

The Alzheimer's Podcast: Navigating Rough Terrain with The Dementia Sherpa
[Episode 100](#): Enjoy Us in the Moment

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Christy: *You're listening to The Alzheimer's Podcast with Christy Turner of Dementia Sherpa, where we're all about bringing the Good Stuff --that's respect, kindness, love, empathy, and compassion--for people living with dementia, their families, and the professionals who support them.*

I'm Christy Turner, AKA The Dementia Sherpa. I've enjoyed the privilege of working with over 1,500 people living with dementia and their families so far, including multiple experiences in my own family. In the course of my career, I've transformed from total train wreck on my first day as a professional to local go-to expert, speaker, trainer, and consultant. And if I can go from scared spitless to confident care partner, I promise you can, too.

Hello and thank you for joining us. Today is The Alzheimer's Podcast Episode #100. Woot woot! I was going to get a marching band and...no, I wasn't. I completely forgot it was Episode 100 until I was talking to today's guest, saying "Oh, yeah, you're gonna be--Oh my gosh!--episode 100." So, I want to thank all of you who have made getting to episode 100 possible. I really appreciate you hanging in there with me, especially those who have been listening from way back and hung with the show after I moved from the featured expert on the show to host, and y'all realized Mike Good genuinely was the engineering brains behind the show. And you've stuck with me during my very steep learning curve on the whole putting the show together/engineering aspect. I really, really, really appreciate you hanging in there with us. Thank you so very much! I look forward to doing another hundred episodes that are full of interesting, relevant, important information for you, however you find yourself in this universe of neurocognitive disorders. Thank you for being a listener. I really appreciate it, from the bottom of my heart. Okay, enough of the squishy stuff!

Our guest today is Jamie Tyrone. I could wax poetic about her for hours, but listening to her in her own words is way better. So, here's part one of our chat.

I am so pleased today to have with us Jamie Tyrone, who is the CEO and founder of [Beating Alzheimer's by Embracing Science](#). And don't worry about

remembering that name because it's got a cool acronym: [B.A.B.E.S.](#) So, Jamie Tyrone has two copies of the ApoE-4 gene, which puts her at a 91% lifetime risk of getting Alzheimer's disease, along with 2% of the US population. A trained nurse and former marketing executive, she's now a full time advocate for Alzheimer's research. She's the founder of B.A.B.E.S., as I mentioned, and that is a nonprofit organization that raises funds and awareness for Alzheimer's research. She's also a founding member of Women Against Alzheimer's, a movement of women, disproportionate victims of the disease as patients and caregivers, campaigning for a new approach to finding a cure and the adoption of a national plan for the prevention and treatment of Alzheimer's disease. She's contributed recommendations to the [National Alzheimer's Project Act Advisory Council](#) set up by the Department of Health and Human Services on their national plan to address the prevention, care management, and public awareness of Alzheimer's disease. Plus, she's written a book. So, we're so excited to have Jamie Tyrone with us today! Thank you, Jamie, for coming today.

Jamie: Well, thank you, Christy. I'm very, very honored. It's been a long journey, a long road that a lot of us have been on and I appreciate that you are helping me lend my voice to the cause of beating this disease. So, thank you. I appreciate it.

Christy: *Absolutely. So before we move on to some other topic, please tell us the name of your book.*

Jamie: So the name of my book is [Fighting for My Life: How to thrive in the shadow of Alzheimer's](#). And I decided to write the book because of the experiences I went through finding out that number one, I have a huge family history of Alzheimer's disease. My great-grandmother, grandmother, two great-uncles, and my father all have succumbed to Alzheimer's. And so when I found out that my genetic status puts me at this 91% lifetime risk of getting Alzheimer's disease, I went into a very, very deep, deep dark hole. And this was about, oh gosh, nine years ago, when I found out this information. And it was all done basically on online-type disclosure, no genetic counseling. And so when I found out this information, it was very, very shocking. And after three years of being told that, *You shouldn't probably talk about this because you might be discriminated against based on the fact that if you know your genetic status, that you could be discriminated against long-term care, insurance, life insurance, disability insurance.*

And so after being, my voice was being silenced, for those three years and subsequently being diagnosed with PTSD and really contemplating very seriously whether or not I wanted to continue living on earth, I then went into therapy. Yeah. I had a plan. It was--anyway, it was, it was because there wasn't really any support then. So, my thought--and my husband said to me, he says, "You know

what? I can't live with you like this. You know, you need to make some sense of this.” And so I knew my, I knew my husband would never leave me. He wasn't that type of person. But that was the wake up call that I needed to finally, you know, figure this out and what this information meant to me. And so what I walked away with is one of the things that contributed to the PTSD is that I felt like I was alone, that nobody really understood what I was in, the situation that I was in, there, that only 2% of the population, the world's population, has this genetic status.

