

Daughterhood The Podcast

Episode #21: BrainGuide with Brooks Kenny

Resources:

[BrainGuide.org](https://www.brainguide.org) or 855-Brain-411

[UsAgainstAlzheimers.org](https://www.usagainstalzheimers.org)

47:38

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Us Against Alzheimer's, Brain Guide, people, brain, caregivers, disease, conversation, resources, talk, Rosanne, communities, important, health, absolutely, doctor, podcast, questionnaire, memory, loved, hope, family

SPEAKERS

Rosanne, Brooks Kenny

Rosanne 00:02

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caregiving from a distance. I hope you enjoy our conversation. I know about the challenges of living with a loved one and all of the challenges that come with being under the same roof you have experience in long distance caregiving. Can you talk about that a little bit?

Brooks Kenny 02:19

Sure, I'm happy to. It's actually really interesting. When I started at us against Alzheimer's more than six years ago, about three weeks into my work here, we started to recognize my mother in law was showing signs of cognitive decline. And she and my father in law live in Florida. And it was a very difficult difficult part of the journey was just trying to figure out the detection and diagnosis of the disease. When she ultimately was diagnosed. We were in a family meeting with the neurologist and a nurse we were given a piece of paper that said the a word but the a word was never spoken in that family meeting. And we really left recognizing that she did have dementia which after reading the paperwork, we understood it to be Alzheimers disease, but we didn't really have a clear path in the journey, we didn't really understand exactly where she was in her stage. We didn't even have the language to talk about the staging. And it kind of really put our family in a whirlwind really quickly. My husband is one of five siblings, one lives abroad, the others live away from their home. And so we immediately had to put a plan of action in place. Our first step was how do we keep her safe? not really knowing exactly where she was yet not knowing is it safe for her to drive? Is it not safe for her to drive? Is it safe for her to take her own medication? Or should my father in law be managing that without her feeling like she's losing her independence? Right? How do we get in touch with all the different doctors should we get in touch with the different retailers where she frequents to make sure they understand that she Mays show repetitive signs or there may be moments where she seems confused. So we really went into a very rapid plan of action, which I'm grateful for. I mean, I feel even though it's my It was my mother in law. I've known her since I was 16 years old. She was a mother figure to me and given my work in healthcare in general. And now being a part of Us Against Alzheimer's, I was able to pull resources together to identify local resources, and we had to put a plan in place on how we were going to manage this from a distance. So we did a lot of different things. The first thing we did was we wanted to make sure that all of us had access to her medical records so that anyone that was visiting or anyone that was calling would be able to check in with a doctor and understand What was happening and be able to ask questions, we thought that was really important. We made a list of all of her medications. And we included contact information that we brought to the pharmacy. And so we said anyone in the family that needs to reach out to you about her medications we'll be able to do so we reached out to her primary care physician and scheduled a meeting to make sure he understood what was happening. Then we put together a schedule where each of us were coming to visit them on a regular basis. And we had a master to do list. I love to do lists. And we had a master to do list and we wherever anybody left off, the next person that visited would resume Oh, well, some of that was making meals for both of them, making meals that my father in law could help my mother in law make. So she still felt like that was an important part of her daily routine, but she could do so safely versus making things from scratch. So a lot of things like that. And and we had a you know, we used, it sounds silly, but we use WhatsApp to keep each other posted. We did weekly updates, we had family calls, we didn't use zoom back then. But we did a lot of family calls and just tried to keep the communication going. We also had to divide and conquer, right? If I had to be the one to manage the paperwork, bills, finances legal, that wouldn't be a great solution. I managed along with my sister in law, we managed more of the care. So when it was time to research homecare options, we did that together when it was time to identify Adult Day services, which are a godsend. We did that together. My husband and his brothers managed many of the other kind of legal paperwork, financial. So we all had our lane and then we came together and share sure there were moments where it was bumpy, or we might not have agreed

