

The Brain Trust - Episode 14: Caregiver Support in ADRD Early Detection

Kate Rowland, MD

Announcement

00:03

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 and 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 thebraintrustproject.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.

Raj Shah, MD

Host

01:07

All right. So welcome everybody to our next session of the podcast series the Brain Trust about the early detection of Alzheimer's and related dementias. Today I'm really excited to talk about a very, very important topic, which is sort of the engagement of caregiver support in the early detection of ADRD. And really today our goal is to describe sort of how family physicians can improve the early detection of Alzheimer's disease by being aware of the caregivers that are involved in the lives of people with dementia or at risk of dementia and to encourage their support as they go along. So today, you know what in our time that we have in the 25 to 30 minutes we'll be talking about sort of what are the opportunities to guide caregivers and families of persons with dementia and then also the ways programs such as the Cure Consultation by the Alzheimer's Association can be beneficial to families and to primary care physicians.

02:04

So it took me a little while today with my travels coming from the west side to going all the way up north to Glenview. There's a lot of traffic as people were heading out to go to the Wisconsin to enjoy the last days of summer here, and I had a chance to now stop by at the program in Glenview and I'm really excited to be able to walk through, and I've been walking a little while in this building, but I'm finally going to be approaching Dr Mark Drexler and seeing him and Mr Gene Kuhn from the Alzheimer's Association. So, yeah, I think I'm finally there at the clinic and I'm just entering the door and I see Mark. Hi, mark, how are you?

Mark Drexler, MD

Guest

02:40

I'm good, thank you. Thanks for joining me Again. I know it's quite a trip all the way from the west side and you know the, I think, my walk was longer just through the hospital to get to your clinic.

Raj Shah, MD

Host

02:49

Yeah, okay.

Mark Drexler, MD

Guest

02:51

Yeah, that's what we hear from all our patients as they try to navigate to our clinic, but I'm glad you're able to make it and I'm really excited to talk to you today about something that's near and dear to our clinic and a lot of the people that we see in the clinic and, again, that's the support for not only our patients with memory loss but also the caregivers and the people around them.

Raj Shah, MD

Host

03:11

Gene is here too. That's wonderful. So, gene, I hope your trip was okay, coming of and representing the Alzheimer's Association and meeting us here today in Glenview.

Gene Kuhn

Guest

03:20

Absolutely, and I think, dr Shaw, I think you and I had the same commute. Oh, okay, but no, I'm excited to be here and to chat with you and Dr Drexler. I know it's going to be a great conversation.

Raj Shah, MD

Host

03:35

Yeah, and Mark, you're the lead physician for the Comprehensive Care Center at North Shore University and faculty at the University of Chicago Family Medicine Residency, and I was just kind of curious, like we always do in our podcast, just if you can give us a little sense of your practice and the setting that we're

in right now and sort of how do you engage with people that are at risk for Alzheimer's disease in your practice and the people that are part of their lives, including their caregivers or care partners?

Mark Drexler, MD

Guest

04:05

Yeah, thank you. So we're on the north side of Chicago, part of North Shore. This clinic is a little bit unique in that we're a multi-specialty clinic. We have three physicians, one of which is a geriatrician, myself who is a family physician, and another internist, and the three of us provide care for a group of about 1,000 patients, of which probably about 90 or 95 percent or over age 60. And about 60 to 70 percent are over the age of 80. Wow, so most are older and in our practice we have the fortune to have a social worker and a pharmacist, a few nurse practitioners. That allows us to really work more comprehensively and closely with patients with medical issues and complex issues, including those with memory loss. So it's sort of a unique practice but still overlaps with a lot of primary care practices that have to deal with older adults that have multiple health issues and memory loss in their patients.

Raj Shah, MD

Host

05:06

Yeah, and in general because of the population that you're serving and those are at the higher risk groups by age as just one of the risk factors for developing dementia, and I just wanted to kind of get a sense of how do you approach sort of the going about of evaluating early people that might be at risk for developing a dementia and how do you work through like some early detection.

