

# The Brain Trust Episode 23: The Caregiver Mini-Series #5 Jeanne Transcript

**Kate Rowland, MD**Announcement00:03

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 IASP 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 [www.thebraintrustproject.com](http://www.thebraintrustproject.com). Cme credit is available for each podcast. The Illinois Academy of Family Physicians is accredited by the Accreditation Council of Continuing Medical. All right, well, today's episode.

**Raj Shah, MD**Host01:07

All right, well, hello everybody.

01:09

Thank you for joining us again for the next podcast in our series, the Brain Trust, by the Illinois Academy of Family Physicians.

01:17

The series has been designed for us to get a better understanding around sort of the early detection of Alzheimer's and related dementia, and today we continue our mini-series of discussions with really an important group and that's care partners of individuals living with Alzheimer's disease or related dementia and to get their feedback on sort of how their interactions have been when they engage primary care physicians for that original diagnosis.

01:46

Because we know physicians tend to learn quite well by hearing the stories and experiences of others and getting some tips along the way, and I hope that today people will be able to, at least by listening to this, understand one challenge that care partners can experience in seeking a primary care evaluation and maybe one thing that caregivers really would hope that we could do to improve the experience of early diagnosis and detection. So today I have Susan Frick again joining me for this mini-series session. So we're heading out of Russia on the west side of the city, and we're traveling to the state of Indiana today on I-94, and then to get down to Crown Point, Indiana, where we'll be meeting our wonderful caregiver who's agreed to be part of the discussion today, Ms. Jeannie Unterfranz and Susan, just as we're getting closer and approaching Crown Point and getting off the expressways here, how did you meet Jeannie and John and what's their interaction been with you?

**Susan Frick, MSW, LSW**Co-host02:46

I met them first in I think it was around 2015, when they started attending our support group without warning, which is for families living with younger onset Alzheimer's disease, and so they were very active participants up until probably we had to kind of slow down with COVID and go on to Zoom, and then John passed away about two, three years ago now and 21. So I interacted with him for a long time.

**Raj Shah, MD**Host03:14

John was a schoolteacher and taught computer science got our directions working okay today and we are in the driveway and let's just get out of the car and, I guess, go to the front door and see if we can meet Ms. Unterfranz. Hi Gina, how are you?

**Jeannie**Guest03:32

I'm fine, thank you.

**Raj Shah, MD**Host03:34

Oh, thanks for having us at your place today and having this important conversation for this podcast. I thought Susan was going to start. You know the conversation a little bit about just you know how your experiences have been, and then I'll kind of add in comments or questions as we go along.

**Susan Frick, MSW, LSW**Co-host03:50

Sounds good. Sounds good. And, Jeannie, maybe you can tell us I know we met in about 2015, but I'm sure this when you first started seeing issues for John was before that and what did you notice first and what problems did you see, and did he see any? And then what kind of prompted you to head to his doctor on this?

**Jeannie**Guest04:11

Well, he retired from school in 2008. I didn't retire until 2011. But between that time, he would tell me often, almost daily, that he was having difficulty getting dressed, getting his clothes on in the right direction and things. So I thought that was a little bit odd. And then if I was in the car with him, his driving was not so good. He would, you know, you're supposed to park between those lines at a parking lot or whatever, and he was on the lines or nowhere near the lines or whatever. So that was a little clue in my head that something was going on.

04:45

He did cut two fingers off when he was redoing the kitchen. I'm not sure if that had anything to do with anything, but his perception seemed to be kind of off. And then, a real trigger, whatever, he was teaching a night class, the same thing that he taught in high school, but this was for adult learners, and he would only do it one night a week and he would spend the entire week preparing for that one-night class. And it just seemed like, wow, why is this stuff not sinking in? And he had gotten a new cell phone, and he just couldn't figure out how to use the cell phone. So you know a bunch of little pieces. He was a huge snorer. So we, you know, we were in a regular in a regular visit to our

primary care provider. I mentioned that he snored a lot, he had sleep apnea, and I mentioned some of these other little pieces. So, he was sent to have a sleep apnea test and it turned out he didn't have that and then the primary care provider referred us to a.

**Kate Rowland, MD**Announcement05:42

Oh I can't think of the lady.

**Jeannie**Guest05:43

Anyway, he had a psychological evaluation and that's where they said we're pretty sure that he has Alzheimer's.

