

The Brain Trust

Episode 22: Caregiver Mini-Series #4 Leslie

Transcript

Kate Rowland: 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. 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

Hello everybody and welcome to the Brain Trust. I'm Dr Raj Shah, a professor in family and preventive medicine and the Rush Alzheimer's Disease Center at Rush University, and we welcome you again to our series about the early detection of Alzheimer's disease and related dementias. And here's another part of our mini series that we've been talking with care partners and getting their perspective of how they viewed sort of that early detection and diagnosis as they were working with a loved one that was experiencing memory problems and needed an evaluation. So today I'm again joined by my colleague and friend, Susan Frick, who's a social worker at the Rush Alzheimer's Disease Center. Yeah, we're able to leave Rush after doing some work downtown and we're driving down 290 and I88 and eventually I355 to get closer to Downers Grove in the western suburbs of Chicago. And Susan, thanks for being able to join again today. It sounds like we've been on the road quite a bit the last couple of sessions over here. But yeah, tell me who we're going to be meeting today in Downers Grove as we get closer.

Susan Frick: 2:18

So we're meeting with another couple from our Without Warning Support group that the Rush Alzheimer's Disease Center hosts for families living with younger onset Alzheimer's disease, and so it's Leslie and Phil. They joined in, I think, around 2014 when Phil was diagnosed and he has since

passed, and Leslie has stayed involved with the group and has been quite involved throughout the years, so I enjoy being able to visit with her.

Raj Shah, MD: 2:46

Oh yeah, that's great. I think when we talked with her and setting up for the meeting and getting the directions out, there is her last name, pronounced like Ureza.

Raj Shah, MD: 2:53

She was saying like that's how she used to teach the children when she was a librarian, to say Ure as part of her name. So that was kind of cute. So, okay, I pronounced it correctly. But yeah, we're in the driveway and getting out of the car now and walking to the front door and there, yeah, we see Leslie there. So hi, ms Ureza, thanks for having us here. I'm Dr Raj Shah and Susan. You know we're here to visit with you. Thanks for having us at your home.

Leslie: 3:17

It's nice to meet you again.

Raj Shah, MD: 3:19

Yeah, so you know, as we talked about, as we were setting up, this session is, we're just trying to help primary care physicians hear the voices of actual caregivers working with individuals living with Alzheimer's disease and related dementias, and to try to help them to, you know, hear more stories about that experience from the caregiver perspective. And I'll turn it over to Susan to maybe just ask a few initial questions about what you were noticing with your husband, phil, that led you to seek, you know, some more input from the physicians that you worked with.

Susan Frick: 3:52

And Leslie, when you first started, or when you first started seeing issues with Phil, what did you first notice and what kind of drove you to say maybe you needed to talk with his primary care physician about this? Well, Phil was very physically fit.

Leslie: 4:08

He loved to jog, so he didn't believe that anything could be wrong with him. And other people didn't believe it either. My daughters would be very much like oh, mom, you're making a big deal out of this, so dad forgot that or he forgot this, and I'm like, no, it's getting dangerous to drive with him. He

will pull over for a fire truck, for instance, on Main Road, 63rd Street, which doesn't. He's not pulling off the road, but when it goes past he doesn't realize he's got to start up the car and go again. He's waiting. And then I'm trying to help him and he's like you're making me nervous, you're making me nervous. That's why I'm making mistakes. And he, for instance.

Leslie: 4:54

We were on vacation and he, in the middle of the night I hear the door of our hotel room open and Phil is leaving. I said, oh, where are you going? And he said I'm just going to the bathroom. And I thought, oh my gosh, he would have walked out and he would have walked down the hall and we you know it was. It would have been very dangerous if he'd have left. He did the same thing in Oregon when we were visiting my daughter one time. He went down, we were upstairs. He went downstairs and right out their front door and they had to run after him and he said I'm just going to go to the bathroom. My daughter was like I don't know if you can come anymore. This is too dangerous. And I was like what?

Raj Shah, MD: 5:40

And how old was Phil when this was starting to happen?

Leslie: 5:44

Well, the first vacation he was about 56. But he was just gradually forgetting things. But he would never admit that he was forgetting things. It was all in my head. He didn't forget anything.

Leslie: 6:02

And one of the things when we were both working I was working in Joliet area and sometimes it would take me longer to get home and he would start dinner. You know, he'd make spaghetti and meatballs or he'd make chili and all of a sudden he had no idea where anything was in the kitchen. He had no idea how to make any food, even a frozen pizza. He was like I don't know how to do that. And I was just like I mentioned that to first of all to my director. I said something's going on with my husband. I said he doesn't, he doesn't even know how to cook basic things anymore.