Mark Drexler, MD

Guest

05:30

Yeah, you know it's something that we tried to do for most of our patients when they come in, either for a first visit or when they come for their Medicare wellness visits, you know.

05:40

So those visits tend to be a little bit longer, so we have a little bit more time to dive into, you know, their health issues and, like you've talked about on several of your other podcasts, you know the mini cog is the tool that we like to use and we've actually trained our medical assistants to be able to do that test as part of the rooming procedure. When you know someone comes for that first visit or for their annual Medicare wellness, although if they already have diagnoses of memory loss, you know we tend not to use that, since it's not really an ongoing testing tool but more of a screening tool. So it's as we're talking about early detection people that don't necessarily have that diagnosis or have a loose diagnosis of memory loss, you know will instruct the medical assistants to do this memory testing and over time we can compare scores year to year and share those with patients and their families to help us with this detection of memory loss.

Raj Shah, MD

Host

06:40

Yeah, that's terrific. And you know, as you bring up the annual wellness visit, you know that Medicare provides some funding for us to be able to engage on sort of this prevention work and risk finding work. You know the tools or the suggestion is kind of general, right Like just assess cognitive evaluation. So you gave, you know, one tool you're using to document a little bit of it by a psychometric screening test like the mini cog. But you know it also involves sometimes asking right like asking the patient what they think is going on with their memory, and sometimes you know they may not see everything that's happening and we need the caregivers. And how do you kind of incorporate maybe the caregivers and who are these caregivers right into sort of your evaluation for the early detection?

Mark Drexler, MD

Guest

07:24

Yeah, those are really important questions and frequently, you know, patients will come with family members or with others. So, you know, certainly our first step is to identify who is it that's in the room with us. You know, either ask the patient or we'll ask the individual directly. And you know, make sure that we know who we're talking to. And often, as we go through our questions, you know the patient is going to be the primary person we talk to, but the person in the room with them will also be providing information and you know whether it's directly or whether you know they pull us aside and ask us. You know, can we talk to you outside of the room? Or sometimes they'll even send us messages before the visit to say, hey, heads up. This is something that is concerning us, but we don't want to necessarily bring it up in front of our loved one. So involving them is different, you know, depending on where they're at and where the patient is at.

Raj Shah, MD

Host

08:16

Yeah, you know, there's some statistics, even from the Alzheimer's Association, like annual facts and figures, right, for every person that has a diagnosis of dementia, there's usually six informal caregivers and there's so much diversity, right. And who becomes a caregiver and comes in with the person? Or they might even not come in with a person, they might be a separate visit just for their care. Can you give us a sense of the range of caregivers you're trying to engage with? I mean, are there like grandchildren sometimes? Are they actually the children or are they spouses? Or who tends to come in?

Mark Drexler, MD

Guest

08:49

Yeah, so in general it's going to be the spouse is the primary person for the most part, although sometimes spouses both have memory losses and that can be challenging.

09:01

So the adult children of patients with memory loss are frequently involved, either directly when they come in or through the phone. You know, oftentimes these family members may be out of town so they don't necessarily come in and we need to engage them either during the visit by phone, or after the visit. Sometimes it is a neighbor or a friend that has taken interest in the individual, sometimes it's someone that was just appointed as part of a legal proceeding, but for the most part it's going to be an adult child or it's going to be a spouse. When, in terms of caregiver versus a care partner, I think, as you pointed out before, these are individuals that have an interest in the on-going of the patient and may require them to do direct patient care and help in their day-to-day activities, or may just be that they are around to assist the individuals with their needs and to oversee and make sure nothing is left to chance or that there's problems with things.

Raj Shah, MD

Host

10:00

Yeah, I'm just sort of curious because in family medicine we do have to see that a range of individuals that come into our practice with our main person and our stand, the holistic view of the entire ecosystem that's there to help provide support and care in their social networks. But sometimes I think people get caught on this idea of, like, I can only talk to the person that's the healthcare power for attorney right, and then if that person is not there, then I can't kind of engage the other person who's recognized as one of the informal caregivers. How do you kind of try to deal with that or do you know in your engagements with whoever the care partner is, or caregiver?

