

## **The Brain Trust Episode 21: Caregiver Mini-Series #3 Donna Transcript**

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](http://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

01:08

Welcome everybody to our next podcast in our series the Brain Trust, about ADRD, the early detection of Alzheimer's disease and related dementias. Today we continue with our mini series talking with caregivers of persons that are living or have lived with dementia and to getting their perspective so that they can help guide us as far as how they've viewed that early diagnosis and detection with primary care providers. And so our learning objectives today are just to be able to understand from the care partner's perspective what are some of their challenges in seeking a primary care evaluation and then maybe one desire that the care partners express as far as improving early diagnosis and detection in primary care. So again today I'm joined by a friend and colleague, Susan Frick, who's a social worker at the Alzheimer's Disease Center, with me and I, Rod Shah, I'm a professor in family and preventive medicine at the Rush Alzheimer's Disease Center.

02:05

We're kind of like doing a big U-turn because I mean I came from Naperville today morning and I picked up Susan and we're heading now back west to visit our caregiver who lives in Kane County, in the rural part of Kane County on a farm by the name of Ghana, and we're just on 88, a little bit past Naperville now and getting closer towards Route 30, where we'll take the exit and head into Big Rock. But, Susan, while I have you in the car as we're getting closer, can you just tell us a little bit about how you got to know Donna, the caregiver we'll be talking about today, and just a little bit about that story.

Susan Frick Guest

02:38

Sure Thanks, Dr Shah, Donna and her husband, Scott. I met because they both started coming to the support group without warning that we run through the Rush Alzheimer's Disease Center and Scott was diagnosed with young onset Alzheimer's Disease in about 2014 and they started coming and continued very active within our group until Scott passed away a couple years ago and they were even involved in telling their story for the documentary that we created. So they'd been very involved in talking about what it was like to have Alzheimer's in regards to Scott and for Donna what it was like to be a caregiver.

Raj Shah, MD Host

03:16

Oh my gosh, I think we're getting close, because I'm seeing a lot of sheep around me right now. They're kind of mixing in with the snow and it's a little bit hard to tell them apart sometimes, but here we go. By the way, how big is this town, big Rock? Do we have any idea?

Susan Frick Guest

03:29

You know we'll have to ask Donna for shirts. It's not huge but it was fun filming here with the sheep and with them.

Raj Shah, MD Host

03:37

Yeah, now we're here at the front door and thank you, donna, for having us over here today, really appreciate it. I was asking Susan and we didn't really know. As we get started, tell us a little bit about Big Rock. It's my first time here and how big is the town?

Donna Guest

03:51

We're only 1,500 people, so it's close enough to Chicago but still have that sense of rural.

Raj Shah, MD Host

03:56

It's been a pretty place to live. Wow, and tell me just a little bit before we get started, just about how did you end up in Big Rock? Did you always grow up here?

Donna Guest

04:05

No, In fact we weren't farmers, we're corporate types. Scott works for M&M Mars and in 2000 he was suddenly discharged and the reason I put that in perspective it gave us a chance to kind of retool and rethink careers and move out and start farming. But in hindsight that's about when his

symptoms started with the Alzheimer's. Oh, wow, he didn't remember meetings and things like that. Even back then that the blessing was we got a chance to be farmers.

Raj Shah, MD Host

04:35

That's a great story. And then, yeah, I'll let Susan kind of start by just kind of getting a sense, as you were telling us a little bit about what you started noticing.

Susan Frick Guest

04:45

But, Susan, if you want to just kind of lead us to that, Sure, yeah, and Donna, when you first, you know and it sounds like there was a period of time there where maybe even now, looking back, you realize Scott was having some issues but when you started to look at having him seen by his primary care physician, what were you noticing and how did that process go for him and for you?

Donna Guest

05:06

Well, initially, like I mentioned, we started farming so we got busy in that lifestyle, but he was showing a lot of irritability and frustration with himself. So he went in for sleep apnea tests at first and then a few years later, that sort of panned out okay. Then they thought maybe it was midlife crisis, because he continued with the frustration and anger, and then it really came to a head in 2014. He went to his primary and he was in tears actually at the appointment. I went with him and he just said he didn't feel right and could remember things and was frustrated with himself. And the doctor looked and said well, we've done all these tests. And I said could it be Alzheimer's? And he looked straight at me, the primary care doctor, and said no, it couldn't be, because he's way too young.

Susan Frick Guest

05:58

And.

Donna Guest

05:58

I said, you know, ironically enough, his aunt was diagnosed at 45. I hadn't thought about it till a minute of this appointment and I felt like I had to share that with you and I never made that connection, you know, seeing him starting to be frustrated and forgetful until the appointment, and I asked the doctor please could we consider that he did follow up and give me your name?

Susan.

