after California in the mid-1980s, Illinois was one of the first states where the general legislature passed an act called the Alzheimer's Disease Act that allowed for sort of broad planning around initiatives that the state would take.

So not only government offices at the state level, but also in partnership with community and private organizations to improve the quality of life of residents that were at risk or experiencing dementia. And every three years, this plan gets updated and is presented to the legislature as an update about our progress, where our challenges are, where we have to concentrate our resources.

And in the past, until about three years ago, most of it was looking backwards. What did we do in the last three years, but more recently in the last two iterations with an amendment to the Alzheimer's Disease Act, they look forward and there's an advisory committee called the Alzheimer's Disease Advisory Committee, run by the Illinois Department of Public Health that supports this work around how the state should approach the issues of Alzheimer's disease and related disorders, and how that affects our families and individuals living with this condition.

Speaker 2: Eukesh Ranjit, MD

Thank you so much for providing me with so much of the information. I didn't know about any of this information. And it's good to know about our history, about how things have evolved.

Speaker 3: Raj Shah, MD

And it's a if I can just state something, it's a little bit of a challenging enterprise, right? Because there's so many moving pieces. And this and the Alzheimer's Disease Advisory Committee brings together experts from all different areas. You know, one way that the Illinois Academy of Family Physicians is involved in this effort is that it gets to nominate a representative to sit on that committee that represents our professional societies.

And they had nominated me to serve on that committee over the last three years. So I help to be a representative in those meetings to not only share the experience that family physicians and other primary care specialists have around the day to day aspect of seeing people with this condition. How do we make the experience better for both the family physicians, the primary care doctors and their teams and the patients and their families, but also for us to learn about what other areas are doing, including the volunteer health organizations like the Alzheimer's Association.

What are the academics, centers that are regional assist centers doing to help support research and education and outreach in these spaces? What are other departments like the L.A. Department of Aging, the department that is associated with disability services, the departments like the Public Health? How do we all work together to understand where our short-term priorities are, where our long term priorities are to improve the public health of people with dementia in the state?

Speaker 2: Eukesh Ranjit, MD

That's really great to hear. How is your experience been so far?

Speaker 3: Raj Shah, MD

It's great to be part of that and to be able to share our perspectives, and I think that's really helped us to also have a more of a voice to do things like these podcasts. With the support of the IDPs and the grants they have provided us, because everybody in the ecosystem, the broader ecosystem, I think in the state of Illinois, understands how important primary care is.

Speaker 3: Raj Shah, MD

Look, you know, at 230,000 people that we think have Alzheimer's disease and related dementias in the state of Illinois, and that number only anticipated to grow in the future as there's more people at risk as they age over time. We just can't do this by just neurologists or geriatricians or psychiatrists being the specialists in this space. We definitely need to build that base of the primary care physicians.

Speaker 2: Eukesh Ranjit, MD

Absolutely. We will be seeing more and more patients with dementia and dementia related conditions in the future, and we need to build upon those. And like I said, we will not have enough manpower and as primary care providers, it will be an opportunity for us to take care of all of the patients with dementia and related conditions in the years to come.

One thing I wanted to learn slightly more about Raj was something called Illinois Cognitive Resource Network. Please tell us more about what it is doing, you know, to support the work of the state with regards to cognition at the moment.

Speaker 3: Raj Shah, MD

Well, I'm glad you asked about what we call ICR, and for short are the Illinois Cognitive Resources Network. So, this was work started about ten years ago that brought together the efforts of the three regional assists, Alzheimer's Disease assistance Centers in Illinois. So, what are these regional Alzheimer's disease assist centers? They are Rush University, ICU and then Northwest.

Northwest. And the idea and the concept is that these three regional assist centers help to train, support, build the capabilities of the primary care workforce, along with the specialty workforce, help to be able to offer assessments of cognition or how do we get better at offering those assessments throughout the state? How do we do research on sort of what is a basic science and needs for Alzheimer's disease and get federal funds to do that work and then support our understanding of sort of what are the risk factors for developing a dementia, what could be modifiable factors that could lead to better treatments and options.

And then how do we educate the public about how to do these things? So, what was happening before? As you say, you pretty much took all of everything below I-80 and supported, you know, a lot of the state with its resources and capabilities. And Russia and Northwestern had different experiences, but concentrated on sort of Northeast Illinois brush, focusing a little bit more on the Alzheimer's disease spectrum and pathway.

Northwestern Focusing on the related dementia pathways, the other causes of dementia. But all of us were working in concert. But one thing we realized about ten years ago is we had to bring in more players together. So, we created this group called ICR, and it's technically supported in the administrative and work by the Rush Alzheimer's Disease Center. But what we do is it's people that are in these spaces with different organizations at the state level, at the voluntary health organization, at our these academic centers that meet together on a monthly basis.

