

The Brain Trust Podcast | Episode 20 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. 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

All right, welcome everybody to the next episode of the Brain Trust, our podcast series on the early detection of Alzheimer's and related dementias. And today we're going to continue with our little mini series that we've added to get the caregivers perspective and in care partners of persons with Alzheimer's disease and related dementias, and really what we're trying to do here is to spend a little time so that we can give you, as our listening audience, some ideas of individuals that have had real world experiences working with a loved one and taking them and engaging in a primary care discussion about a diagnosis and getting a sense of what challenges may be there and being able to identify the challenges and then describing where care partners now, looking back, would think about early diagnosis and detection and maybe encourage us about how we can get better or to build our skills over time. So for those of you who don't know me, my name is Raj Shah. I'm a professor in family and preventive medicine at the Rush Alzheimer's Disease Center at Rush University in Chicago, and today I'm again joined by Susan Frick, who's a social worker at the Rush Alzheimer's Disease Center.

02:18

We're in the car. We're getting closer, after about a 45 minute drive from downtown on the west side of Chicago to visit our guest today, James Litchfield, and so we're on our way to Crystal Lake, right, Susan? That's where we're heading over to, you know, while we're getting close to the coffee house we're going to meet up at in downtown and I'm about to start parking here Do you want to just give us a little bit sense how you knew James or how you met him as part of your work?

Susan Frick

Guest

02:45

Sure thing. I met James and his dad buddy, when they started coming to our support group called Without Warning, which is for families who are living with young onset Alzheimer's disease, and so James reached out to us about eight or more years ago and came for a period of time with him and

his dad, and then I've known James through the period where his dad declined and then passed away during COVID, and so what I think is interesting with James is hearing perspective of a son caring for his dad and also someone who was long distance for a while and having to negotiate that yeah.

Raj Shah, MD

Host

03:22

And Susan remind me, but I think I've met James before. Right. He wasn't he at one of our early presentations as we became dementia friendly Illinois.

Susan Frick

Guest

03:30

He was. He came down to Springfield to join in for our day workshop when Illinois became designated as a dementia friendly state.

Raj Shah, MD

Host

03:39

Oh, that's great. Well, I'm glad we have an opportunity to meet him. So, yeah, I was lucky enough to get a parking spot. It must be a good time today, a weekday, in downtown Crystal Lake. So we're here at the coffee shop and just entering in right now. Do you recognize James?

Susan Frick

Guest

03:54

Here he is. Oh, there he is Okay.

Raj Shah, MD

Host

03:56

Good to see you, James hey.

Susan Frick

Guest

03:57

Susan, you've met Dr Shaw before.

James

Guest

03:59

Dr, Shaw, good to see you again.

Raj Shah, MD

Host

04:01

Yeah, great. Well, thanks for taking some time out of your schedule and joining us today, and I thought I'd have students, Susan, start a little bit with some of the discussion that we'll be having today about just your experiences taking care of your father and working through some of the challenges of engaging primary care and how that experience went so we can all learn from it. So we really appreciate your time today. Susan. If you want to get us going, that would be great.

Susan Frick

Guest

04:26

Sure, sure, and I know, James, for you it was. You were a good distance away from your dad and having to kind of realize that there was something going on. And so how was that time period and what did you see first that kind of alerted you to. You needed to maybe bring this to that someone's attention with your dad.

James

Guest

04:47

Oh, thank you, Susan, and thank you both for coming out here to meet me and valuing what my experience was as a caregiver, and to your audience as well. Thanks for spending the time listening to this podcast. I was age 32 when my dad took early retirement from Virginia Tech University at age 62. He took a retirement option, and he later told me that he took that retirement option because he was forgetting some of his tasks or even committee colleagues. Coming out of committee work, he would forget what his to-do items were, and then he started forgetting names of colleagues that he had worked with for years. And then any new platform that came out computer-wise, he learned email and their card catalog system went to digital. He learned that, but then when the research items started going to a digital platform, he could not learn new platforms, and so he enjoyed retirement for two years before in 2014.