but not many. And I think that's because we put a plan of action in place from the beginning. You know, the other thing I would just share with you Rosanne that we did that I tell a lot of my friends who are coping with parents that are starting to have declined, whether it from all timers or something else, you probably know this very well. But you know, people that are experiencing memory decline often don't want to talk on the phone, because they may not recognize the voices, and they may not be able to keep up with the conversation. And I know there's FaceTime and things like that now, but not everyone. I mean, my mother in law used a landline every time we spoke. So on one of my trips to Florida, I put together a poster and on the poster I had each of her children from oldest to youngest, and if their name and block letters with a photograph, and then next to each sibling, I put their partner and then each of the kids, okay, if not all of us had kids, it was a mix. But so when she would get on the phone, for example with my husband, Peter who has a twin brother, so they sound the same. So she would get on the phone with Peter and could look to the right and see. See my photograph with my name Brooks and my two children, Paige and Shawn. And I don't know if it made a huge difference. But I think it might have given us a few more moments of connecting with her when we weren't with her in person. And we encouraged my father in law to bring her over to that spot whenever she was on the phone just to give her more comfort because she loved her children. She loved her grandchildren, they were everything to her and we wanted for her sake and ours frankly, we wanted to keep those conversations going as long as we could.

Rosanne 08:38

That's brilliant. And seriously, that's brilliant. Who came up with that idea?

Brooks Kenny 08:43

Well, it was me because I was just noticing that I was watching my husband have some heart ache when she wouldn't be on the phone for as long or when she wouldn't mention my kids names. And I could see it hurting him so much. And I knew it was hurting her. And so I just thought of it, you know, kind of randomly and asked everybody to participate. And everybody did. And it was a really beautiful thing.

Rosanne 09:11

It sounds it. I mean, it really does. And the fact that you all came together, and we're on the same page is is rare,

Brooks Kenny 09:18

Right

Rosanne 09:18

And really, I think that probably helped out a tremendous amount because you were all your goal was all the same.

Brooks Kenny 09:27

Correct.

Rosanne 09:27

So we're none of none of his siblings were like, Oh, I don't believe this or I don't think she's that bad, or there was none of that.

Brooks Kenny 09:36

There was a little bit of that I would say in the beginning, but I don't there was never any anger towards each other. It was more perhaps everyone took their their own time and paste to kind of come to terms with what was happening. And I think there might have been like a bit of disagreements here and there, but it was pretty remarkable. But that's the family I married into, you know, they're, they're a team. So I'm really grateful for that. And I'm grateful that they allowed me. It makes me tear up, you know that they really, they've always treated me like, it doesn't matter that I'm in law, it matters that I'm family and they knew I had a passion and could help. And so they let me in, which was a also I think doesn't happen all the time.

Rosanne 10:28

No, you're right, you're absolutely right. And the importance of having a plan, whether pre plan, or, okay, this is where we're at, we need to plan right is super important. And, you know, people don't like to think about power of attorney and wills and how you want to be cared for writing down how you want to be cared for. But it's so important through the whole journey. What can you how do you advise people to put a plan together? And what would that plan look like?

Brooks Kenny 10:56

Yeah, I mean, I think it's important. I mean, there are wonderful resources out there on the internet, certainly, that can give step by step. But I think certainly having a power of attorney, I think making sure you know, what your healthcare wishes are making sure that you talk about your end of life decisions, you know, what, what do you want for yourself, I mean, I know my father has already kind of planned out what he wants his funeral to look like, we have all his he's gonna be at 85 in August, and he's healthy as a horse, as they say. But he's realistic. And so you know, we we know about his financials, we know his, you know, all of his legal information that we need to know he's designated, who is going to be the executor of his Will, I think the only thing he didn't do yet is talk at all about his obituary, and I said to him, when we spoke, you know, Dad, you're going to need a obituary, I'll take that one. And I can't, I'm a good writer. And he said, I'll take a first draft and send it over. So we just try to talk about everything. Because I truly believe that communication, even when it's hard, is the most important thing we have when it comes to our health and well being, which is why it's so frustrating when I think about a disease like Alzheimer's, where we don't we're so far behind other diseases and how we talk about it. And it's programs like this, that are helping to break that silence. And I'm really grateful that your listeners are tuning in and getting to have that experience through this work.

Rosanne 12:35

Agreed. And I feel like that there's a change coming, where you don't talk about that, because, well, if I talk about it, then I'm going to die. It's like, no, you're not going to you're going to die anyway. But we need to talk about this. And it's important to talk about this for both the person and for their caregivers, right? Because then the caregivers are just flopping in the breeze not knowing what to do.