**Susan Frick, MSW, LSW**Co-host05:51

That was November of four, uh yeah, for of 2014 so 14, okay, so for you, you sound like you were seeing some like perception issues a lot of it.

**Jeannie**Guest06:01

Yeah, yeah did you notice?

**Susan Frick, MSW, LSW**Co-host06:02

Did you notice any issues? Well, obviously he was having trouble like putting together tasks for his class. Did you notice any memory issues with him?

**Jeannie**Guest06:12

Well, he took the car out once and he couldn't. He was going to I think he was going to a wake and he got lost on the way there. You know repeating things himself around the house but I didn't really pay attention to those kinds of things too much Just trying to do things that he had done his whole life with this new cell phone. And you know, I always relied on him to know how to do the technology stuff and he just could never figure out how to use that phone. And you know the little things just like.

**Susan Frick, MSW, LSW**Co-host06:40

Well, this is just not right, something is not going the way it's supposed to go, right, and thinking about his using the cell phone. That must have been a little alarming, since he taught computer science Right that that would have been something he was good at.

**Jeannie**Guest06:55

And even the looking back now, the work, the quality of his workmanship was not as good as it was like in the 90s. So I think that had something to do with the perception. And then that's when he ended up cutting two fingers off at the first thought. So he claims that had nothing to do with anything, but if you put all the pieces together, it's a wonder that was in 2011. So that seems like that might have had something to do with something.

**Raj Shah, MD**Host07:25

Yeah, and how old was he? About 2011?

**Susan Frick, MSW, LSW**Co-host07:28

one thing you started noticing things uh, in 2011 he was, he was 61, so he was 58 okay, my goodness, yeah, and so did you go along to his doctor's appointment when the doctor encouraged, like the sleep test or the evaluation no, I took him to those things.

**Jeannie**Guest07:46

They wouldn't let me stay. The evaluation, that was a two-day thing. They didn't let me stay.

**Susan Frick, MSW, LSW**Co-host07:51

So the evaluation, but what for seeing his primary? Were you in the office? Yes, I was Okay, and did you go purposely because you were concerned about him?

**Jeannie**Guest08:00

No, because we just always went to doctor's appointments together.

**Susan Frick, MSW, LSW**Co-host08:04

Okay, so that wasn't out of the norm. So when you went to that appointment, did you bring up the concerns, or was it the doctor kind of picked up on stuff?

**Jeannie**Guest08:12

Kind of both. This doctor was a very, very easy person to talk to and he really really liked John, so it was kind of easy to throw in, you know, the sleep apnea part he was, you know, because I don't know, I said something about his snoring so he said maybe we should look into that. And then, as the conversation rolled along, then I started throwing in some other things and you could see something in his head clicking that maybe there is, maybe there's more to it than just sleep apnea.

**Raj Shah, MD**Host08:39

So and how long did both of you know that primary care doctor? I was curious. He had been our doctor for maybe three or four years before then care doctor. But then there's the nurses or the front desk staff and it's sort of everybody's sort of involved in sort of creating that environment and atmosphere. Were there other people that kind of you talked with in the office, even in preparation for the discussion about like, oh, I'm coming in because I'm concerned about the memory, or they were-.

**Jeannie**Guest09:19

No, no, it was just true. The nurse would come in and take his blood pressure and those kinds of things, but she never asked questions about our main reason to be there. It was usually for our annual checkup. It was more the doctor who was getting me to talk more and John never complained that he couldn't drive right or that it was taking him a long time to learn things. He was really kind of unaware. I don't think he was in denial, but I don't know that he was really aware of

what was happening other than the getting dressed part, and that was getting kind of frustrated, but he would laugh about it.

**Susan Frick, MSW, LSW**Co-host10:01

So that part was good, yeah, when, when they sent you off for the or sent him off for the or sent him off for the evaluation with the psychologist or psychiatrist, were you thinking it might be Alzheimer's, or did that come as a surprise to you?

**Jeannie**Guest10:13

then you know it really didn't come as a huge surprise. I have my sister as a nurse and I have a dear friend who was a nurse and I would talk to both of them and my friend kind of sent me some Google things to read up and so I was really going through my own little checklist of like he does this, this, this and this. So when the doctor finally said this is what we think it is, I don't I, you know, I was devastated, but I wasn't really surprised. I guess that's the word I want.

