

# The Brain Trust Episode 19: Caregiver Mini-Series: #1 Katrina Transcript

Kate Rowland, MD: 0:03

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: 1:08

Welcome everybody to our Brain Trust podcast series, the next one in line. We're just recovering in Chicago from a really cold spell after the new year, but today we have a really special start of the year with a new mini-series. We're starting to really get a sense of the care partner perspective for somebody living with Alzheimer's disease or related dementia. So we've been lucky enough to be able to connect with multiple caregivers from different perspectives and backgrounds and today will be the start of that series. So joining me for these sort of set of presentations and the podcast for the Brain Trust will be a close colleague of mine at my work at the Rush Alzheimer's Disease Center where I'm a professor in family and preventant medicine, and that's Ms Susan Frick who's a social worker at the Rush Alzheimer's Disease Center. So I was able to pick up Susan in my Toyota Corolla and we left the parking lot at Rush about 30 minutes ago, heading south to Lansing to see a wonderful woman by the name of Ms Katrina Miller, and we've got about five minutes or so before we get to her place. So I thought I would just even start by asking Susan a few questions about sort of her experience working with caregivers and especially in a program that we have been offering for many years in the Chicagoland area that she oversees with individuals experiencing dementia and their caregivers, called Without Warning. So, Susan, thanks for joining me on this little trip and field trip we're making to Lansing today and I'm glad that. What roads are not too icy today. But tell me a little bit about, and our audience a little bit about, without Warning.

Susan Frick, MSW, LSW: 2:51

Thanks, dr Shaw. Yes, we've had, without warning, going now for almost 20 years. It'll be 20 years this April, which is We've known each other for a long, really that long, yeah, yeah. And this group is for people experiencing younger onset Alzheimer's disease, so under the age of 65. And it's a group that I find just an amazing group of people in that we support both the people with dementia and their family members. And over the years, our group, when we used to meet in person, we would be sometimes 80 people at a meeting, you know, just because it was, and we would break into so many different groups. Now we've been meeting on Zoom, which has some nice benefits in that really anyone we have people who zoom in from Florida, delaware, all around Illinois, so it's not that you have to be local to the Chicago area to be able to be there and it is. There has been some, you know, even though COVID wasn't expected or you know it's nice to be in person. There's been some benefits to being on Zoom too, and what the group has really taken on over the 20 years is telling their story and and helping. They've created a documentary. They've created a lot of little vignettes that are online about what it's like to live with Alzheimer's and what it's like to be a care partner to somebody living with Alzheimer's.

Raj Shah, MD: 4:17

Yeah, so maybe if you can tell us a little bit about who we're visiting today, Ms Miller, from your experience working with her I think you mentioned she was part of one of those like presentations before about telling the story and then just getting us as we get closer, just giving us a sense of who we'll be talking with today.

Susan Frick, MSW, LSW: 4:34

You bet, you bet. So Katrina's been part of the group for a couple of years now, started through COVID and is caring for her husband, michael, who is a very, very, very important person Michael who his care needs have increased over the time, and she has been our caregiver group through since COVID has been actually meeting weekly on Zoom, because it was easy just to turn on our Zoom and be there and people were needing such support when they were so isolated and lonely. So she has been a wonderful resource to other family members. She, as you mentioned, we do a lot of panel presentations and she was part of one of our panel presentations for what we call the dementia leadership course and it was for people who work in the field in all different areas but are leaders in wherever they work, and so she was part of a panel that I think had maybe seven or so caregivers and she shared her story of caring for Michael.

Raj Shah, MD: 5:33

Oh, that's terrific, yeah, so I'm really looking forward to meeting with her. So it seems like we've pulled up now close to her driveway here, and so why don't we just get out of the car briefly and walk over and ring the front door and see what's going on? Oh hi, miss Miller, how are you? I see you. You were prepared for us coming into the parking lot there, so really appreciate you opening the door on this cold

day. So my name is Dr Shai. I know we're meeting for the first time, but you know Susan who's right here.

Susan Frick, MSW, LSW: 6:00

Hey, good to see you. Good to see you. Thank you so much for doing this with us. And actually, Dr Shaw, when you said to say my relationship with Katrina, I realized all my interactions with Katrina have been not in person. Oh my gosh, so this is the first time you're making a first visit.

Raj Shah, MD: 6:16

Oh wow, what a special day that. Okay, that's terrific.

Susan Frick, MSW, LSW: 6:19

Yeah, it's been on Zoom. So, Katrina, could you maybe start, because we're really wanting to kind of hear about your experience and your experience with Michael in how it was first getting the diagnosis, being able to interact with your primary care physician, you know, and helping those who are listening to know what they could do to support someone who might be coming to their practice. So could you maybe say how it was when you first went, like what you first started noticing with Michael and how it was getting talking to your primary the first time or his primary the first time.