And so I really felt like I needed to tell and share my experience in the, the pros, cons, and pitfalls of what it is. And help people decide, *Do you really want to know this information?* and what you would do with it. And then also in the book we talk, I talk about brain health and what we can do to help decrease our risk. Even though we do not have a prevention or cure, we do have ways that we can help decrease risk and increase our cognitive reserve. And then also talk about caregiving. And sharing a couple of beautiful stories that I've had with my father that, growing up we had a little bit of a contentious relationship, but after my father was diagnosed with Alzheimer's but actually, I learned to really love my father and consider it a blessing that we actually had the time together during his journey with Alzheimer's disease. So that's kind of it in a little bit of a nutshell.

Christy: Yeah, there's a lot to unpack there.

Jamie: It is!

Christy: Staying with your dad for a minute, what was it that you feel like flipped that switch for you? Because I think that a lot of family care partners do have an experience where they've had a historically difficult relationship, challenging relationship. In fact, I've worked with people who have experienced childhood abuse and then we're essentially left holding the bag as the primary care partner when their parent was diagnosed. And there was really no one else around. So--and I'm not implying that you experienced childhood abuse--but just that people can come from challenging backgrounds and have a great deal of difficulty getting over that hump. So I'm wondering, it sounds like you have some insight for us?

Jamie: Well, I did have a challenging background. The question of--it was probably more emotional abuse with my father. And so there were years that I didn't even speak

with him. But when he became ill and I looked through his eyes and realize that that could be me in that, but it wasn't so much about me so much is that I had to learn to learn to love myself, to love him again. And I didn't love myself for the fact that I retreated when there were instances of conflict, that I just, just didn't speak with him for years. I didn't like myself. And so I've realized that he was a human being, flaws and all. That he was a person. And that if I can embrace what he was going through, then I can embrace myself.

Christy: So it was part of a healing journey for yourself as well as a shift in perception of him.

Jamie: Absolutely! Because all of a sudden there was no more strife. There was forgiveness. And once I could forgive him and myself, all of a sudden we could have more of an authentic relationship and I could bring the stigma of Alzheimer's out of the shadow and love him for who he was and what he was going through and to accept some of the behaviors and actually have fun in the behaviors. And I'll share a story with you, that I actually have written in the book and that my family just absolutely adores and that is that when my father, probably in his mid stage, that he had, should we say, he developed sticky fingers, and things, he would pick up out of the grocery store and kind of hide them in his pocket and take them home. And so--

Christy: We like to call that Unauthorized Shopping.

Jamie: There you go. Exactly. It was, he definitely, he was unauthorized. And so, my stepmother, bless her heart, she would be embarrassed by it and she didn't know how to deal with it. And that was frustrating because it made his behavior more, there was more anxiety behind those behaviors because of how she was uncomfortable in how to deal with it. And so anyway, after she, after he was placed in a memory care community, I was visiting him one day and my father always loved to have one glass of beer when he got home from work. And so, you know, that was part of the reminiscence. And so I said to him, I said, "Dad," I said, "I'm going to go on a beer run now." Of course, it was non-alcoholic beer, but he didn't know the difference. And it looks the same; the bottle was green. He goes, "Well, can I go with you?" And I'm like, "Sure, come on," forgetting about his unauthorized shopping. We go into the grocery store and immediately, he

beelines to the loose candy section. And he starts taking this candy, putting it in his pocket. And I said, "Dad, you can't do that." He goes, "Yes, I can." So I'm like, "Okay, well, Dad, here, take a bag. You can put everything you want, just put it in this bag."

"Nope!" And he kept going into his pockets. And so I'm like, *What am I going to do here?* So I went to the manager of the store and I said, "You know what? My father is having a blast right now in your candy department." And I said, "So, it's in his pockets; not in a bag. But you know, whatever you think that he may be taking, just double it and I will pay for it." I said, "But right now, he's having such a good time," I said, "I don't want to stop him." And he said, "You know what?" He said, "We know your father. And we call that sampling." And at that moment--I know--and at that moment I thought, *You know what? Bringing it out of the shadows and sharing that with the manager of the store? It also gives him the opportunity to extend his kindness to me and my father.*

Christy: *Right.*

Jamie: And I thought, *You know, that was a beautiful moment because we all walked away feeling good about it, especially my father.* He probably had candy coming out of his pockets for days. I think those were the moments that I realized that he was a human being and that he had the right to enjoy his life. And there were things that I could do to work around those behaviors that made me really embrace and enjoy that time with him. And that left me with a beautiful, funny memory and story that, so much to the point where I wrote about it. And to this day, my family just, you know, those were the fun times that we, that we have with my father. And those were the times that I, again, I was able to love him.