Donna Guest

06:27

So a neurosurgeon at Edwards and I called. That's how I got a hold of Rush first. I called Susan first and see, you know, what could I do, what kind of test or who could I see? And I remember seeing that it was too long, you know, the wait list was so long. So that's why we went to the neurologist at Edwards.

Susan Frick Guest

06:49

So did you purposely go along with Scott because he was going to be bringing up the issues of memory problems?

Donna Guest

06:56

I wanted to represent what my perspective was. Sure, Scott was still in denial. I don't think he would have given a total picture of a lot of the issues. You know that I was able to and I have to give credit to the primary he did listen to my perspective.

Raj Shah, MD Host

07:15

And about how old was Scott at that time when you went?

Donna Guest

07:17

into the primary, 54.

Raj Shah, MD Host

07:20

54. And then you had. And then how old was he when you said you thought he might have? You know, when you retired and you first started farming, and maybe started noticing some time.

Donna Guest

07:28

44.

Raj Shah, MD Host

07:29

44. So about 10 years or so, you were noticing some changes going on no-transcript ny numbers Chaotich.

Donna Guest

07:51

Let's consider the Alzheimer's. Did we start the ball rolling to get him tested?

Raj Shah, MD Host

07:57

And was that really? If I can kind of just clarify my mind about what made you insist at that moment, it was the history of his aunt that you remembered and recalled, and that's what made you say oh, but he may not have told you that his aunt had this.

Donna Guest

08:12

No, Scott had told me. In fact it was the day we were getting married. She was diagnosed, walking down the aisle and thinking till all-time or still as part. Wow, yeah, but you know I put it in the back burner because I didn't really want to focus on it. You know we were married 34 years but it was at that appointment almost in desperation, because I know we've gone to download the blood work and medical and you know sleep apnea and midlife crisis issues and I was it with them because I could just see him starting to tear it to tear rate. He's tried to take like part-time jobs. You know, even though we were farming, we weren't making it financially so he kept getting fired. Or his inability to remember to punch in or do the job or remember anything online, that attributed even more to the frustration.

Susan Frick Guest

09:02

Sure. So when the doctor said to you oh, he's way too young, couldn't possibly be Alzheimer's, how did you two leave from that appointment? What did it feel?

Donna Guest

09:11

like I was just for Lawrence, you know, because I said, oh, now what? You know where do I go? And then I got a call from his office with your name. So again, he did listen, mm-hmm, and he did pursue you know, possibilities of you know who could I go to after that?

Raj Shah, MD Host

09:31

And then the next so in some ways there I just want to kind of clarify. So you brought up the issue with the clinician that could this be Alzheimer's because of the family history? Yeah, and it was mainly that you were at that point. The primary doctor gave some resources to look for things but there was never was there an evaluation. The primary doctor did for the memory concerns at that moment, like just check where he was at with like a short test, like we call the mini mental state exam or the mocha exam, anything like no, no but then when?

Donna Guest

10:01

he recommended. You know I couldn't get into rush that would have been my preference, but it was gonna be a long wait. Then when we went to the Edwards neurosurgeon she did that test and she did not listen to anything that I have in terms of observations and so I know it's not the primary, but it does show another example in the cog of what's somebody shouldn't do at an appointment. She looks straight at sky and said, oh, he has it bad, he has it really bad. After he did his and Scott squeezed my hand so hard and started crying, cognizant enough to know that she was saying he's got it bad, you know. And so she did refer me to the Neurostychiatrist.

10:47

I think I actually just found this report the other day. It was in some billing files and it was really sobering because to bring read, you know, scott's commentary of how he knew he was deteriorating, it was touching on neuropsychologists. Mm-hmm, he was really a gentle giant need to eat because both on and did this and so, even though I had it said over a Rough rough, you know, appointment at the no neurologist Dr Wurling gets was very gentle and this is a kind of a common story.

Raj Shah, MD Host

11:17

We sometimes hear right like it takes a while for the family to To recognize something might be going on. It takes a while for the you know, primary physicians to rule out other things that could be happening, especially in somebody younger, like sleep apnea or some other features. And then it finally comes to some Moment where things start moving, you know in a direction and then you have to go to. You know the primary doctor has to coordinate with another provider that you know, like the Neuro neurologist, and then maybe the neurologist will also ask for, you know, neuropsychological testing. So did you feel like all those connections were being made or were you having to like really advocate to make every connection Move forward for your husband?

Donna Guest

12:02

the connections were made, but what was missing and thank heavens for, for Susan's group and for rush there was no follow-up with. Now, what do you do? No, I was given the diagnosis and it was like yep, end of discussion. I never saw any of the other doctors, his primary never called us again, and so unless I found Susan, I would have been just at a total loss.