Leslie: 6:41

And the reaction was oh, your husband cooked. Oh, aren't you the lucky one? And I'm like no, that that's not the point. No, the point is he doesn't know how anymore. Like he's totally confused, like I'm thinking maybe he just doesn't want to do this anymore and this is his way of suddenly getting out of it. You know, like, but because I'd say, did you forget? You know how to make this. No, I didn't forget anything. Why, why did you think?

Susan Frick: 7:14

that I'm forgetting things. So you were really seeing this. How did you then bring it? It sounds like if you tried to bring it to his attention. It wasn't. He wasn't going to acknowledge it. How did you bring it up? Eventually, get it brought to his doctor?

Leslie: 7:28

Well, first I said you know, I think you need to talk to your doctor about this. I there's nothing to talk about. They said would you mind if I come with you in the doctor's office? And he said you can come with me if you want. I haven't got anything to hide and I said okay. But when I came in, the doctor spoke directly to Phil and I sat on the side and I mean I totally respect that. I think that you know the doctor should talk to the patient. But I said I do have some questions for you. So then, after he talked to Phil for a while and Phil told me his health was good and everything was fine, I said he said no, what, what did you have a question about? And I could go.

Leslie: 8:14

Phil is forgetting how to do a lot of different things. He's having more trouble with driving and he doesn't cook. And I got the same response from his doctor oh, aren't you lucky? Phil used to cook. And I was just like yes, I am lucky. Yes, he did. Then he looked at Phil and he said is this true? Are you forgetting things? And Phil said no, I'm not forgetting anything. I don't know why my wife is saying that. And the doctor. That was it, that was it.

Raj Shah, MD: 8:48

You know that was it and then was there a doctor that I was curious was the doctor somebody Phil had been seeing for a long time. Was it a primary care doctor you had been seeing for a while?

Leslie: 8:59

Well, we had gone to Downers-Girl Family Practice from like the 70s and, I mean, the doctor saw our kids more and he did see a different partner usually, but that partner was no longer there now and we were seeing one of an actor that I felt was the most respected actor there, but Phil appeared to be. I mean, his health seemed fine. He was still walking the dog all the time, he was still jogging. It was like I was the only one that was noticing this, you know. But one of the men that taught Phil punching your high and that would be enough to give you dementia, I'll tell you. He taught next to this man, and the other gentleman developed a brain tumor and I said you know, maybe there's something in your building. Maybe you know there was. They were in Franklin Park, which is pretty close to O'Hare Airport. They had, you know, airplanes flying over all the time. I said, you know, maybe you have a brain tumor. You know, I'm worried about you. I'm not trying to trap you into

something, I'm not trying to make you know I'm very worried. And he said, oh, oh, I could have a brain tumor, you think. And so he. I said, well, will you talk to the doctor about that. So then we went and the doctor, you know, said I will, I will schedule him for an MRI. And after he scheduled him for the MRI, we came back and he said there is no sign of a brain tumor. But I do see indication that the brain is shrinking. You know that there are. It could be developing dementia. And all Phil heard was there's no brain tumor. So when my we talked to my daughter that night, they were, they were just like he. He said the doctor said I'm 100% fine, I don't have a brain tumor, there is nothing wrong with me. And my kids were like oh, that's great, yeah, that's great. And I'm like no good, now I'm the one that has to tell them. He prescribed some medication that was currently being given to patients, but it was the.

Leslie: 11:21

Unfortunately, we had taken a year of HMO insurance. Every other year we'd had PPO, and I asked him if he could write a referral to the rush memory clinic. And that was because my daughter, court me, was seeing an epileptologist at rush and she said mom, they have a really good clinic for memory. You know you should get dead in there. He said no, I, I can't write you a referral for that. Fortunately, though, it was like three months later that our insurance was going to change, and then I just made an appointment at rush memory clinic as soon as we could and, and they'll, went and took the test, the battery of tests.

Leslie: 12:08

He came back into the room Laughing. He was like, oh my god, he goes. When I was in grad school I couldn't have passed that test. Oh, difficult questions. And he thought this was whole. I mean, he's laughing and realized, telling me about this.