**Raj Shah, MD**Host10:44

Yeah, and I was kind of curious because it is a, you know it's a coordination pathway there too. So you brought up the memory concerns with the primary doctor. They looked at the sleep apnea test. That didn't look like it was the cause and we asked people to look for common things that maybe have a solution first.

**Jeannie**Guest11:01

Yeah.

**Raj Shah, MD**Host11:01

So that was you know the right things to kind of start doing. Maybe have a solution first. Yeah, so that was you know the right things to kind of start doing. And then you know, when it came down to before like saying, okay, I think I needed him to see the to go for some more testing for the cognition. Were there any things that were done in the office to look at the cognition? Like, did they do a screening memory test or did he ask questions to you and to Not that I can recall.

11:31

I can recall the primary care provider asking yeah, and then once the report went out that you know you taught, did you get the diagnosis? Was that provided after that evaluation by the doctors or the team that did that evaluation, or did they send the report to your primary doctor and then your primary doctor talked to you?

**Jeannie**Guest11:48

about the report. No, we talked to actually to the doctor, the psychiatrist. I think she was a psychologist. I forget what her title was, but the two of us met with her in her office.

**Raj Shah, MD**Host11:58

Okay, okay. And then was that information transmitted back to the primary care doctor and they bring it up at the next meeting and then talk with you about things.

**Jeannie**Guest12:07

He did. Every time we would go back he would ask me you know how's John doing? And he was the. I mean, he was a wonderful person, still is. He's still my doctor. He was the one at one point that said I think John might be ready for palliative care, which was really something completely new for me. So I was happy that he kept track of us. I guess is the right word I'm looking for.

**Raj Shah, MD**Host12:30

Because that is kind of an important role of you, role of a primary office that knows you for a while, that there's an engagement, even after, say, a review by a specialist and a diagnostic help, but then to follow up and to see what's happening and to give suggestions or connections again. Did they do any other work like getting a blood test for thyroid or B12 or getting a brain scan or anything else like that? Was that ordered in the primary care doctor's office or with the specialist, or neither?

**Jeannie**Guest13:01

I. He had to have something, though, but I think that was because we were enrolling in this clinical trial at rush, and I think he had to have a test done here in indiana, so that he oh, now I'm getting confused.

**Raj Shah, MD**Host13:14

Don't worry, it sounds like there was a couple of avenues for you to get some of the testing done. How did you find out also about the clinical trials early on? Was that just a friend that?

**Jeannie**Guest13:27

was my friend who's a nurse. He lives in Texas now. She sent me this information and said I think this would be something, I think this would be some. I think John would fit right into this. So we went in and we qualified and it was a wonderful experience there. Unfortunately, after maybe a year and a half, I think, the trial was discontinued because they figured it was not working.

**Raj Shah, MD**Host13:48

Yeah, but I mean that's an important. Other piece that people can provide sometimes is oh, we don't have the best options right now, but you could also be part of the study and just encourage that engagement. So it sounds like you got that from the community, your network and support. And then how did you find about Susan's stuff and joining without warning?

**Jeannie**Guest14:08

That was my sister, different sister, no-transcript. I think he really did enjoy it. He really liked the music part. He wouldn't tell you that on the way there because he really wanted to put his brakes on about going out, and not that he was in denial that he had something wrong, but I think he just was comfortable only being within my. He wanted me to be in his eye all the time.

**Raj Shah, MD**Host14:54

And that just brings up another thing that happens is I even find it as somebody who was seeing people for a long time for the evaluations at Rush is I would learn about what community resources and other resources were available through hearing from persons I was taking care of that had Alzheimer's and what they were finding and locating in neighborhoods, and then I could share that with another group. And you know, did you end up sharing like this information when you went back to see the primary care doctor? Would you tell them like, oh yeah, we found this like group.

**Jeannie**Guest15:29

Yes, yes.

**Raj Shah, MD**Host15:30

So yeah, so it's always that two way street of learning kind of a thing you know, and it just gets people's skills better. Yes, yes, I tried to get into a support group myself, but I didn't have.

**Jeannie**Guest15:39

you know nothing in Indiana had something that I could bring my husband along. So you know, I couldn't go most of the time because he couldn't come along with me and, as you know, the years went on he wasn't capable of staying home by himself. So this was wonderful, it was a good experience for him and then it was a really, really good experience for me. So I really enjoyed my time there.