Mark Drexler, MD

Guest

10:40

Yeah, I think that, as long as decisions don't have to be made, the information that you can collect from those around the individual is really, really important.

10:50

So taking the time and asking those individuals that are with the patient or they call in to say you know our goal, our objective really is to help the individual or to get as much information as possible, and so the power of attorney factor doesn't really impact our ability to collect information. If a major decision has to be done, we'll want to include the power of attorney, and you know that may or may not be possible. So you know we'll even engage those that are not power of attorneys during the visit to say this is our plan moving forward. I'm going to reach out to the power of attorney to have that conversation, but I'd like you to take this back to those individuals. So it depends on who's there and what information needs to be communicated, and power of attorney is going to be involved, but those around the individual at the time of the visit are just as important to engage and to utilize the information they have.

Raj Shah, MD

Host

11:44

Yeah, and many of these caregivers don't recognize they're in these caregiver roles right, like they just think of them as the friend or the son or the daughter in law or whatever it might be, you know, the spouse in their relationships and they also kind of need help right to recognize and understand their key role and sort of being involved in the early detection of dementia. And so what are some of the resources or tools that you've been, you know, engaging with or using with caregivers to help in their engagement around sort of early detection and diagnosis?

Mark Drexler, MD

Guest

12:20

Yeah, you know, I think there's a couple of different things.

12:22

Certainly, as families or even as patients recognize they start to have memory loss, most important thing is to have them continue to monitor what's going on and to look into the community and see what resources there are in the community to get their individuals involved with things, get them out, you know, engage them in activities, because we know isolation and things related to, you know, challenges that they face day to day can be improved as they go out and do things.

12:52

And then you know there are various programs that are available to these individuals in the community. So pointing them out, you know the Alzheimer's Association is a tremendous resource and being able to connect them to the Alzheimer's Association to learn about what to expect and how to assess things has been, you know, a tremendous resource and tool. And we've been fortunate to be able to engage in a program called the Nite Grant program, which really allows us to connect patients that have issues with memory or even just beginning to show signs of memory loss with this organization. And you know their expertise can be provided to these families to provide more information and support in the everyday challenges that these patients and families face.

Raj Shah, MD

Host

13:38

Yeah, I think our audience will be really interested in kind of learning a little bit more about this program you're engaging with with the Alzheimer's Association and you know I'm glad we have Gene here today. I think he can maybe give us a little bit of some of that broad overview about sort of the program that the Alzheimer's Association has to work with primary care physicians to support those caregivers and helping them through these stages of the experience, right in the early detection and then follow

through. So yeah, gene, can you tell us a little bit? Is this a care navigator program? I just wanted to make sure what the terminology is.

Gene Kuhn

Guest

14:11

It's called the Nite Family Dementia Care Coordination Initiative, or oh, okay, see for short, but it results in a care consultation for the family. So, okay, care consultation, all right. So I'll back up a little bit. I'll kind of give you a little bit of background on what this is. So, thanks to a generous philanthropic gift from the Nite Family, the Alzheimer's Association launched the Nite Family Dementia Care Coordination Initiative, or DCC for short, here in Illinois back in 2020.

14:40

And North Shore University Health System is one of our five health system partners in Illinois and they were actually the very first one to sign on and partner with us on this and Dr Drexler and his team there at the Comprehensive Care Center.

14:53

They were one of the first two areas in North Shore to work on this with us. So we're extremely grateful for his help in kind of getting this out there. And, to put it very simply, the main objective of DCC is really to try and improve care for individuals and others, or trying to improve care for individuals with Alzheimer's and other dementia by connecting their families with education, resources and support earlier in the process as opposed to later. I know you guys see it all the time, and so do we, but families often wait for a crisis to occur before asking for help, and we're trying to change that. So really the main focus for us is on that caregiver as opposed to just the patient. We've really found that throughout the years the caregivers are often the forgotten ones when dealing with someone who's in the dementia, so we want to make sure they have what they need as they kind of go through this journey.