Brooks Kenny 12:57

And you don't want to get it wrong. I mean,

Rosanne 12:59

Right.

Brooks Kenny 13:00

You know, that's the thing. I was speaking at an event before the pandemic, in a was a small evening event. And I was on a panel talking about caregiving. And I was talking about the need to have these conversations early. And at the end of the panel, a couple came up to me and they said, we're turning 70 next month, and we're trying to get our adult children to sit down with us to talk about our will to talk about end of life to talk about what our wishes are, should something happen to us, and they are resistant. And I said to them, I have an idea for you. Why don't you let them know the only thing you want for your birthdays this year is to have the conversation. That's it. And I gave her my card. And I said let me know if it works. And she didn't never got in touch. But I know but I just you know, it's so interesting. It's it's and it's very individual, because, you know, in that scenario, the the older adults wanted to have the conversation but the right, the adult children didn't sometimes it's the adult children and you know, the family members that are resistant. And you know, I just think we can push through this and we can start we can take the first step. That's the other thing. I would tell people, you don't have to talk about everything. Right in the first conversation. You can even talk about talking about the conversation you can say, right? It's not going to be fun. But one of these days, we're going to need to sit down and talk about what your wishes are, as you get older mom like that is a way to start and then not bring it up for another month. But anything you can do to begin these conversations I think is powerful.

Rosanne 14:40

I agree with you. I agree. And the fact that like you said, Here's your diagnosis on a piece of paper, we'll see.

Brooks Kenny 14:46

Yeah

Rosanne 14:47

Good luck to you. Hey, talk to a lawyer See you later. Right. And we wouldn't accept that for other diseases we wouldn't accept Here, take this. It might work. It might not work, but it's not going to stop anything and it's not really effective, but you can try.

Brooks Kenny 15:02

Right?

Rosanne 15:03

And I don't know how we change that?

Brooks Kenny 15:05

Well, I think one of the ways we change that is by encouraging earlier detection and diagnosis through a conversation around brain health. I really believe the lens here is less disease focused, if we can, I mean, certainly there'll be those scenarios. But I think if we get people thinking about their brain health, thinking about their own health and wellness, and having these conversations sooner, it might get us to a different place, you know, we would never accept a cancer diagnosis in stage three or four, no, the cancer advocacy community would be screaming from the mountaintops. And it's time to prioritize Alzheimer's disease, we need everyone to be able to answer the question here, what are the stages of Alzheimer's disease, you know, we need everyone to be able to say what's good for my heart is good for my brain, our brains are the most central part of our bodies. And it's the least talked about organ in our healthcare conversations in our dining rooms, on our walks with our friends, we are talking about it.

And I just I'm a true believer that if you look at the trajectory of so many other public health causes, when people stood up and started talking, look at the AIDS epidemic, right. And the act now, I mean, look, if you look at that movement, no one wanted to talk about AIDS, there was so much stigma. And now it's like, you know, there was so much poured into that movement, thank God. And, you know, the research dollars came after that. And now there's medication that allow people to live, you know, with HIV and AIDS for decades. And I just, I think that it's this is our time for the Alzheimer's movement to really change the conversation. I mean, obviously, I'm very passionate about it. I'm ready to jump out of my seat, but with my clients, but I really believe in it. I believe in it. I really believe it's our time.

Rosanne 17:08

I agree with you. I agree with you. And I do feel it a shift. And I think part of this is the stigma, the stigma for the person living with dementia and Alzheimer's and the person who's their caregiver,

Brooks Kenny 17:21

Right.

Rosanne 17:21

And I don't know how we change that. And I, every time a celebrity comes out with I have Alzheimer's, I hope that that's going to be the person that rallies that everybody kind of gets behind. And every time it becomes that same, it's that same pattern of they're diagnosed. Oh, that's a shame. Oh, they still know their kids, though. Okay, story's over.

Brooks Kenny 17:42

Right.

Rosanne 17:43

And then we never hear about them again.

Brooks Kenny 17:44

Right? Yep.

Rosanne 17:46

And I don't know how we change that.