It used to be a phone call now that, you know, Zoom and virtual things came in, we do it monthly by Zoom, but we share ideas and concepts. And a big thing that we wanted to do when we started this is to break down silos and how we approach providing resources across the state to support the state, actually getting more federal funds to become dementia capable by grants.

Because when we started this process, Illinois was a state where we actually gave more taxpayer money. Nationally, federal money and other states were using those funds to build dementia capability, and we weren't competitive and getting those funds back to Illinois. But I would have, I'm happy to say over the last ten years by working together, sharing, growing, learning each other's language and experience, we've been able to bring significant funds federally that go to places like the Illinois Department on Aging, the Illinois Department of Public Health, and then some of the academic centers and even community organizations so that they can do some more work around building this infrastructure and capabilities.

Speaker 2: Eukesh Ranjit, MD

That is really great to learn. I understand that as a part of this, there has been a movement that has developed, and it's called dementia friendly Illinois. Is that correct?

Speaker 3: Raj Shah, MD

Yeah. So about six years ago, seven years ago, one of the things we were keeping our attention on through the Illinois Cognitive Resources Network is what was going on nationally around helping communities to reduce stigma around dementia. So we felt that was still a big issue, even with all the education and training that was happening is we kept hearing in our offices as when I was medical director of our clinic here at rush hour multi-specialty clinic, every time I would see a patient, right, like there would be this discussion that would happen where people would say, Oh my gosh, you just made this diagnosis of dementia.

Boy, we're going to get isolated. Nobody's going to want to talk to us. We can't talk to anybody about this. And we feel low in going through this. And, you know, one of my goals and learning about being a geriatrician and even it came even my days of being in family medicine is our goal is to not help people feel alone.

It's to help them feel they're part of connected in a journey. And we are part of that. As the physician and the team in primary care, taking care of them. But also, we need help. Like we can't do everything. I'm only seeing that patient, you know, once or twice a year, you know, for a follow up to see how they're doing when we were doing follow ups.

And so, I don't get the full story about what's happening in their day to day life and their ecosystem. But I did start learning just by practicing and listening to other patients and their experiences, what was in their community where they could connect more regularly. And that was when I would talk with the community partners what they would tell us is, boy, we have our doors open.

We want to help you write, like we want to give services to support people with dementia, so they don't feel so isolated. But we are they don't come in our door, they don't find us. Nobody refers them to us. So, you know, you got people and their homes sitting where they feel alone. You've got all these services in the community that are designed to help them, who aren't getting enough throughput and are thinking about, well, how am I going to survive as an organization?

And so, we have this like market problem where there's supply and demand, but they're not connecting. And a lot of what we were trying to do is understand how to break that down and what was happening started in Minnesota was this model around dementia friendly communities. They had done some funds from the Target Foundation to apply public health principles about creating dementia friendly communities and where people would have multiple sectors come together from the community, like the restaurant owners, the lawyers, the emergency services, like the police department, the government, the hospitals and health systems.

And they would all meet and collaborate with the patient and caregiver voice from their community to be able to structure a plan about how they were going to make their community more dementia friendly. And then that movement got picked up by the White House Council on Aging and became a national movement, and they were asking for state technical resources.

So for Illinois, we were following this pattern and we decided the ICRC, even though we're not a not for profit organization, everybody's volunteering their time. We thought we could be that state technical lead. And I'll be happy to say, you guys, you know, I didn't expect this when we started it. I thought I was going to be a long haul.

But in about four years' time, there are 23 communities in the state of Illinois. Oh, wow. I've gone through National Review and been recognized as a dementia friendly community and they're all over the state. They're not just in the northern part of the state. They're in southern Illinois. And it's just this wonderful, like feeling of community is trying to come together.

It's a hard work. It's never easy, but we're trying to maintain this momentum and encourage, you know, more and more communities in each of the planning service areas and Illinois to really be there and to signal to their families and their communities that it's okay to be part of our community. We value you. We want you to come out and to go to the coffee shop and participate in that life and experience.

And we'll train the workers in the coffee shop so that they are ready, that you're going to have problems, you know, like reading the menu and ordering your coffee latte with sugar and cream. And everybody is going to get impatient in the line behind you. And how do we structure it? So, you know, let's make it simpler for you so you can still come feel part of connected but don't feel overwhelmed.