Katrina Miller, Caregive: 6:56

Well, probably prior to our actually going to the doctor and voicing concerns about him, I'd noticed maybe six months, probably longer, but just within six months it was starting to increase just different changes with Michael. He was forgetting his keys, leaving things at home. We had a daycare center, a standalone daycare center with a huge staff, and he was just. They were calling me more often for things than typical because he was forgetting, and it wasn't just your usual things. I think the main reason I was like we've got to go see a doctor is my husband wore a suit basically seven days a week so he could tie a tie in his sleep. And one day he came in the bedroom and he was getting dressed and he was like I mean, can you help me tie my tie? I can't. For some reason, I can't tie my tie and I about fell off the bed. I was like you can't tie your tie. And he was serious as I was attacking. He was like no, michael, I don't know how to tie a tie. So I'm like where can Google it? If you know, figure it out. And he was eventually, you know where he was going. He was like, oh, just get somebody else to help me. So I knew then there were a lot of things that were happening, but that was like, okay, we got to see a doctor. Now, I have to say, we had a doctor, his primary care physician, michael, for months, anytime he had to go see him, he had some issues with GAL and he would go to the doctor by himself and I'd say, did you, did you mention to him about? You know your memories I'll not forget, I'll tell him next time. So he'd gone maybe two or three times over the course of maybe about a year. Finally, I was like you know what, let's, we need to switch doctors. I wasn't real thrilled with him, so I was like, well, we need to switch doctors, I'm going to find another one and I'll go with you because it's about time for your annual checkup. And so we go, I

find a doctor and just hope and pray that she would, you know, be okay. And we get in there and it turned out to be the best experience ever.

Susan Frick, MSW, LSW: 9:02

Were you at all nervous when you went in there like to bring up the subject about memory loss, and was it hard to say it in front of Michael?

Katrina Miller, Caregive: 9:11

It was. It was even though I'd been encouraging him to talk to the doctor. I knew he wasn't because he didn't want to bring up the subject to them, but he's always been like a really even keeled person. So I knew it wouldn't be a problem to bring it up, but I needed to find a reason to be there with him. So since we were switching doctors and not yet we had the same doctor and I was not I hadn't switched myself over yet I said, well, let me just go to meet her too and I'll just go with you to your appointment. And he was fine with it. So yes, I was nervous, mostly because I felt like I didn't know how she was going to take it, just meeting us and then me just throwing it out there. It was his annual visit. So I thought, well, we'll just let her go through the whole visit thing and then I'll bring it up if he doesn't bring it up. So yeah, that part was kind of a little. It didn't make me a little nervous, not so much about him but more so how the doctor was going to take.

Susan Frick, MSW, LSW: 10:11

From that appointment. How would you say life has changed.

Katrina Miller, Caregive: 10:14

That set you on the course, then, of getting the diagnosis, and that was when I said earlier, it was like the best visit she turned out to be. If I could have chosen how things went, I could not have done a better job. We went in and she sat down with him and she went through the whole His regular physical thing and then she asked him. She was like, oh, is there anything else, Mr Miller? And he was like nope, Yep, that's about it. And I was like, well, I do have one question and I kind of threw it in there and I was like you know, he's been having some issues with his memory. And she said really, Mr Miller, you're having problems with your memory? And he's like, no, not really. I work with a lot of women and they just stress me out. It's just, I'm just stressed out. And when I tell you, it took about two or three questions for me to realize that she was giving him the MMS.

Raj Shah, MD: 11:10

MMS right Mini-Metal State.

Katrina Miller, Caregive: 11:12

Exam, when it took a few questions for me to realize what she was doing I don't think he ever did. It was just that smooth that moved from my question to giving him this test. Just the way she did it, it was so personable. You know, when he mentioned oh yeah, I'm under stress, she asked him about what kind of work that he did and it just kind of went from there. You know, your anniversary, your wife, your this and I was literally shocked at some of his answers because he was so far off, and so that was hard, because she didn't seem to flinch from his answers. You know, she asked what month it was. He didn't know. She asked him the day. She asked him what year it was, and that really threw me. I had to kind of look away when he didn't get what year it was right, because I had no idea. I had no idea he didn't know those things. But I was so impressed and from there she went straight to. Well, you know what, mr Milliar, there are a few things that I'm concerned with that you didn't remember. And he was fine, he didn't seem to be upset about it or anything. And she says we're going to start off just doing block work to rule out anything physical as to why, you know, your memory is getting bad and we'll go from there and he's like, ok, fine, and it was. For me it was just like, oh my God, he's worse than I thought he was. But for him and her they're just like we're OK, we're OK, we're good, we're just going to go on with the next. And she made sure she got all the blood work done. You know, set us up we was Northwestern Set us up with their Alzheimer's clinic and he's got the clinical testing and all of that done. It took about nine months from the time we saw her initially till the definitive diagnosis, just getting into appointments and covering everything. And I felt like she was just so thorough in making sure that we had all of that taken care of. You know, down to the spinal tap was the last thing, or?