Brooks Kenny 17:47

I don't either except, you know, to, to keep in the fight. And I will say, you know, a couple things that we believe here at us against Alzheimer's, we really believe that the key to this, you know, is a three pronged approach, right? I mean, certainly, we need policies in place to support caregivers, to incentivize providers to have these conversations to use these screening tools. We need providers to be more educated, right? I mean, the reality is, you know, there are states that where no neurologists even exists, and primary care providers and family practitioners have too many other things to do. So it's hard for them to have a detailed conversation about memory, women mostly only see women with a doctor oftentimes only see an OB GYN or GYN. So they're there, we have to get creative with the provider community, we have to give them guidelines on risk reduction guidelines on on what to say to their patients, because there are things to say now you it's not just about the lack of treatment, but there are risk reduction guidelines that people can hear and think about to reduce either the pace of decline or the decline at all. And then the third leg of the stool are consumers, we have to create

consumer demand. We need to empower consumers to ask the questions. We did a survey with women across the country, ages 35 to 70. We asked them how important it was to talk to their doctor about brain health. And overwhelmingly they responded, yes, it is important. 70% of them said, I don't know how. Right? Back in the 80s when it was breast cancer. And there were there were all those amazing public health messages about self breast self exam, and when you should be getting your mammogram we all felt empowered to go into our doctor and say, here are all the reasons why I think I should get a mammogram before this age or you know now I guess the age has changed, but back then I think it was 50. And I think we need to be doing that with our brains. We need people to feel like they can go to any doctor and Say something isn't feeling quite right. I'd like a baseline or I took this memory questionnaire and I didn't score very well. How can What can we do? Sometimes it could be hormones, it could be something else going on. Right. But sometimes it might mean something different. It could be it could be Alzheimer's disease. I also really appreciate your point Rosanne around celebrities, because we really believe and honor any celebrity or influencer that comes forward. Right. I mean, it's

Rosanne 20:32

Absolutely,

Brooks Kenny 20:33

you know,

Rosanne 20:34

Courageous it's courageous

Brooks Kenny 20:35

Tony Bennett, you know, Dory. Yep. I wish more more. I agree with you. I wish that the story continued on and there were there wasn't just the one kind of blip when I think about people like Pat Summitt. Yes, right? Who Yes, you know, you wouldn't expect to hear that she had an Alzheimer's diagnosis, because most people think of it as someone who's much older. Yep, we have Mandy Moore as one of our ambassadors, you know, she's a young, you know, woman, new mom, and, and she's playing a character called Rebecca on NBC, this is us. And she has said to us, I'm blown away by the fact that 60% of cases go on recognize that early detection and diagnosis rarely happens. So she's really lending her voice and her influence to our cause. And I think the more we can get multiple ages, multiple, you know, ethnicities, lots of different people, it will start to normalize. If we all kind of rise up together and say, our brain health matters, I think it will help to change the conversation. But I think we need to address all three of those legs of a stool and a lot of my work right now is on consumers and trying to empower as many people as we can to feel strength in in asking the question and being able to raise the topic at home or, you know, in their health care setting.

Rosanne 22:06

No, absolutely. And it's funny, because there are nuances between normal quote, normal aging and memory issues right there. It's it's a very nuanced game, and when the doctors aren't either trained in that, or take the time to drill down in that that's part of the issue,

Brooks Kenny 22:26

Right.

Rosanne 22:27

And the fact that there's not enough geriatricians and it's like a big, where do you start?

Brooks Kenny 22:32

Right.

Rosanne 22:32

It's, it's Which way do we go here?

Brooks Kenny 22:35

Right. Well, and it's and it's, I think there's a general lack of understanding among the population, right? You know, I have friends because I do this work. I have friends that say to me, I often forget where I left my keys. And I've learned this from experts that I've listened to who have told me if you forgot where you put your keys, it's probably more of the fact that you were multitasking or that when you put your keys away, you didn't pay attention to where you put your keys. The bigger issue is if you forget what the keys are used for. Right, exactly. So it's one thing to forget where you parked your car, it's another thing to forget driving to that, what the cars for what the car should be doing.

Rosanne 23:19

Right.