05:55

Our big indicators were he got lost driving from Virginia to Illinois, to Crystal Lake, which he was driving by memory, and he got lost on Route 66, which ended up being a Phillips 66 gas station. That was 10 minutes from my house, so he was almost there and a gas station attendant helped link us up and I went and found him and then, stupidly on my part, I let him drive home a week later and he ricocheted his minivan off of a concrete barrier in Louisville and thankfully didn't harm himself or anyone else and got the van back to Blacksburg and parked it and voluntarily gave up his keys and never drove again. He really scared himself there. And then for like a month or two his friends reported to me that his house, which was kind of a social hub of career Virginia tech workers these were smart people.

06:53

My father had two master's degrees in history and library science. He was closing his house off to his friends. He stopped playing golf because he couldn't make eye contact with the ball. They stopped inviting him to bridge because he couldn't bridge it's very intellectual, could not keep track of the cards played and he closed off his house to people coming to socialize at that time, have a drink or whatever. And it started to hermitize and his friends reach out to me.

Susan Frick

Guest

07:22

Yeah, so really was it the car incident and then the friends reaching out that alerted you that there was something going on?

James

Guest

07:29

Yeah, instead of just oh. This is just a funny thing that dad did was kind of had happened, you know, a year or two before, but this was people reaching out for help on his behalf and I applied for FMLA leave from a school administration job and went out and spent a month with him in October of 2014. And in that month is when I really got to know his primary care doctor that my father had known for decades a family physician and that begins our journey with that doctor.

Susan Frick

Guest

08:05

And how did you decide, how did it go and how did you decide to bring it up to the primary care physician for your dad?

James

Guest

08:12

I started very basic with the Alzheimer's disease website of are you having these issues with a loved one? I want to say it was like 10 or 12 questions and if you, if you answered yes on more than half or something, then you could take that paper to your primary care. And my father was very trusting of me. So my parents had divorced when I was very young and so he had never remarried or never even had a serious girlfriend that was going to take on this caretaker role. He trusted me right away and I said to him let's just use this document right here to bring up the conversation with this doctor that you trust for decades, and I'm going to be there with you. And so I immediately approached it from a we stance. I never asked for time with the doctor alone, I always approached it with. These are things that we are noticing about buddy we was, was, was family, me, my brother, and buddy himself was willing just to start with that basic worksheet.

Susan Frick

Guest

09:16

And what I'm curious, were you thinking Alzheimer's? Like how did what got you to the Alzheimer's website before you had that conversation with the doctor?

James

Guest

09:23

I think I went there because of the memory he started to expand on. I've been driving to your house by memory and I couldn't learn or memorize steps at work and that's why I went for retirement. So I think it was the memory that went down that path. But also knowing that on his side of the family there was a history of memory and mental health issues, and I don't think it was a doctor that sent me to the Alzheimer's I think it was me searching for for support that landed me on that website.

Susan Frick

Guest

10:01

And kind of like you really did your steps when you were going in there with that sheet of paper and with buddy and being there with a physician. Were you nervous or was it? How did you feel about bringing this up in front of your dad?

James

Guest

10:13

Yeah, the nerves were definitely there because through divorce and alcoholism and failed relationships, we didn't have a relationship that was a lot of sharing. There was a lot of visits and a lot of father and son time, but this was going to be a big step for us so I was nervous about that. He was nervous of the stigma of the diagnosis and he immediately started to think about others and how they were going to perceive him with this diagnosis. So you immediately started thinking about how are my friends here going to treat me and what's the family going to think, and so he was more worried about the stigma. Once the primary care doctor helped us through his approach, which I'd like to discuss his approach more in depth.

Raj Shah, MD

Host

11:05

Oh, I was wondering before we get to that, James, just as you set up the appointment, did you mention we're coming in because of memory concerns, and that's what the office took down as like the main issue that was going to be brought up.