Leslie: 12:27

And and then when we saw you know, the neurologist at the end of the meeting and he, you know, was just, it was as though he was sitting in the principal's office and he was a bad boy. Yeah, shrank he does. The more she told him of you know the areas he had problems with, she recommended he not drive anymore. Yeah, he was very Embarrassed about that. He was very, you know, shy about it, and she explained to him that if he were in an accident, even if somebody else hit him, then he could forget about who did what. Right, you know, he would be responsible, because he didn't have his memory of what had happened. And Years after that he carried his driver's license in his wallet Because the state just gave him a new one because he hadn't been having any problems drive and but he was.

Susan Frick: 13:29

How long would you say it was from that first time you talked to the doctor Till he had this test done. What was the period of time that it took to get all of this done? Oh, I'd say four or five months.

Raj Shah, MD: 13:42

Okay, okay, I was also curious if we can go back to that original engagement with the primary doctor. So, if I heard this right and correct me if I'm wrong so Phil was seeing the doctor, you would encourage him to talk about these things. He never kind of brought it up to your knowledge. And then you came to one of the appointments and the doctor asked like what you you thought was going on and you were worried about the memory and you brought up what you were noticing with this function. The doctor heard that, asked Phil what he thought. Phil said nothing's wrong with me and then this other incident happened at work.

Raj Shah, MD: 14:17

So you were like okay, maybe that's a brain tumor, maybe we can talk about getting a scan. They get the scan. The doctor sees the scan and says I'm seeing these changes of you know, kind of a loss of brain tissue on the scan Could be fitting with dementia. I'm just trying to understand like was that pretty much it or was there a sort of? Did he also at that point asked more questions about what was happening around the dementia, like how long it was good or the memory problems, how long it was going I was affecting? Did he order any blood tests to check to see if there's things like thyroid problems or B12?

Leslie: 14:52

I don't recall those things, but I do recall him doing the you know basic test then, where he had him draw clock, no okay, he did that okay.

Leslie: 15:04

Yeah, he put all the numbers one through twelve in the first quarter Quadrant of the clock and then he he asked him to remember and Phil was just, you know, like five minutes later. He asked him about it. Phil said I have no idea what you want me to say, because I don't know what you're talking about. And the doctor looked at me like I'm sorry, you know, like Obviously you know things are going on here that I didn't know about. But we didn't really have a long time, we didn't have a conversation and he didn't say like I think you should see Neurologist. He said I'm going to put him on some medicine, okay, who tries to keep his memory level at the same level. And I just knew I needed more information and I was. When I went to the memory clinic I was very pleased with Everything and they did say to both of us you know that there was a support group without warning and and the doctor, you know the neurologist explained it and said you're really gonna like Susan Frick, she's in charge of this and we want.

Leslie: 16:15

When we walked out he looked at me and he said I am not going to that dating group I was like it's not a dating group, it's, you know, people that are having the same kind of problems. Well, I'm not having. You know he still was in. I'm not having problems. You know, like the problem too was that his father had had schizophrenia and his older sister had also had schizophrenia. So any suggestion there was a problem. He had memories of all these problems with his father especially, but I don't think we ever discussed that with the doctor. I mean Now, looking back, I think I should have probably phoned or sent a met, you know, even a letter to the doctor ahead of time.

Leslie: 17:11

So oh yeah understand what the situation was, but it never occurred to me. I thought, you know, once I tell him, you know he'll notice. And so many of my friends would say to me I don't, are you sure he has. You know, even after he'd been diagnosed and you know, years past he would be a very quiet listener. You know they would be. Are you sure he has all three? Like? He doesn't look Like he has Alzheimer's. I don't see it.

Leslie: 17:42

And I thought that it's something you know, I that even doctors may not realize. You don't see it. And that Bill legitimately didn't know he was forgetting things. I think I have read, like it's about 50, 50 or something, that 50% of the people do know right away and they get angry because they're forgetting things. They'll never get angry about it. And then I was the first person. He forgot who I was and it was one night. He woke me up and he told me he didn't know who I was and that I had to leave his bed Because he didn't know how I got in this house or who I was. But I didn't belong there.

Raj Shah, MD: 18:27

And it.

Leslie: 18:28

Just, you know, I didn't know what to say. Oh my goodness, at first I was so confused so I'm showing him the pictures on the wall and telling him you know, this is that's our daughter, court. He's, that's our daughter. More again, this is you know. And he was like, please seem like a nice lady, I'm gonna walk you home. And, and so I put my coat on over my pajamas and I, we went out the front door and we started walking and we lived near a high school and he recognized that and he was. Then he was like In a whole different headspace and he's just like, oh my goodness, she goes. That's my neighbor's house and he goes, there's my house, he goes. I want you to come in and meet my wife.