Raj Shah, MD

Host

15:47

Oh, that's terrific. Wow, that's really great to hear about this program and you know that five places are working on this since 2020, you know, even in the midst of a pandemic. So that's great to hear that these resources have been available and are being tested in Illinois and we have Mark here to kind of talk to us about that. And, mark, you know your sense. I mean, in a very complex time to like launch this program right. Maybe it was even more needed right during the pandemic in some ways, as caregivers needed more resources to work with individuals with, you know, the early detection of dementia, especially if they were like, more sheltered in place and being, you know, in more close contact that they recognize something might not be right. What sort of successes have you had? Early successes with the program and engaging with sort of the, you know, care coordination.

Mark Drexler, MD

Guest

16:33

It's been really great.

16:34

It's an easy referral into the system and you know the team at the Alzheimer's Association will reach out to the family members around their schedule and really try to focus on what the needs are.

16:45

So they'll take time to go through what are the problems that they have, what are the challenges, what information or resources or support do they need, and then provide a plan to give them options.

16:56

They don't push that they need to follow up or do anything, but they provide options and resources that are far more robust than what I can do in any you know 15 or 20 minute visit and so I've had probably a dozen patients go through this that I can think off the top of my head that would come back and say really appreciate the services. You know I feel a lot more comfortable being able to handle these things. They're plugged into support groups to you know, talk to other people and you know it doesn't get beyond the fact that they still have a lot of stress in what they're doing, but at least they have a support network and a group of people that they can lean on to be able to navigate the challenges that occur as the memory issues, you know, change or progress over time and the needs that they have changed and you know that makes a lot more calm and, you know, comfortable for them as they have to help their loved one.

Raj Shah, MD

Host

17:49

Yeah, and you were kind of hinting at at least one loop right which is so you as the primary care physician working with the caregiver and the loved person that has a risk for dementia or early dementia is that you get feedback from the caregivers when they come on follow up. But you know also, primary care physicians also want to know sometimes the feedback, maybe before that appointment and some ways, about the you know program and the connection with the navigator from the service providers. And I was just kind of curious if you know Gene or Mark, if you wanted to talk a little bit about do the primary care physicians in this program get feedback from the actual care coordination part?

Mark Drexler, MD

Guest

18:27

Yes, so we do. We get a fax from the Alzheimer's Association and it's usually like a two page form that summarizes the conversations. It doesn't necessarily list the full discussions, but it gives a good summary

of you know what this discussion with the recommendations were. Gene, do you want to maybe provide more about that?

Gene Kuhn

Guest

18:47

Absolutely so. Dr Shaw, you kind of hit the nail on the head in regards to making sure that everybody is kept in the loop in terms of what's going on, because the way we see this is that we are all a team together, that enough physicians, you know. So Dr Drexler and his team, they're providing that clinical care for that family, for that patient. Then they have social workers that are providing additional resources, support. Well, a family can never have enough of that. So that's why, when they're referred to us, they'll meet with one of our care consultants. They are all masters level social workers or counselors and we're really going to talk to that family about what they're seeing at home. What particular help do they need, what are they stressed out about? What level of education do they need? Because oftentimes families don't know what they don't know, and so we're going to try and kind of fish that out of them, see what else we can provide, and then... After we've talked to them, then we're gonna help provide a care plan for them on that social aspect at home, and it's gonna be three, four, five bullet points, very simple things that they could be successful at but are going to help them at home. We will then send that care plan back to the family, to that caregiver, but then also back to Dr Drexler and the team. That way they can include it in the medical record.

20:01

So it's kind of a 360 degree spectrum of care for that family and that way when they come back in, dr Drexler can see okay, I saw you met with the Alzheimer's Association and talked about this. How did that help? Or did it that? What else can we do? But bottom line, it also helps develop that relationship with the association, meaning that family can call us back at any time. We have a 24-7 helpline if they have additional questions or they need have other needs or if something changes and they want to be re-referred to go through the process again. You bet, best of all, it's 100% free, free to the system, it's free to families. We don't ask for insurance information, nothing. It literally is free support.