Christy: *I really like that story. That is a fantastic story because it's such an unusual response to what people would usually do, which is, Oh, my gosh, I'm so mortified. I'm so embarrassed. Can't take him anywhere! Or, No, you do need to take those out of your pocket! And you just showed what a great way of thinking outside the box, of, He's experiencing joy in this moment. So I'm going to look for a way to that and still be consistent with my values, or with what the situation requires. I love that. Thank you so much for sharing that story.*

Jamie: Oh, you're welcome. And it's, it's a fun memory that I have. And you know, we'd be out in restaurants and he would kind of just--he was very social and he would

just go up to people that he didn't even know, whether it was appropriately as they were eating, and interrupting. But I would just go up to them and I would say, *You know what? My father has Alzheimer's and he's really enjoying visiting with you.* And it just changed the whole tone of the whole, you know, event, that, the interaction that was happening and, and they would get their children involved in the conversation with my father. My father would just be beaming and it could have, not have ended that way. I could have pulled him aside and said, "Dad, stop that!" But you don't; you learn to, to just put yourself in it and their moment and what they're going through and letting people, letting people have the opportunity to be kind in return.

And I found that most people, you know, all of a sudden were like, *Oh great, no problem! Let me, let me interact. Let me come into your world.* I don't ever remember, personally, a bad situation that I had with my father. You know, unfortunately--but bless my stepmother, she tried her best, but she came from a generation in which there was stigma behind the disease. And so she was embarrassed by his behaviors. And you know, the sad thing is, is I tried getting her to seek support and in how to learn how to live with what he was experiencing. And it was very challenging for her. And I, and I feel bad for both for them that um, she was of that generation where she wouldn't seek out help; she would try and hide it. And it really, gosh, we just need to bring this disease out of the shadow and it's amazing, the beauty that we can find in doing so.

Christy: *That is absolutely true, and certainly the experience that I've had, also. When people are given an opportunity to be in on what's going on, you know, strangers out in public? People are very surprising, in a very positive way and--*

Jamie: It's unbelievable.

Christy: *A lot of it is really us, right? Getting past whatever thing we have of putting ourselves out there. And that's one thing: it is definitely a mindset shift in realizing, This isn't about me; it's about my person. So I am going to extend myself to total strangers. I don't know how they're going to respond to this, but I'm going to put the information out there and give them the opportunity to step up and step into this moment with us. It's really amazing what happens when we allow other people the opportunity to do that, rather than sort of having the conversation in our own head, not involving them, and then making a determination on their behalf, right?*

Jamie: Very true. It's extremely true. Very, very true. And there is a person inside. In fact, I'll give you an example of where I wasn't so good. I have my slip ups and I guess, you know, I have to realize I'm not always going to be perfect in these situations.

Christy: *Yeah, you're still human.*

Jamie: I'm still human, exactly. And forgetting and not quite understanding, in the disease process. So, I have a very dear couple and his wife has Lewy body dementia and so she got to the point where she's rather aphasic. So, I didn't think that she understood. None of us at the table thought that she understood the conversation that we were having. And the conversation was about having her in a memory care facility, community.

Christy: *Oh, boy.*

Jamie: And we didn't think that, we didn't think she under--you know, we all were just kind of stupid. Just one of those stupid moments. And even though she was not able to articulate what she was thinking, she got very, very quiet. And boy, did she give us The Look!

Christy: *Yeah, this is a great reminder for everyone that aphasic is not the same as hearing impaired.*

Jamie: Correct! And at that point in time she heard and she was able to understand to some degree of what we were talking about and she let us know. And so her husband, bless his heart, I mean he treats her as a person. He is, like, definitely the example of how to be a beautiful spouse. And he immediately held her hand and he said, "I am so sorry." He goes, "Are you upset with me?" And she still gave him The Look, which was the answers that he, you know, that she was trying to tell him. And we at that moment and we knew that she understood at a certain

level. And I learned from that, and as we all did at the table, my husband, her husband, we all learned. And shared it with our mutual friends that, *You know, she still has some awareness here.* but it was a learning, it was a sad learning lesson for me because I know we hurt her. But we learned.

Christy: *That's the best that you can do after a situation that doesn't go the way that you, in retrospect, would have wanted it to go, is to learn what you need to from that and continue on. Just really points to, again, one of the things that we know is not a great idea is to talk about people as though they're not there--*

Jamie: Right!