Susan Frick, MSW, LSW: 13:10

that anymore. But anyway, when it sounds like in that moment you really appreciated her, taking what you said seriously and just weaving it into the appointment, yes, absolutely Absolutely, and she didn't ask any questions like to make me feel like, oh, you know he's saying he's just under stress.

Katrina Miller, Caregive: 13:31

She just took it and just to see, like she needed to see for herself, and I just felt like this was exactly what I needed. I needed someone to just kind of because you don't know what direction to go in. You know you need things going a little odd with your loved one, but just not knowing and I wouldn't have known. Ok, we'll get in touch with this person or get. So she just kind of took the ball and ran with it and that, for me, took away a lot of the pressure too. Wow.

Raj Shah, MD: 14:02

Oh, now, that's a terrific story about an experience. That's like a master class of what we would want all primary care physicians to be able to deliver. But I'm glad you had that experience and I'm sure a lot of families have that experience. But sometimes we don't always talk about that like the good and also

some of the more difficult parts of a visit and setting up that entire, you know, engagement, you know, with the first visit, getting to know somebody, then hearing this information about memory and then seamlessly flowing through it. That's really nice and I'm glad you know you were able to express how you felt in that moment. You were nervous but she kind of helped to kind of work you through. It never put you really on the spot for bringing up the issue and then just working with him so he was comfortable, so you could get the information and then having a plan of you know how to approach things. I was curious in that you know nine months like she would order the test right or, you know, set up the next appointment. So it sounds like you were having in the diagnostic period as you were trying to do the other aspects of everything she was. Also you were connecting with her again and again until that nine months happened and you got the final diagnosis.

Katrina Miller, Caregive: 15:09

Yes, she actually. Until we started dealing with the Alzheimer's memory clinic, she was the one that made sure that all of the other testing was done and she followed up. I mean, they were kind of it was easy, you know, for her to get the test results when he got his, when he took the tests with the neurobehavior tests and those kinds of things. But she always followed up and that was the good, the good part. I was so impressed with her. I changed immediately and switched up. He's not missing a knee in between, but just in the period of time where she Michael would come back and see her. Her engagement with him was always she was very, she was very much a part of that whole process. You know, as things happened she would get in touch with us as well as the the behavior clinic itself. It was that part of it was helpful because you know, dealing with a lot of different doctors sometimes is hard, but dealing with one that was there from the beginning and knows where you started, that that makes that.

Raj Shah, MD: 16:14

Yeah, that definitely helps to kind of quarterback with you, to kind of, you know, help you, you know, you know, integrate all of those different perspectives and then to ask questions and to share information. And then I was kind of curious also because you know, usually in a primary care setting, you know the doctor plays a bigger role but it's really a team approach now and I was just kind of curious were there other people in the office that also made the interaction better for you as you received and work through the initial and diagnosis part?

Katrina Miller, Caregive: 16:46

His primary care physician was in contact with the behavior clinic. They also put us in contact with physical therapy well, we're paying out there and social workers. So they all worked together and as his medications were adjusted once he was diagnosed, they all talked with regard to that which medications would be best for him, because he does have high blood pressure and was dealing with a few other things. And so they they did talk amongst themselves Because whenever one of the appointments was made, she always knew and she'd you know when we come back and follow up with her. She was always

very well aware what new medications he was on or knew anything that was going on with him and was just really good about his check. Because once he was diagnosed, the changes I would say they were, they became very, they were more pronounced and noticeable after the fact and she adjusted how she dealt with him. You know there was times where he couldn't get up on the scale or he couldn't get up on the, the examination table when he would come in for visits, because he went to see both every six months and she would. She just adjusted and in just everything about her. She's gone now, but she went to another state, but Okay.

Raj Shah, MD: 18:09

All right, we got to hunt her down somehow and find her and have a discussion with her for this series so I might ask for her information offline. But the other thing I was curious about, because you also mentioned, you know it is not just the loved one that has the memory loss and how we approach them in a humane and dignified manner to help them out, but you're like the spouse right, the caregiver, and you also made this decision to change your care to her, and you know we always think about it that it's not only the person that has the dementia and gets a diagnosis that is affected by it, but it's also their loved one right, their spouse, their caregiver, their care partner. So I'm kind of curious, like you know, did you feel supported as even a caregiver, to have your own concerns, questions sort of answered, whether when you went together or you had time separately, when you met with her for your own visits and things like that?