Speaker 2: Eukesh Ranjit, MD

It's wonderful the kind of work, you know, that we can do when the whole community comes in together. And, you know, the old saying was it takes a village to raise a kid. But, you know, when it comes to dementia, it takes a whole village. The whole community, to take care of patients with dementia. And I'm happy that in our state at least we're doing some work. And the work sounds very promising and, you know, thank you so much for sharing this. And you.

Speaker 3: Raj Shah, MD

Know, sample is exactly where you're at. I mean, we were so happy when Springfield, you know, work through their area agency on aging and went through this process as one else. They are now recognized as dementia friendly Springfield Yeah and see you and the team at the regional Alzheimer's Disease Assist Center played a big role in helping to support part of that network in moving forward.

And we know that the primary care physicians, if they were just aware like if they go to al brain health dot org our website and look at what are the dementia friendly communities I think they would be really you know find it valuable for their patients to say, oh, I'm in Springfield, I'm a primary care doctor know, by the way, we are a dementia friendly Springfield and here's a place where I can connect you with getting some more resources and services to help you.

Speaker 2: Eukesh Ranjit, MD

And so that brings me to my next question. So how does the work of family physicians connected to the work that you guys do?

Speaker 3: Raj Shah, MD

Yeah, we think family physicians can play a really important role here, right? One I mean, one role they can play in this multisectoral mix, right, is they can be part of these committees and planning committees and groups. I've always felt that, you know, especially the places in the state of Illinois that have family medicine, residencies, what would it mean?

You know, if somebody in the residency program could be a lead to sit on a multisectoral committee for the community with the police department, with the fire agency, you know, with the library is play a big role in this space with the housing for people that have dementia. And they all work together and talk through where are ways we can help each other out.

Because what happens in the community side is the community is like, we're going to find people that are going to come to us and say they're having problems with dementia, or they're worried about their thinking. We want them to go to a place like that, knows what dementia is, knows how to detect it early by listening to these podcast, having physicians that are prepared so that they can then get a good evaluation.

And then what the primary care doctor needs to know, the family practice needs to know as well. If diagnose somebody and they're having problems with transportation because they can't drive anymore, because they're having difficulties, how can I connect them with the transportation offerings that can be available through an area agency on aging in our community? And if we can make those connections

and cross connections work better, we strengthen the ties family physician, family medicine has with our communities and our communities.

Trust us more as a family physicians and delivering that care.

Speaker 2: Eukesh Ranjit, MD

Absolutely. We have very recently been starting to pay attention to the social determinants of health, and I think a project like this would, you know, improve the social determinants of health immensely, basically. And that's, I think just being tied to the community. You know, not just for dementia, but I think it would be good even for things like vaccination and, you know, spreading information that are true and genuine and building a community which would help not just for dementia but for other purposes as well.

It's a great job. You were talking earlier about your website, Illinois Brand Health. Could you please tell us more about it?

Speaker 3: Raj Shah, MD

Sure. And, you know, we started that with none of us knowing how to build a website ten years ago. And it was really like a disaster. But we worked our way through it, and we've been lucky enough to have the opportunities to update it and iterated over time. But we're still very academic. I mean, I have to say.

So, it's not one of those sites that was something that was really usable. It had a lot of words to it, not a lot of pictures. People weren't connecting as well with it. And then what happened is about a year ago, the state through the general legislature, provided a little bit more funds to the IDPs to put out grants around how we can create these one stop shop electronic platforms where people can go to find resources.

And what was driving that was some of the efforts of the current lieutenant governor was that personal experiences taking care of people with dementia. And she did a listening tour pre-COVID with the Alzheimer's Association. And one of the things that really came out to people was this market force problem that I was describing, that people feel alone and they don't know how to connect to people that are actually there to provide services to them.

And could we create a space that would have that? So, it was a really short turnaround. It was like one of these grants that you had to put in like in six weeks, and we didn't think we had a chance, but we did put it in as the ICRC and with Russia sort of acting as sort of the administrative lead.

And to our amazement, we got it. And so then we spent six months using those resources to update our website, and we used the design thinking method at IO Brain health dot org, where we talked to family members, community members from diverse communities in Illinois. So rural, urban, African American, Latino. And what we found is that how people wanted to think about information and resources was to not be overwhelmed by it, because sometimes it's a lot to take it right, Like when somebody first gets a diagnosis.

Speaker 3: Raj Shah, MD

And if we give them a ton of information, they just stop, they freeze. But is that something where we can get really specific information about like what is Alzheimer's disease? What are the causes of it, of dementia? They wanted to connect. They wanted to hear authentic stories of people going through these experiences that they could resonate with and maybe even small video snippets to just help explain things like, Well, what if my husband is having more difficulties, like taking showers with his dementia now, how do I handle that at home?