James

Guest

11:19

Yes, and also this doctor was retiring and we had started to dabble in this conversation of Buddy moving to Crystal Lake, and so we went in with saying goodbye to the doctor and wanting to get your records. But also we have this bigger concern, before he's meeting a brand new doctor.

Raj Shah, MD

Host

11:39

Okay, and then, before you even got to see the primary care doctor, how did the rest of the office interact with you in that visit? Because usually it's a team that provides care and engagement. You're working with the front desk staff, you might be working with somebody who helps check you in and get the vital signs and things like that. How did that go before the doctor actually came in, and did some of them actually get more information about saying, oh, you're coming in from memory loss, I see, and then collect some information about what might be going on?

James

Guest

12:11

Yeah, I remember them addressing us together and helping us make sure that Buddy, when he because he still had so many, so many faculties and abilities still that he signed off on the correct

paperwork so that I could be fully involved. So I remember the admin team helping there before we had a power of attorney official document, so that was very helpful on their part.

Raj Shah, MD

Host

12:36

And then you were about to say and tell us a little bit about the approach, the primary doctor's book, when you went in.

James

Guest

12:43

So this primary doctor that knew Buddy so well I didn't know that this was unique until I started comparing to other caregivers but he went with this approach of I'm going to make it referrals for you, buddy, while you're here in this area, so that you can address the known things that may help you down the line. So Buddy was no, he had cataracts that had been established but had delayed on getting them repaired. And so this doctor said, buddy, with the help of your son, I think you should get these cataracts repaired from this ophthalmologist. I'm giving you the referral so that if down the line you're having trouble tracking your glasses or vision becomes an issue you know you've addressed the cataracts. That was one example.

13:27

And then he sent Buddy for a Doppler of his carotid artery. He said I want to make sure you're getting all the blood flow possible to the brain, that there's not a blood flow issue. And so we went and did that and here's the referral for the CT scan so we can establish a baseline of where your brain is now. And I just was like I was happy as a caregiver that I had things to do and places to take Buddy for these appointments. And then the final one was the neurologist, and so this primary care doctor said I'm going to get all these reports, but you're also going to see this neurologist if there is a diagnosis needed.

Raj Shah, MD

Host

14:03

Yeah, and then can you go back a little bit, because usually in you know, when you're interacting with a primary doctor before they give you the recommendations to do all of these things, and you may have started that way. He saw the main concern was memory loss and he said well, I've known you for a while, let's get all these tests done and then we'll talk about it. Or did he ask questions about like, well, how long some memory loss has been going on? What have you guys been noticing? Do I exam like a neurological exam? I'm just trying to understand, like the other pieces that he might have done before giving you those requests to go.

James

Guest

14:34

Yeah, he knew Buddy so well that he trusted Buddy. If you have this concern about bridge and golf and driving. He trusted those main things for me. And then he did the basic exam with the questions about time of month visit and all those kind of things and that was so. It was through two or three visits before it was. Here's the referrals I'd like you to go down. Okay.

Raj Shah, MD

Host

15:02

And did he say something about like okay, you came in with memory concerns and I did some of this work up and I'm thinking that this might be fitting with Alzheimer's disease? Or did he just say I'm worried about this memory loss, but I need these couple tests and I might need the neurologist opinion, and then we'll kind of talk about what we think might be going on?

James

Guest

15:23

He jumped on board right away with the we approach and so he was saying I hear you about these concerns, your family and you, buddy, and I support you, based on those initial exams and the discussions with Buddy, and I support you and so here's how I think you should tackle it. So the support I remember that word really reassured Buddy that we weren't imagining this.

Susan Frick

Guest

15:47

Sounds like you left at least first or couple appointments, feeling supported and feeling that he heard you and was taking action.