Brooks Kenny 23:19

So those nuances, I don't even think the general public has a good understanding of and no, listen, you know, it's scary. Right? I mean, I think if you were to ask most people, well, we know from the data 50 people 50 plus cognitive decline is their number one fear. No one wants to forget their memories. No. Right. And so no, I also think a big way to overcome stigma is to get more people living with the disease in front of the camera. I agree. Right. You know, we we have a wonderful spokesperson named Doreen Monks who was featured on our, in our some of our media coverage, and she says it beautifully, you know, she says, we can't there, 6 million people out there affected probably more sure more, and we can't just leave them in the corner. We have to bring them out. I mean, Doreen is thriving. She has early onset Alzheimer's disease. She's a former nurse, she has a community around her that supports her. She's thriving, she's advocating and she is a really great example of someone living with the disease. And we just don't see a lot of people living with Alzheimer's disease speaking up and speaking out. And I think once that starts to happen more and more, it's going to change the national dialogue as well. And we got us against Alzheimer's, we are really committed to this idea of being a voice for patients and so we you know, we try to incorporate the patient voice and all the work that we do, whether we, whether it's on our, during our convenings, or the summit's that we host we always have a patient or a caregiver as part of the experience because their voice is so important. It's also I think, important to know that women are disproportionately impacted by Alzheimer's disease. I'm sure your listeners are well aware of that.

Rosanne 25:23

Absolutely.

Brooks Kenny 25:24

And you know, by 2030 40% of the Americans living with Alzheimer's will be black or brown, you know, in this data, it just, it's just unacceptable, right? It just is. So we need to make sure people have are the information they need to take action and to speak out.

Rosanne 25:41

And you look at it, you think, why isn't this? why doesn't everybody know this? It's frightening. And you think, why isn't this talked about? And I think it's because of the fear. Nobody wants to look at it,

Brooks Kenny 25:52

Right. Well, it's scary. And when you go through it, and you watch your loved one decline, and you're constantly strategizing and thinking about new ways to do things, so that they can have as much quality of life as they can. And the reality is, and I'm not trying to overuse the statement that I'm sure has been used a lot, there really is no playbook for all simers disease. And I think caregivers out there should not be ashamed of needing not only support, but I'll say training. I mean, we worked with a homecare company, and an expert in the local community, who helped us think about things like when my mother in law, what didn't necessarily want to go into the car to go on an errand or maybe didn't want to go to the doctor, you know how to use different techniques in order to encourage that. And I think that these are not, you know, just innate skills that were born with. I mean, you know, that you're caring for your mother. I mean, there are things to learn about the about this, this experience, and it is a long road. Yes. So I really, I hope that when more people learn about it, and get trained and understand what's coming, and then they share their stories, right. I mean, it's Yes, it's it's all about the stories, I think, I mean, I did a local, we had a local newspaper from my hometown, which happens to be where Doreen lives.

Rosanne 27:34

Oh, wow.

Brooks Kenny 27:35

So we reached out to the local paper there to just tell them about the launch of our new platform brain guide. And I posted it on my Facebook page. Okay, just you know, wanted, I want my friends to know, I have a lot of family and friends still in New Jersey. And I have to tell you, I received comments far and wide from childhood friends, so many of them saying My mother has it. My dad just died. I think something's wrong with my aunt. I mean, just the the floodgates opened. And I thought to myself, alright, I know, I'm just one person, you know, with one Facebook page. But I thought, you know, a lot of lives were touched in that moment, and maybe just by sharing it in that moment, few days where we were all commenting. If that moves us a little bit further moves each of them a little bit further, you know, when that's something positive. I know that sounds really silly. It's only a small example. But every little bit helps.

Rosanne 28:38

Not silly at all. It's not silly at all, because we are all connected with our stories.

Brooks Kenny 28:42

Yeah.

Rosanne 28:44

And you never know when your story is going to help somebody else in that same position. Either advance further, or help them or just let them know they're not alone.

Brooks Kenny 28:57

Yeah.

Rosanne 28:58

So I don't think it's silly at all. I don't.

Brooks Kenny 29:01

Well, thanks. Yeah.

Rosanne 29:03

Now, now your brain guide. I'll be honest with you. I took the test. And I held my breath.

Brooks Kenny 29:11

Right

Rosanne 29:12

Because I wanted to see how I was going to score. Thankfully, I'm fine. But it was great. It was a really comprehensive, but non-threatening way to take this test. And I mean, I I I just I thought it was great. Can you tell me how you came to this developing the Brain Guide and why it's important and who you wanted to reach?