Susan Frick: 19:16

So, leslie, do you ever feel like with the doctors? Did they Check in to see how you were doing through all of this, or give you any Resources about how to be a caregiver to somebody with dementia?

Leslie: 19:28

Not really.

Susan Frick: 19:29

No, that that didn't really come, came more from the support group.

Leslie: 19:33

Oh, definitely, okay, Definitely, that the support group was a lifesaver, you know, and, and the people in the support group, I mean I would say to a doctor to recommend a support group. I did find out like Good Samaritan had a support group, but I went to that and it was basically adult children of, you know, 80, 90-year-olds who were having problems with dementia and I thought, no, it's not the same, you know, it's not the same as if it's your partner. And that was the really great thing about With All Warning is that we sat and talked to other caregivers and we shared ideas about how to deal with this, and people shared ideas about finances and what to do and where to go.

Susan Frick: 20:26

And that was all so kind of being able to find those people who had a similar situation of what you were going through. Yeah, absolutely. And you know, and I appreciate you being able to say like maybe calling the doctor ahead of time at that first meeting would have been something to try. When you look back at that period of getting him diagnosed, is there anything else you think could have gone differently? Or sometimes going four to five months to actually and Dr Shaw probably can speak to this is actually not that long for finding a diagnosis, but is there anything you'd wish you had done differently besides calling the doctor?

Leslie: 21:05

Well, I wish I wouldn't. I've got, you know, I mean it would have been my reaction to build things that were happening, you know, just it's hard though that would have been, because I couldn't reach him as far as getting him to understand that there was something wrong and I wanted to trust him to go

into the doctor. Now, I mean this was in May of 2013. He passed out outside. We were sitting at the picnic table, you know, and I was with Courtney and myself and we look over and Phil is allowing out of his mouth and his head is over and be completely out.

Leslie: 21:47

And I thought maybe he'd had a stroke. And I said, Courtney, go call 911. And then I, you know, I was like Phil, Phil, can you raise your hands, you know? And he looked at me and he goes what is wrong with you? And I said you were unconscious. And he's like I doubt that. And I said, well, the paramedics are coming to just check you out. And he goes I'm not seeing them. And I said no, I think it would be a good idea if you did. And they were wonderful. They dealt with him perfectly. They talked to him and they ended up putting a pacemaker in that weekend because they said he was, you know, during the night he had passed out a couple of times. So then I thought, well, maybe that had something to do with it. A neurologist did come in and I said to her you know, do you think this could be related to dementia, Alzheimer's? And she said no, I really doubt that.

Raj Shah, MD: 22:48

I was like, once again, yeah, and I guess, as we kind of felt finished with our visit with you today, I just wanted to get one other piece just to try to understand the story. You know, in a primary care office, especially a busy one with multiple practitioners, there's it's a team right. There's like nurses and receptionist and others in the primary office. Did any of them, did you interact with any of them in sort of like kind of getting the diagnosis or getting some support, ideas of what to do?

Raj Shah, MD: 23:19

Not really, not really at that point no Okay.

Leslie: 23:22

Not at that point.

Raj Shah, MD: 23:24

So it's really helpful information that you've been able to share with us about your experiences and my hope is it will help us, you know, as primary care physicians, to continue to work on listening to these stories and improving how we approach things and help families out in these difficult situations, especially early on, where a person may not know and be a good reporter of what is happening to them.

Raj Shah, MD: 23:47

And I really appreciate your suggestions about, like, trying to think through, like is there better ways to connect with the care team, you know, by sending some prior notices about why you want to see them as part of a visit, when you haven't been coming before as the care partner.

Raj Shah, MD: 24:01

But you know, I think we're approaching the end of our time today and so we really do appreciate you being part of the conversation and having us at your home, and you know we'd love to kind of talk with you another time to follow up on some of the other aspects of the care over time and how we can get better at that too. Back to our audience, I hope you enjoyed the program today and you kind of can pick up on some of the issues as far as barriers that families can face and kind of getting that initial evaluation and diagnosis and then some of the tips or suggestions of how that can be better, and we appreciate you listening to us today and we'll be back for another one of these episodes soon. Until then, thank you so much for your time, and thank you so much, Leslie, for your time today Really appreciate it.

Susan Frick: 24:46

Thanks, Leslie.

Leslie: 24:47

Thanks again.

Kate Rowland: 24:52

Thanks so much. 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.

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