James

Guest

15:55

Yeah, and he also empowered us when he said I believe that you may be having dementia or Alzheimer's, that this may be a diagnosis. Then he provided us with the additional research or additional resources that were in that area. But he also he was hearing us about the move. He could build the bridge Okay, if you're going to move Buddy to be closer to you. He took it very seriously on documenting what he had done and sending us with a complete record, because Buddy came out of the MRI machine or CT machine and said I'm never doing you to get, okay, you got my baseline, I'm never going in there again. And so I wanted to be able to take those discs and those reports and this primary care doctors notes with me to Illinois, and he was very supportive in that.

Raj Shah, MD

Host

16:47

So it sounds like you had a good experience because of a long relationship and somebody who kind of helped you to navigate this transition, which is great to hear, but a little bit about then the transition to coming to Illinois. Right, like you do all this work, you get some of the sense with the. Oh, by the way, the neurologist visit was in Virginia and then the doctor talked to you about the end, about we think this is Alzheimer's disease, and then you established the move here. How was it like establishing primary care here in like Crystal Lake or somewhere in that area? Once he moved up with you?

James

Guest

17:21

Yeah, I went down a path of doctors that I trusted that I was already working with. So my primary care was accepting new patients and so I do remember describing to him about my dad move coming up and that he was willing to take on new patients. And the neurologist that we ended up with in Illinois went down one more path of the sleep apnea concern and I felt like that was another thing that we addressed that got buddy some better oxygen when he was sleeping. That could have maybe elongated the time that I had with him. So I went with an approach of doctors that I knew and I said to them here's this big change that I'm bringing into my life, moving someone here to care for them.

Susan Frick

Guest

18:07

And how would you say life changed Because you had so much occurring in buddy too, but for you too, in such a short period of time of being a distance away from your dad and then all of a sudden being the main go to person and then bringing them here. How was that all for you? And do you do the primary realize everything you were doing, and was it help with that for your, your own?

James

Guest

18:32

mood. Yes, being a caregiver changed my life forever. People told me it was going to happen and when I was in the midst of it it's kind of like people telling you to enjoy every moment with your child, type of thing. Yeah, yeah, yes, I am. It changed my life forever and I will never regret those years with that I had with him. But I was, I was. I took on a caregiver role. My second child was born in 2015. I took on a higher leadership role within a school building and we moved all in 2015. So my just moved within Crystal Lake, but my primary care doctor was very adamant that I establish a counselor for myself.

Raj Shah, MD

Host

19:15

Oh, that's really great, because I was going to ask about that because they need to. Yeah, we know it's a team right Like it's not only the person with living with the condition but also their care partners that need primary care too. So it sounds like you had a relationship with the same doctor that your dad started seeing, but they actually did recommend counseling for you, which is really good, I mean, I think, to support you in that moment. Was there anything else they did to help you kind of go through it?

James

Guest

19:42

Yeah, the referral to the neurology through Rush. When we when we linked up then with that level of support that we didn't have in Virginia, that's when I remember the first time any discussion about being a part of a research or being part of Susan's group for, without warning, getting the support for buddies so that he didn't feel alone, and meeting with other early onset patients, and then I was in a separate room with caregivers. We started to really look forward to those visits. It became a

community for us. So that level of referral to something that's a luxury I guess in Chicago having that resource available.

Raj Shah, MD

Host

20:24

And you know, looking back at kind of that initial period and the transition period and the support you were getting, you know if you had to give a message to our audience right where mainly in family physicians or training to be family physicians and supporting work in primary care practices you know what were the things that made you feel was done well and then maybe you know what was the challenge. Now that you look back at, you wish you know that could have been delivered earlier, something a little bit different.

James

Guest

20:55

Early on. I remember buddies a first neurologist in conjunction with his primary care provider Early on. It was very checklist approach for caregiving. They brought up the notion of the power of attorney right away so you need to work with a lawyer because eventually he won't be able to sign for himself, type of thing and then selling his van and moving him. It was all very checklist, which is great for my type of personality.