**Susan Frick, MSW, LSW**Co-host16:17

And that's nice to hear, jeannie. I was wondering when they told you it was Alzheimer's, you said it didn't come as a huge shock to you. Was there any? Did John respond at all? Was it surprising to him or did he not really have the insight?

**Jeannie**Guest16:31

I don't think he really had the insight. He would joke about it with his friends about how don't you know? Don't count on me to remember anything because I can't. So that part of me he would joke about. But at first he never. The only thing he really questioned was the doctor told him that he can't drive anymore. He was very, very upset about that and I said well, you can't, it's on your record now. So you have to listen to what the doctor said. He did, he did. He never attempted to take the keys and go out and drive. But he wasn't happy. He didn't like her because she had the bad news psychiatrist.

**Raj Shah, MD**Host17:14

That was the psychiatrist. Yes, Okay, got it. And did that issue get brought up sometimes? Because people will go back to their trusted primary care doctor and said, oh, the specialist told me not to drive and I really don't think I should listen. Did that come up again with the primary doctor, or that?

**Jeannie**Guest17:24

reinforce. No, he was not happy, but he did accept it, so he didn't really go out a lot on his own anyway, so it wasn't like he was missing out on anything If he wanted to go see his friends. They were friends of mine also, so it was convenient for me to drive.

**Raj Shah, MD**Host17:43

Yeah, and looking back at the experience, especially what one of the things we're trying to get a better sense of is, from the time people start noticing things happening as a family right to the time they talk to their primary doctor about it. It's a pretty long time sometimes, right, Like I think in your case, maybe it was a couple of years, Does it sound right?

**Jeannie**Guest18:04

Correct, yes.

**Raj Shah, MD**Host18:05

And you know, part of that early detection and diagnosis is just recognizing that it's important to maybe bring up those conversations a bit earlier so that people are just primed for it and be able to support people at an earlier stage of knowing what's going on. What do you think, if you look back, would have maybe encouraged you to talk with the primary doctor a little bit earlier? Was there anything that the primary care office could have done to make it easier for you to bring up the issue? Would there be things that you know youth look back at and said maybe I held myself back because I was just looking for other things or not sure about what I was seeing, and so I just wanted time to wait and to see, like, how that's developing.

**Jeannie**Guest18:49

Well, to be perfectly honest, he was retired and I wasn't. I was still working full time. Well, to be perfectly honest, he was retired and I wasn't. I was still working full time. My can't figure out how to get your pants on or your shirt on the right way. You know, when you look back then it's you know, hindsight is 20-20. So I don't know that there was any really major red flags that would have gotten me to get him to the doctor any sooner than that.

**Raj Shah, MD**Host19:26

Yeah, and then sometimes it's harder when people are experiencing this like before sort of Medicare onset, right Like after age 65, now we have these annual wellness visits as an option, you know, in primary care, where you can go in and talk to the doctor about your general health and making sure you're following through on any preventive work, and that's a nice opportunity for the doctors to just even prompt and just ask like, oh, are you noticing any memory troubles and start the conversation. You know it's sometimes a little bit harder for people that are younger onset maybe on other insurances, for people to think about that right, like in bringing those issues up.

**Jeannie**Guest20:03

Well, I think too. I think nobody wants to admit that there are any problems. I think you see too much on TV, on tv or whatever it is, and you think, well, if I say I've got this kind of an issue, then I'm going to end up like that person in a movie that you know, whatever. Um, I do have a friend who's in her early 60s and she was diagnosed maybe six months ago and she keeps saying I know the doctor, saying I know the doctor's wrong, I know the doctor's wrong. I just, you know, just because I keep forgetting a few things.

20:36



Yeah, so I think you know if she were, or even if her family and they're very much in denial, I think if they could get on some kind of a, you know on the right page or whatever. But they don't want to other than taking her to get her diagnosed. They don't want to join a support group, they don't want to. You know, I have sent them some information about clinical trials that I've seen on my phone and they don't want anything to do with any of that stuff. So I think, oh, you're really hurting her and I have no idea what their doctor is like. I don't know how assertive he is or she is.