Raj Shah, MD

Host

20:46

Oh, that's great to hear, and both of you have touched base a little bit on some of that positive feedback that has come from that program, with individuals as they come back and finding some benefit from this. I just, in the time that we have, I just wanted to kind of get a sense a little bit about how do we especially, mark, because you're also part of a family medicine residency program the goal is to teach the next generation of physicians also about some of these tools and these capabilities of using these things to support caregivers and persons at risk and the early diagnosis of dementia. So how have you talked about this program or this engagement to support these caregivers with the family medicine residents that you work with, maybe with the other clinicians in primary care that are kind of like you know, you

run into and are just asking like, oh, what's this program? You know how's it going. How do we like disseminate or share these tools?

Mark Drexler, MD

Guest

21:36

Yeah, you know, I think, really experiences and conversations around what we've found to be helpful about it, and just reminding the other physicians and residents that you can't do this all by yourself, that the experts and others that have the time and the resources are important to engage and really, at the end of the day, you want to think about not only the patient but also the family member and caregivers that are working with them and the importance of providing them the information. So, you know, really just reinforcing the strengths and the benefits of these programs and the resources that are available.

Raj Shah, MD

Host

22:13

That's great and yeah, hopefully we can, you know, kind of learn from all five programs a little bit more over time as the activities go further. And then you know, as we kind of close up for our time today, just a little bit about just you know, how do we continue to maintain that support for the caregivers in a regular patient visit that could be really tight right, like you only have a certain amount of time, whether it be a televisit or an in-person visit, you're mainly focusing on the person that you know has the condition and spending time with them. But how do we incorporate, you know, into those you know time that we have scheduled, that support for the caregiver, making them feel part of the team and that they're a provider of information? That's so important for us to, you know, make diagnoses and to, you know, think about treatments?

Mark Drexler, MD

Guest

22:59

Yeah, you know, that's really an important point and, you know, often these people have the information that we need to make our decisions. So, trying to engage them and at least acknowledging that they're part of this process and that the information they can provide is important, so making a concerted effort to, you know, turn towards them, to ask them or at least to thank them and even sometimes to check how they're doing, make sure they take care of themselves along the way, because their health is just as important for our patients as the patient's health. So, if nothing else, really just trying to give them time to provide the information or to ask their questions.

Raj Shah, MD

Host

23:39

Yeah, you brought up some really important points right, like it's not only allowing the person who's experiencing the changes to be heard in that setting, but then also the caregiver, because in many ways, you know, if the caregiver doesn't feel heard right of what they've been observing 24-7 for a little while and finally got the courage to bring everybody in for an evaluation, then they're going to pull back right and not engage with us and do things. And so, yeah, just giving them that time to be heard is really important. And then taking that time because we know in, you know about studies going 20 years that we have, you know the caregivers also experience, you know, depression, anxiety, stress from dealing with these things and also feeling alone, isolated sometimes. You know it's just a matter of like, how do we allow that time to also say you have to take care of yourself, right, and give them some tips and tools around that. Absolutely, that's really important.

24:30

Yeah, no, this has been a great conversation today, you know, understanding a really important piece of the entire ecosystem and supporting our caregivers and care partners in the early detection and diagnosis. So I really thank you for taking the time today to talk with us both Mark and Jean, and we'd love to hear more about the program, you know, as time goes on, and see how we can scale it to make sure that more primary care physicians, family physicians, get a chance to see how this works and maybe help their patient populations. So thanks again, and that will wrap up our podcast for this time. And now I've got to figure out my way to walk down this long corridor and get out of this busy little and find my car. Yeah, it's probably my memory test for today. It will be okay, all right, but thanks again for taking your time. It's great seeing you All right talk to you later.

Mark Drexler, MD

Guest

25:15

Thank you very much. Okay, safe drives, bye-bye, bye-bye.

Kate Rowland, MD

Announcement

25:19

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@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. Subscribe to this podcast series on healthcare now radio, spotify, apple, google Play or any major podcast platform. Thank you again and we hope you tune into the next episode of the Brain Trust.