Katrina Miller, Caregive: 19:03

Absolutely, absolutely. When I would have my appointments. Initially I went by myself. Eventually he was with me all the time, but she always asked, you know, would ask about him and how I was doing. You know, is there any, any additional help that I felt like I needed just the care that she took in in asking about me with regard to the situation, not my visit to her or made the world of difference as well. I must say I felt the same way, not just about her as the primary care physician and his, but also with the support staff in the neurobehavior clinic. The same thing. They were very conscious of what I needed and how I was adjusting to, you know, taking care of Michael. There was never. I never felt like I was being abandoned, like it was just about him. It was always. I've never felt this. When Susan was never first talking about doing this with you, I was like, oh, I had the best experience. I'm sure other people have not had the best, you know, because sometimes you know you get lost in the shuffle, but I never had that feeling. So, yeah, I can't.

Raj Shah, MD: 20:21

I know that's great. No, thank you for sharing that and I'm glad you were able to get that support too, because you know it's it's as important to keep the caregiver feeling connected and strong and engaged and maintain their health as it is for the person that's experiencing the memory troubles and the dementia due to Alzheimer's. And maybe I can turn it over to Susan to just kind of you know, as you reflect on that process now, maybe some of the things you you kind of take as learning points that you

might want to share to our audience of you know, usually primary care physicians at practice, sometimes residents, sometimes medical students and then staff at primary care settings and family medicine around the state of Illinois and others. But yeah, susan, if you wanted to kind of follow up on the reflection piece.

Susan Frick, MSW, LSW: 21:05

You bet yeah. And you know I was kind of curious, katrina, because your appointment went so well, which is so great, but you did have that like year period. It sounded like about a year where you were hoping Michael would bring it up at an appointment and he didn't. So that must have been a stressful time, I'd imagine, because you were seeing these changes and they weren't really getting addressed. Like. When you think back on that time period up until you had this appointment that went so well, is there anything you wish you had done differently or anything that you look back on and go, oh, we could have done that. Or was it just that it needed to develop for a year before before you brought it up to the doctor?

Katrina Miller, Caregive: 21:46

There have been times where early on I kind of struggled with that. I was like, oh, I wonder if I'd have said something if I had gone with him to his appointments when he, when he had those appointments that I was like, don't forget to ask about your memory issues. So yeah, I would say, if I could do anything different, I would have probably addressed it a little sooner, maybe six months sooner, me physically going with him and asking. But then I go back to at that time we would have been with the doctor that I wasn't all that in group with and things may not have gone as well as they did at the time that we actually went right, Not to say that he wouldn't have but it may have just been a totally different experience going with him. I don't think I would have had the same experience had I gone sooner. So I didn't really dwell too much on the fact that, oh man, I should have gone. You know, if I'd have known this was going to be the outcome. I knew something was going on in my head. I was thinking it was something more physical than in which Alzheimer's is physical, but physical like a physical problem that was going on, that was affecting this memory and I would have definitely had a different experience had I addressed this with his doctor. So part of me, yeah, felt a little guilt about it taking so long, but then when I think about the experience that I had, I'm glad that it happened the way that it did, Right.

Susan Frick, MSW, LSW: 23:15

And I'm not saying you should feel any guilt on this, because I think it did all work out so well in how it came about for you then. And I think it's hard because, like you said, you were thinking it would be something different than Alzheimer's. And so it takes, I think, what I've heard from families and without warning, it takes a while to like wrap your head around what's happening and what's going on. And I've had so many families say the six-month thing that they almost feel like they feel like they were always about six months behind in reacting to something which I think is so typical.



Raj Shah, MD: 23:49

Yeah, no, and I definitely think I appreciate you sharing all of the stories and your insight. I think it's gonna be very helpful for our audience and this is a great opportunity and I know you've got a really busy schedule and working through things and we appreciate the time and you're welcoming us to your home today to talk with you a little bit about your experiencing, your experiences and sharing it with a broader audience. And, yeah, I'd love to connect with you afterwards and see if we can follow up, maybe at a later date with another conversation about then after the diagnosis and the care received and how that went with the primary doctor and the things you wanted in that setting. And then also just understanding engaging even with the primary care doctor that you saw, just to understand, like, where do they learn those skills? Right, because it's always important that we share that and we explore it. But thank you again, Katrina and Ms Miller, for all your time today and we really appreciate it.

Katrina Miller, Caregive: 24:47

Welcome no, and yet I'd welcome another visit. That would be fine.

Raj Shah, MD: 24:51

Oh great, thanks so much, thanks so much.

Kate Rowland, MD: 24:58

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.