Speaker 3: Raj Shah, MD

So, I don't burnout as a caregiver, and they could hear other caregivers that were kind of giving some of that feedback. So, people wanted to connect right? They wanted a place where it was not overwhelming. They could connect to some stories that were authentic, that they could see themselves in and see their own community in. And then they wanted to see that that resource could help them throughout the entire journey.

Because it's not just one point I make a diagnosis, That's it, right? Like we have to keep following and working with people as conditions change and adapt and people have to continue to learn and grow. So it was a bit of a challenge and we took the first pass in a relatively short amount of time, but I really do, and we made sure the platform would work on people's cell phone so that it's a little bit easier for them to look at.

But I would definitely recommend like members of the podcast to spend a little bit time, go to your brain health board and look at some of the resources there because you maybe then be able to connect people that come to the clinic and say, Hey, you know, I know there's a lot here, but if you want to go to I'll brain health dot org, here's the website you can find some basic information and then we can talk a little bit more about what's helpful or not.

One of the neat features we put in was that you can search by zip code about resources that are close to you so you can find out like I live in 60563, I could put in 60563 on the website to find resources for things such as like Meals on Wheels or how do I get aging services or where is there an adult day center?

So it's not perfect yet, but it's definitely a better platform. Um, and one thing we can see where family physicians and their offices can get involved with is if they could name somebody to be sort of that dementia champion for their organization, we could highlight them on the website. And then so somebody would say, okay, well, I need to know who can go to get a diagnosis.

Right? And then we could put that information on the website, right. Like, here's some potential sources where you could go to get a diagnosis in a primary care setting.

Speaker 2: Eukesh Ranjit, MD

That sounds like a very nice concept, a dementia champions. And I am happy that there is a website where you could actually find information, local information, not just know general information, but local information for us as providers, for patients and the family as well as the caregivers. Thank you so much for all the information about this. Raj, anything else that you'd like to share about the work, the wonderful work that we are doing at the moment?

Speaker 3: Raj Shah, MD

Raj Yeah, I think the other small piece I'd put in and it's on our website too, is what we want to encourage is not only communities and all the different sectors and organizations working together, which is sort of the dementia friendly Illinois movement. But there's another movement that's for the lay public called Dementia Friends Illinois. And we have over 7000 people who have at least gone to a website, gotten about 10 minutes of training or gone to a 30 minute presentation given by Dementia Champion and their community that just says the basics.

It's sort of the white belt of dementia, like this is what dementia is. It's not a part of normal aging. It can be something that you should go see a doctor about. It's, you know, and know how it can help you. So, we want to keep building that. Again, I think that's an area where family physician offices can be involved.

If they can have somebody go through the dementia friends champion training, then they could offer that. So like an example is in Hyde Park, when they got dementia friendly recognition, they have some social workers that are trained as dementia champions and it doesn't have to be a social worker. It could be even a front desk member or it could be anybody else.

And they can give talks. So, they give talks to the patient population about dementia, 1 to 1, so that people just are more available in their community to see some is struggling to find their directions and they can say, hey, can I help you? Right? Or can I offer you some suggestions? So we have a lot of work to do and I'm really glad we were able to spend.

And you asked these questions because sometimes it can feel really overwhelming as a primary care physician that I have all these things. I've got to help this family out about, you know, with all these issues that are going to come up with dementia. And I don't know where to turn, but we have these resources in the state. And Illinois is a pretty big leader in our efforts to work through how we can help to make the state more dementia capable where there is no wrong door.

If somebody comes to any one of these services and says, I have a dementia issue or I have a need around my cognition, we can connect them to the right spaces. And family physicians play a huge role in that network and need to be supported in that network and then can give back to that network.

Speaker 2: Eukesh Ranjit, MD

Thanks so much for all the information and sharing everything and for the work that your wonderful work that you're doing in Illinois listeners. That was Raj Shah, a professor at Rice University and a geriatrician and a family physician who shared what he does and the great initiatives that are undergoing in Illinois at the moment, being, as we could see, primary care physicians.

You know, we do our part, but we are a part of this great ecosystem within Illinois in which there are different health care providers who are providing different kinds of services for people with dementia and related diseases and learning about these different components would help us immensely in serving our role as primary care physicians. I hope the podcast today was helpful to you and your practice and to we meet again.

Thank you for tuning in.

Speaker 1: Kate Rowland, MD

Thank you to our expert faculty and to you, our listeners, for tuning into this episode. If you have any comments, questions, or ideas for future topics, please contact us at podcast at theBrainTrust.com. For more episodes of the Brain Trust, please visit our website, TheBrainTrustProject.com You'll find transcripts, speaker disclosures, instructions to claim CME Credit and other Alzheimer's resources as well.

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