Raj Shah, MD Host

12:28

So can I confirm something there? So, as you said, primary never called us again, but was it for that issue of the memory? But Scott's still seeing him for like other health conditions afterwards or he didn't have any other health conditions.

Donna Guest

12:40

He'd been really healthy. So, no, there wasn't a need to really see him. So, you know, it was just a total loss, I mean financially. He had been fired, so we had no health care. So that was one motivation of not just going in for well checks and whatever because we didn't have any health care. My health is also deteriorating and so I had no health care and so we had to wait till he was. Finally I did all my applications. Thank heavens I'm not, you know, scared of doing filing, but I files for his disability and then, waited two years for Medicare, so we were without any kind of financial support.

Raj Shah, MD Host

13:19

And learning to do some of those things that came through the without warning group and kind of like listening to other families.

Donna Guest

13:25

Women's support was in step, so it was very beneficial and the way I got through all this and continue to get through. I still sit through meetings even though I'm a widow, but it's an extended family, I mean, it's better than family. My family didn't even get it as well as in somebody that's actually going through it.

Susan Frick Guest

13:44

Right, and do you think, being in a rural area, do you think it was harder to find people who understood what was going on?

Donna Guest

13:52

Not a good example. You know rural America. It's a nice place to live but it's conservative in terms of a lot of philosophies of life. And Scott was in the driveway when a neighbor pulled up and said did you hear such and such wife? She's acting like she's got old timers, but she's just being lazy, she doesn't want to do her housework and she just doesn't want to contribute to the family. And Scott squeezed my hand again. That was a little simple and he goes. You know what? It is actually a national disaster, or you?

14:22

know, it's happening, it is real. He was still co -parent. He's a very articulate gentleman. He was like no, they need to listen to her and get some help, because it's real. And pretty much people saw him as being healthy and they kind of thought I was making it up and trying to make excuses. So no, and my church community he was very involved, played guitar, just totally abandoned us once we came

home but he went over to check. So we didn't have a church support, we didn't have community support. It's just. It's kind of like he felt like you were a leper. You know, when I found the church and I think the thing is with the younger onset, you got the golden nest egg and the idea you'll retire and we were that that you know reminder that maybe that isn't life, that may not be the way you head toward life. So so I use it as an opportunity when I tell our story to say you know, front load life.

Susan Frick Guest

15:24

Remember, you know life isn't always guaranteed when you need to front load it and show each moment is secure, right right and it sounds like from your first few appointments you know, if you hadn't gotten connected to the group and be a part of the support group, that having that emotional resources was really important for you and for Scott too. I know like, do you feel, like If?

Donna Guest

15:49

I hadn't found you because I wouldn't know where to turn. There was no recommendations of, like you know, a social worker or financial consultant or anything. We were just pretty high and dry. The way we actually made life work was my dad had died the same time, scott was my most and my mom had Alzheimer's, so we moved her in. So I was the major caregiver from both the early onset and the senior, all time Wow, for eight years. And you know she helped us get through that time financially until the Medicare kick in. But I don't know, I would have just not known where to turn if I hadn't heard about the group. So yeah, that would be my one recommendation that you know, once it's diagnosed that there's a follow up with the caregiver and family, you know just to provide recommendations for social services or you know how to cope.

Raj Shah, MD Host

16:43

We've been talking about. You know it's it's not only just the person who's living with the Alzheimer's disease or related dementia that needs a support and medical care and coordination. That, you know, has to happen sometimes in a primary care or family medicine setting, but it's really about the caregiver too, and you know the informal caregivers is there's more family members or others that are involved. They also need, you know, to also maintain their health and well being and support. And I'm just curious in your case, you know, did you, did you have a primary care physician? Did you talk with them about being a caregiver? Did you get any support for that role that you played?

Donna Guest

17:20

Well, I didn't have that financial ability to go see a doctor. We had no medical knowledge, so no, informally, I had a chiropractic that was also a friend and so she did kind of just support me as a friend. That matters in medical and professional until I could get coverage. I have to get on my platform for a minute. I actually also feel how important it is to follow up with the caregiver even



after the patient has died, and I don't see that too often. I've been volunteering carrying across generations as a fellow for them, and a lot of different universities want to talk to people as they're caregiving, but not after the fact that a person dies. What do we still have to go through? My case broke my back in the process of caregiving and trying to get back. I can't walk unassisted and trying to get myself back in order and Arizona State recently called and I interviewed and that's the first study I've ever seen them focus on what happened after your loved one died.

Raj Shah, MD Host

18:29

It's a really important point to bring up and a nice, important message for our audience to hear about, sort of the continuity. We think some of these are like transitional roles, but they do have lasting meaning and a need for continued care and support. So thank you for bringing that message up. And then, as far as you mentioned a few things that you would have maybe wished a little bit more with some of that follow-up care and support as you were going through it with the primary care team. Is there anything else you would have hoped to be slightly different or you would want for other individuals living in small towns and communities in rural Illinois and other places, what would you, based on your experience, what would you kind of want as far as from the primary care clinic and physician and team engagement to help in this early diagnosis phase?