21:23

But long term I was very thankful that the second group, the prime, second primary care in conjunction with the second neurologist in Illinois, took more of the social or the emotional mental health support for buddy and me. It didn't really dawn on me having buddy be able to talk to other early onset patients because he wanted to move to Illinois and try to extend as much time as he could on his own and time with his grandkids. So going someplace where you're saying you know I have Alzheimer's, it was a big step for him but I'm glad that that topic came up Eventually I was lucky to have a second set of providers that brought it up and then a challenge or something you'd want the system to improve in and, you know, helping you through the process of that diagnosis phase.

22:16

When we showed up to the second neurologist with results and reports from Illinois, there was a bit of time. There was an appointment or two of no doubt or rejection. Just I like to get my own data approach. That was the approach from the doctor and I understood, and some of them were going on being a year or two old.

22:39

But I guess, having the background that just getting my father to the appointment was a challenge and he would almost try to study on the way there, like working out the window, okay, I see the snow, it must be winter. You're not going to tell me the month, are you? I was like no you know type of thing. He was like trying to cram ahead of it, but just the process of getting him ready out of his apartment and so we both had a lot of anxiety about, okay, you're asking us to go get another CT scan. Just having that background, we got there eventually with the doctor, but it wasn't our first interaction was you're a new patient, I need my own data. And we were still just getting through the adjustment of moving.

Raj Shah, MD

Host

23:24

Yeah, no, that's a good point we to make. You know, sometimes even our systems don't communicate that well with us, and so if we don't see it in the right format, it becomes like easier to just ask people to, you know, get another test done. But sometimes that adds a lot of burden on the family, and it sounds like so that he actually did go back. Then he had another scan. You got him to go to a scan a second time.

James

Guest

23:45

Yeah, I got him to, I got him to go again and I used for buddy going out to eat afterwards was always it was always a treat. So I had my certain angle and we still had the level of trust. I mean, at this point in time he had trusted me to move him and he had said he wanted to give his friends the gift of not seeing him go through dementia and Alzheimer's. And so he gave these friends in Virginia the gift of remembering how he was and so he visited a time or two to like a specific friend or two, but the trust was there. When you know, if James does asking me to get this scan again, and those scans did reveal a lot more issues in the brain each time. So, yes, we got there to where he was able, willing to do, and started to get to a point where he had forgotten that he had done one. Now I see.

Raj Shah, MD

Host

24:38

Yeah, yeah, yeah. Well, thank you so much, James, Mr Litchfield, for your time today. Really appreciate it and really bringing your insight. That's going to help our primary care physicians, family physicians and those in training to really understand what it's like from the caregiver point of view and how we can continue to build skills that help people, especially on, as you said, not only the diagnostic part but then the social and emotional part, Susan. Any final comments or questions?

Susan Frick

Guest

25:05

No, just thank you, James. You always done quite a bit of presenting with me and have always done such a great job.

James

Guest

25:10

Thank you. I have one more point that I had written down here and that was for primary care physicians supporting a caregiver. One way that it changed me at our relationship is I started calling my father by his first name instead of dad, and whenever I would help him go see his friends or go see family, I would call it traveling instead of vacationing, because it was always so much work. And so just, I guess, noted for primary care physicians to notice if, like the vocabulary changes, that that was something that my wife ended up bringing up to me. Just the vocabulary changed for me, but the primary care doctors had empowered me and Buddy to have the same vocabulary about

Alzheimer's. So when we left after our initial meetups, being able to have some terminology that we could both use was very helpful.

Raj Shah, MD

Host

26:07

Perfect. Well, thank you for that last point. Well, we appreciate meeting you in Crystal Lake today and thank you to our listeners for being with us on this really important episode, and we look forward to seeing you again for another part of this mini series, as we learn from care partners for persons living with Alzheimer's disease and related dementias and their experiences in the early diagnosis and detection. So join us again for our next Brain Trust podcast in the near future. Thank you, everybody.

Kate Rowland, MD

Announcement

26:39

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