Brooks Kenny 29:37

Sure. Well, kudos to you for taking it. So Us Against Alzheimer's. You know, as a nonprofit patient advocacy group, our focus has always been to tackle the toughest problems in this disease. And we really think that overcoming the barriers to early detection and diagnosis is central to solving for this disease and our first effort was a consumer campaign called Be Brain Powerful, which includes a series of brain health challenges. And we received a lot of good results from that it was specifically targeting women, we kind of did a limited release a bit, if you will. And as that was happening, our early intervention work was continuing. We were working with providers to try to educate them, we continue to do that work, we're working on policy actions. And we realized we had a major opportunity to advance that consumer pillar I was speaking of earlier. And so we collaborated with medical experts and a wide range of organizations. In order to build this new platform, we received financial and in kind support from Biogen and Amazon Web Services was our technology partner. So the whole platform is built on state of the art technology. Yeah. And it includes a couple of key things. So there's a website that you can visit my brain guy.org, or you can call an 800, number 855-Brain-411. And in both scenarios, you are given the opportunity to take a memory questionnaire, so you can take it using a voice spot, or you can take it via the web and by answering questions, and that you can take these questionnaires for yourself, or you can take one on behalf of a loved one that you see often based on the results of these questionnaires, we curate a tailored set of resources based on where you are in your journey. And so anyone whether you are concerned about your own memory, whether you're experiencing memory changes, maybe you just want to learn more about brain health. Or maybe you're caring for a loved one with Alzheimer's or perhaps worried about someone that hasn't yet received a diagnosis, you can go online or make this phone call and go through a private confidential questionnaire, we do not store any of the data, we only capture your email address, so we can send

you the curated content. And once you have that content, you can print it out, and you can bring it to your doctor and you or you can bring it to a loved one and say I did this memory questionnaire I do so great. I think there might be something amiss here. And so the other thing we're doing Rosanne with this is we have tip sheets on how to raise the topic, how to talk to your loved one, how to talk to your doctor. So we're hopeful that wherever you are in kind of your journey with brain health, that you are able to get helpful resources. On your next step. We're not talking like I said earlier, we're not talking about every step. But just Where are you right now, because we know people are overwhelmed. So they don't want to go on to Google and you know, start searching but but having some curated materials from trusted sources. They're either original content based on expertise at us against Alzheimer's or there, we have links to resources that are trusted from credible organizations and groups, and the service is free will always be free. It's available in both English and Spanish. And our hope is that this will be accessible to all communities, we were very thoughtful in the development and the design, wanting to ensure that the reading level was appropriate for all communities. As I said it was translated into Spanish from day one. And right now we're partnering with anybody that's willing to bring this to their audience. So doing podcasts like this with you. We're talking to community partners that are reaching folks and community centers, hospital systems, employers, patient advocacy groups, we just think this is a way to very safely give you a tool to spark that conversation. So people can just take the next best step. They don't have to take them all but the first step is important. So it's been an incredibly exciting. We, you know, more than 100 people worked on this project during a pandemic.

Rosanne 34:18

Yeah

Brooks Kenny 34:19

We started in September. And you know, I've often said to our team, I don't know if we would have been able to pull it off.

Rosanne 34:25

Really?

Brooks Kenny 34:26

If we were in person because why right, we would have forced ourselves to get on airplanes and fly and have meetings. But instead, we made technology work. We had meetings every day. We had team playlists where to motivate us in the long hours. And it was really, it was really a highlight for for me personally and certainly for us against Alzheimer's and we're just getting started Of course, but in the building of it was a pretty, pretty remarkable experience to be a part of.

Rosanne 34:59

And let me just say, Great job.

Brooks Kenny 35:02

Oh, thank you.

Rosanne 35:03

It was seamless. It was seamless. It wasn't one of those websites that you go on, and it takes forever to load, or you don't know what you're looking for, or you're trying to get somewhere. You don't know where, but you're trying to get some. Everything's laid out it. Five stars from me.

Brooks Kenny 35:20

Well, thank you. That is huge. I'm gonna pass that along.

Rosanne 35:25

Absolutely. Five stars.