Donna Guest

19:23

I know it's a little bit early to have the primary mention about hospice but thanks to my friend who also was a doctor, she said about consider hospice earlier rather than later and so that was something stuck in my head and Scott actually started having seizures. He had childhood seizures and seizures kicked in sooner with his Alzheimer's and he got on hospice for over three years and had good care physical care, physician through hospice and I got my support through them as well, having people come in, but I always thought it was only six months before if somebody died. So it would be helpful in a gentle way, I know, as your first diagnosis isn't the moment you say and think consider hospice, but the continuity of calling up and checking on the family and, as you knew, the timing got closer to mention consider hospice would be valuable to you.

Raj Shah, MD Host

20:26

And in many primary care practices now there are teams right Like the doctors there, but there's usually nurses or there's front desk staff or others that you interact with as a caregiver or somebody with ADRD and who they have to interact with. How did you get that sense of that connection and that office Was there? You know, sometimes maybe the doctor may make the diagnosis and be involved in sort of the ideas, but sometimes other team members may be involved in like looking up resources or knowing what's in the community. Did you get a sense that there was sort of a team understanding in the primary care clinic that you interacted with?

Donna Guest

21:03

No, the primary care team. There was not a team at all and maybe things changed because it's been quite a few years now, but there wasn't any mention on. You know and these other people could give. It's just two names. It's handed Susan's name and the neurologist's name.

Raj Shah, MD Host

21:21

And that was it. Yeah, I'm really kind of curious at some point to know how he got Susan's name. Unless he had some experience or somebody had mentioned it, but it was just interesting that that's somehow connected right.

Susan Frick Guest

21:34

But I just know it happened. Yeah Right, unless he went and looked something up, considering he had just told you young onset didn't happen as much it must have really bothered him enough to research it and find out.

Donna Guest

21:45

Maybe he Googled, you know, yeah.

Susan Frick Guest

21:48

And he gave him credit for tracking down additional resources for you and getting back to you.

Raj Shah, MD Host

21:53

Yeah, and it's such an important way we learn too, I think, in primary care is we live. You know, we have to hear what's in front of us and what our patients are experiencing and their caregivers, and then sometimes it is like a well-established primary care doctor starts learning. Well, there's always going to be things I don't know or can't keep up with, but I've got to be humble enough to recognize that and then get you know and still connect people right, like to still figure it out. So I think that's how we always learn. You know is just being part of those stories and people's lives and then understanding like how we can maybe further it a little bit along and we learn in the process. So definitely a really important story to share. You know your experience and the engagements there, but are we missing anything in our conversation today that you would like to let you know? Primary care physicians and training and currently practicing in Illinois know about that. We haven't touched base yet.

Donna Guest

22:52

Yeah, I think a follow up, you know, to reinforce that it's important even after the fact. There's another gal in my support group that lost her husband and his neurologist calls to see how she is, even though he's passed and he's no longer on the billing cycle. But that particular doctor cared enough to see how she's doing now that he's gone. And so along the lines you know, when it does affect a whole family. A little bit of that would go a long way.

Raj Shah, MD Host

23:24

Yeah, yeah, no, it's a really important message. So well, honestly, we really thank you for taking time out of your busy schedule to spend some time with Susan and me visiting Big Rock and your farm and talking with you about your experiences. I think our audience will really find a lot of value in this. So, Susan, did you have anything else before?

Susan Frick Guest

23:43

No, no, just thank you, Donna. You've been such an advocate for sharing your story and I think it's important because we don't always hear from people who you know we're struggling with insurance or in a rural area, and maybe the resources weren't as easy, so I think there's probably quite a few people who are going to benefit from hearing this. Thank you for having me.

Raj Shah, MD Host

24:02

Yeah, thanks again and hope things go well with the sheep farm as we head out. So again to our audience, we really appreciate you listening in to our podcast today with a really engaging conversation we've had and we look forward to being with you with another podcast in this like mini series of talking with caregivers from different backgrounds about their experiences. So until next time, thank you again and we look forward to seeing you in the near future.

Kate Rowland, MD

Announcement

24:34

Thank you to our expert faculty and to you, our listeners, for tuning in to this episode. If you have any comments, questions or ideas for future topics, please contact us at [podcast@thebraintrust.com](mailto:podcast@thebraintrust.com). For more episodes of the Brain Trust, please visit our website, [thebraintrustproject.com](http://thebraintrustproject.com). You'll find transcripts, speaker disclosures, instructions to claim CME credit and other Alzheimer's resources as well, and 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 in to the next episode of the Brain Trust.