**Susan Frick, MSW, LSW**Co-host21:12

Yeah, you know, and I think it's hard in that beginning phase of I think it takes time for people to kind of wrap their head around everything that's going on. When you look back at this time when he got diagnosed, is there anything you wish you had received from any of the doctors you were involved with or any of the staff Are there for either your well-being or his well-being. Is there anything you wish had happened?

**Jeannie**Guest21:38

being or his well-being. Is there anything you wish had happened? You know, I don't think so, because my family my own family was so good.

**Kate Rowland, MD**Announcement21:44

I'm going to cry.

**Jeannie**Guest21:45

You know, they just made my kids, my siblings, made a really terrible experience, not as terrible as it could have been. So, you know, my mother always said it is what it is. And this is, you know, a prime example of that. So I don't know that I would change anything he wanted. The day the doctor, you know, said this is what you have. On the ride home, he said to me you're not sending me to one of those places, are you Meaning a nursing home or a? And I said, no, we'll stay. You know, you'll stay at home. And there was.

22:16

You know, after a few years I thought, whoa, I hope I can, you know, hold up to my end of the deal. It was challenging. But to do things differently, no, I, you know, wish, in hindsight, I wish we had done a whole lot more with our lives before we were diagnosed. Because we didn't. We were both working, so we didn't travel, we didn't do all those fun things that people do. And then, all of a sudden, we, you know it was, traveling was difficult. So, doctor wise, I don't know that I would change anything. He loved going to our primary care provider. He was a very soft-spoken young gentleman and so that made things really easy. And you know, at home he was pretty content to be home and not do a whole lot.

**Raj Shah, MD**Host22:58

Yeah, that's good to hear. Like you know, that relationship and that building also brought him some comfort to go to see a doctor that had developed over time throughout. Whatever that experience was, I'm curious because you were also seeing that doctor, I think for your primary care.

**Jeannie**Guest23:13

Correct yeah.

**Raj Shah, MD**Host23:14

Was there any discussions that you had with the doctor about sort of your processing of what was going on and having to take this role of a care partner or caregiver?

**Jeannie**Guest23:24

I mean he always asked me how am I doing? I'm not really one to complain because I thought, well, you know whatever. But he did make and he still does, because I still see him. He will always. How are you doing? You know other him, he will always. How are you doing? You know other than just physically. How are you mentally doing and are you able to keep up with this, that and the other things? So he's.

**Raj Shah, MD**Host23:44

It's nothing but a good experience with the doctor that we had gone to because we know that's just an important piece is for also that care partner to feel supported and to have an avenue to talk about their own health and role as a care partner. You know, to support other things, like your family network that helps to build you, and also, you know, like formal programs, like Without Warning. I'm glad you were able to put all those things together. But you know we're nearing the end of our wonderful conversation here today and I just wanted to just ask you if you had any final comments or thoughts that we haven't quite covered that you wanted to maybe bring up with our audience.

**Jeannie**Guest24:23

No, I would just tell anybody to get in touch with Susan at Without Warnings. It was the best experience in this situation. You know it was she's soft-spoken. The people that were there had all sorts of good tips and information. It was just a good. I looked forward to it, you know I really it was just a nice experience and the people were good and I learned lots of things and you know the good, the bad. You know, when we started there was people who were much more advanced than John, so that was a little bit scary, but at the same time I thought I can't stick my head in the sand and pretend that nothing is going to change. So that part was good. At some point he will be at that stage. So it was just a very good experience. And the Alzheimer's Association we became very involved with them.

25:11

And that's been. I have nothing but good words to say about them. I am now an advocate for them. So I've met wonderful people. This experience opened up all sorts of other doors in my life.

**Raj Shah, MD**Host25:25

I know Well. I mean, you've learned a lot and been able to share a lot of that experience with everybody here today on our podcast and we really appreciate this opportunity to visit you at your home in Crown Point, really appreciate this opportunity to visit you at your home in Crown Point and hopefully we'll have another chance to talk about future things and continue that great work and

advocacy that you're doing For this session. We come to a close today for our podcast. We hope that we can connect with you, the audience, again in the future about other topics in the space of early detection and diagnosis. So stay tuned for our next session, thank you.

**Jeannie**Guest26:00

Nice to meet you. Thank you, thanks, gene.

**Kate Rowland, MD**Announcement26:06

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](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. 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 in to the next episode of the Brain Trust.