Brooks Kenny 35:27

Nice of you to say.

Rosanne 35:27

It was a wonderful, it was just and the information that you have is great information.

Brooks Kenny 35:34

Thank you. I'm glad to hear that.

Rosanne 35:35

Because here's the thing. Absolutely. And I've always been a proponent of knowledge is power. Even if you don't like what it's telling you, it still gives you power. And it gives you that ability to go forward. You know? And, and that you can't ask for anything else than that. And it's clear and concise. And I think it's great. I do.

Brooks Kenny 35:58

Thank you.

Rosanne 35:59

You're welcome. You're welcome. You talk about the importance of knowing your local resources,

Brooks Kenny 36:07

Right

Rosanne 36:08

Because everybody's, you know, everything's different. No matter wherever you are in the country. How do you find out what your local resources are? And what are you looking for?

Brooks Kenny 36:16

Yeah, well, I, I say this with from personal experience, right? I mean, care is local.

Rosanne 36:21

Yes.

Brooks Kenny 36:22

And we have included on the website links to actually we have fact sheets that explain the value of local resources, which we thought was really important for people to know. We also are sharing a resource from the National Association of Area Agencies on Aging, which is called the eldercare locator, which has links to local resources. And we're also partnering with n for a in order to provide that support to people that visit the website or people that call the 800 number, because we know that they have

access to local resources. So you know, things like Adult Day services, which you and I have talked about often get a bad rap. And I think it's because of this stigma, and the language you're using, if we call it something different. I don't I think most people would be on board I agree with you know, it's a wonderful resource. It's a wonderful place for people to go, it's provides respite to the caregiver, depending upon where you are in your health, because it's not just for all timers, but where you are in your health, you can participate, you can volunteer and you know, you can serve meals, you can, you know, do music, you can participate in the activities. And I just think it's wonderful. I also believe strongly that knowing your local community center, knowing the senior centers that are available, knowing the homecare companies, the local franchises that are available, all these things really matter, because it's where the care is going to happen. And so having access to the end for a resources is is really critical. And it's very reassuring, if you're caregiving from a distance, knowing that you are able to build those relationships on behalf of your loved one, at the local level.

Rosanne 38:33

Absolutely. And I often say you know, we, you can find everything out about a refrigerator that you're going to buy, but you don't you can't find out about the care that you want to provide for your parents, or your husband or your spouse or whatever. It's it's disorienting, because you're trying to make the best decision, but you don't have all the information to make the best decision.

Brooks Kenny 38:56

Right.

Rosanne 38:56

And that locator I went on that also. It was really great. I mean, it's it's very comprehensive.

Brooks Kenny 39:03

It really is. And I I tell folks, you know all the time about it when people reach out to me just personally, and I always say well give me your zip code, and I'll sometimes plug it in. But I also provide it to people to help them think things through because you are making really important decisions. I mean, listen, there's the same resource exists for childcare.

Rosanne 39:27

Exactly.

Brooks Kenny 39:28

And this I know that organization well, and it's a fantastic group, and we just have to understand that our population is aging, our loved ones and us we're all getting older, but we all want to thrive and we need support to do so. And that's why tapping into local resources can mean so much

Rosanne 39:50

Absolutely agree with you. You know in going forward with everything that you do, what do you see is the next look what's on the horizon, the Brain Guide, obviously, but in developing and in sharing the resources and information, what do you think is the biggest obstacle going forward? In all of that?

Brooks Kenny 40:11

It's a great question. You know, we're we're just out of the gate, we've been, you know, we launched mark, at the end of March, we already have 60,000, people that have visited the site, we have 30,000 people that have taken the brain guide questionnaire, which were, well, 30,001. Now,

Rosanne 40:29

It's me!

Brooks Kenny 40:30

I got this number, right before I caught we got started. And, you know, honestly, Rosanne, our focus over the next year is to really get this into the hearts and minds of as many people as we can, through collaboration and partnership, we have a long term vision roadmap of features, I can imagine a day where people could come on to the site and create their own user profile. And you know, come back a few times and take the memory questionnaire and see how they're doing. Or perhaps we can add notifications of, you know, tips of things to do for your brain health, we have lots of great ideas, I think our first step is to just ensure we take that first step of getting it into as many places as we can. And that's why we wanted to make it accessible, we wanted to make it free, we have tremendous feedback from the community that the phone number will likely be utilized a lot by different communities, specifically Spanish speaking communities. So we're excited to just create partnerships, and work with anyone that's interested to bring this to as many people as we can, we feel like there's enough, there's this pent up need for information. And there's so much fear that we're hoping we've kind of landed in a place where it's safe and private and secure. It's, it's simple. And hopefully it will spark that conversation. I mean, my vision would be for anyone that's having a fear or worry about themselves or a loved one will go to my brain guy.org or call 855-Brain-411. So they take the next step. Because if that many people start talking about it, more groups, like you keep showcasing it, maybe that stigma can be diminished. I mean, I don't know, maybe I sound too lofty, with you know, one, one program isn't gonna solve the world. But I'm very, very excited about the early data. And I think our goal for the next year is to bring this to as many people as we can. It is version 1.0. So there are going to be ideas, people are going to give us ideas, and we're going to take them in and we're going to continue to do user testing, we're going to continue to add new resources to the content library, as well. But we really are focused now on getting the word out.

Rosanne 43:02

Now being on both sides. Obviously, you were a caregiver, and you work in this field. Having that perspective, and looking at the future going forward with Alzheimer's research and treatment and information. Do you feel hopeful?

Brooks Kenny 43:19

I do. I feel very hopeful. I think there's so much need out there. I think there are treatments on the horizon, the science around brain health and risk reduction is catching up. We're actually sometimes using the word prevention in the same sentence as Alzheimers disease, hallelujah. I feel like the narrative is changing, and more organizations are picking up the topic. And what I would really hope for is a narrative that is less about disease and dread, and more about health and hope. Because I do think there are things that we can be hopeful about. And listen, I know for the millions of caregivers out there who are caring for loved ones that are in the advanced stages of Alzheimer's. I'm not suggesting that what they are going through is not excruciating, and challenging. I just really believe that. For all those caregivers, there's hope for their brain health. Right. And so if even if their loved one is in the advanced age, there are things they can do for themselves that hopefully bring some positivity, you know, to their

life's experience. So I really am I am hopeful. I believe that working in collaboration with other organizations and partners and stakeholders, we can achieve great things. We don't anyone to be left behind without from Alzheimer's disease. And we believe strongly that the path to overcoming Alzheimers is early detection. And talking about our brain and our brain health is easier than talking about disease and Alzheimer's. So I am hopeful the narratives changing, even if you watch, you know, different television shows, we were featured on Good Morning America. And it was a very hopeful segment. It was and that's not always the case. If when you think about segments you've seen around this topic. There also a lot of movies coming out talking about Alzheimers disease. And I think that is going to help normalize the conversation as well.

Rosanne 45:50

Absolutely agree with you. Yeah. And the more it's out in the mainstream, the more it's not the boogeyman,

Brooks Kenny 45:56

Right.

Rosanne 45:57

Any final thoughts on Brain Guide and what you want people to know about?

Brooks Kenny 46:01

So I guess I would say that Brain Guide is really about empowerment. It's about health care equity, it's about hope. And it's about making information accessible to all communities in as many ways as possible. So I would just encourage your listeners to check it out and to pass it on.

Rosanne 46:24

A big thank you to Brooks Kenny, Executive Director of the Women's Network of Us Against Alzheimer's. For more information on brain guide to take the test and check out their comprehensive resources, go to my BrainGuide.org or call 855-brain-411 for one one for information in English and in Spanish. I hope you enjoyed our podcast today, head over to Daughterhood.org and click on the podcast section for show notes including the full transcript and links to any resources and information from today's episode. You can also find us on the Whole Care Network as well as anywhere you listen to your podcasts. We are also on Facebook, Twitter, and Instagram at Daughterhood The Podcast. Feel free to leave me a message and let me know what issues you may be facing and would like to hear more about or even if you just want to say hi, I'd love to hear from you. Also a very special thank you to Susan Rowe for our theme music, the instrumental version of her beautiful song Mamas Eyes, from her album Lessons In Love that you can find on the iTunes Store. I hope you found what you were looking for today, information, inspiration, or even just a little company. This is Rosanne Corcoran. I hope you join me next time in Daughterhood.