Christy: *Because we, we honestly just don't have enough knowledge at this point about any type of neurodegenerative disease or condition to let us know about those moments when the neural pathways are sizzlin' and information is processing. So just a good rule of thumb is, you know, Don't do that.*

Jamie: Right. Well, no, and I mean, gosh, we all felt so bad. Like you said, the fact that she couldn't speak? She *heard*, and that was a big lesson for us. And that every moment that we are with her or with anybody with a dementia is that err on the side of, you know, positivity, err on the side that they can hear you, because most of the time they can and there's some level of awareness and--

Christy: *Yeah, err on the side of dignity.*

Jamie: So those are some of the stories that I have gone through. And I'll share one other story that I had with her also, which was beautiful because I started looking into reminiscence therapy and you know, the area of the brain that it triggers and again, the enjoyment of, of going and reliving the past. And so she had actually all her, through all her years, she had saved all these fancy dresses that she had worn to special occasions. And so her husband, I kicked him out of the house. I said, "Go do what you want to do." I said, "Helen and I are going to play in her closet,"

and we did for several hours. And she checked out each dress. And she told me where she wore it, where she bought it from. I mean, she was clear as a bell. And then we sat down and you know, listened to some of her favorite music. And you know, she was so--he got home that afternoon and he said, "I don't know what you did with her." He said, "But she had a wonderful evening. She was calm, she wasn't anxious." And I thought to myself, *Gosh, here is the beauty, once again, of realizing that they have their personhood, that they are still a person.* And these are moments that we have the power to give, to give them.

Christy: Yes! Yes!

Jamie: To give everybody.

Christy: *Absolutely. Absolutely. I love that too. And music is the secret awesome sauce. And I don't know why--*

Jamie: I love you.

Christy: *It is still, for some weird reason, it is still, like, a well-kept secret, that music is so powerful and I, I just really can't recommend it highly enough. It, it creates magic and that just really sounds like I'm fun afternoon.*

Jamie: You know what, we both enjoyed it. I had a blast hearing her stories and just, and her face light up. So I enjoyed it, too, you know. It was a win-win for both of us. And I think if we learned to realize that, that we, just enjoy them in the moment. And I say "them" and it sounds so third-person because I, you know, I don't know what else to say that, you know, I, it should be, *Enjoy us. Enjoy us in the moment.*

Christy: *When you're with your person, have a good time because what the heck, you're there too. mean. One of the things that I like to help care partners remember if*

they've forgotten is the environment that you create in your home, you know, if your person lives in your home or, if--no matter where your person lives, when you're in that environment with them, you're with them. So you--it benefits both of you to create a positive environment and experience. You both get to have a good time.

Jamie: Absolutely. And bringing it back to my father, I mean, those were the moments, when you asked me how I could love him again. Those were the moments that I then cherished. And then it brought me back into the time when I had the moments with him. Not the bad moments, but the good moments and all the fun things that he did and his sense of humor. And so it brought me back to those times. It magical, actually.

Christy: *Yeah. So where you're in an odd 91% club, right? A 91% club that nobody wants to be a part of. How has that, or did that, inform your relationship with your dad once he had developed the disease? Where you, in moments, looking at it like, This could be me. How would I want it to be? Or were you more just kind of about your dad in those moments?*

Jamie: That's a very, very good question because I had seen the toll that caregiving had taken on my family and um, yeah, I mean it was just, it's just horrendous. I mean, emotionally, financially, it just, it's, it was very, very draining. And so I, when I got this information that I had this, pretty much, if I was a betting type of girl, gambling type of girl, I mean I would, I would place a huge bet that I will be getting Alzheimer's disease. And you know, I thought, I was so anxious and I wasn't worried about me so much because I was worried about my family because I didn't want them to have to go through what we've already been through. And so, and, and I'm going to share this story with you. It's in the book. My husband is a very humorous man and that's why I married him. He goes, "What are you afraid of?" And I said to him, I said, "Sweetheart," now mind you, he's 13 years older than myself, I said, "Sweetheart," I said, "I'm so afraid that you're going to have to take care of me and go through what we've been, you know, my family's been through." He looked at me and he said, "Don't worry about me. I'll be dead by then."

I mean, and I started laughing. Well, that's a pretty true and accurate statement. And the next morning he went and he increased his life insurance. So I would be taken care of. Yeah. And so that--

Christy: *Did you fall in love with him all over again? Oh, my gosh. I'm getting squishy.*

Jamie: Oh, well, okay. So that brings me back to another--when I first met him, I was having some neurological issues and I was actually diagnosed with MS. So, um, I thought to myself, *Okay, you know, on date number three, if I feel that it could have the possibility to lead to something in the future that I was going to just disclose that.* So I said to my husband on the third date, "You know, there's something I want to share with you." And he said, "Well, what?" And I said that I have MS. And he said, again, he said, "Well, what's your biggest fear?" And I said, "Well, that I'll end up in a wheelchair." And he said, "Well, that's great," and I looked at him. He goes, "Because then you'll never be able to run away from me."

Christy: *And so you were like, "Either I'm going to marry this guy, or he's a weirdo."*

Jamie: No, no, because I actually, well no, it was a, "I'm going to marry this guy" because I had known him from work and I knew who he was as a person and I knew his sense of humor and I knew how he, how his relationships were and what a committed man he was to his job and profession. So I already knew he wasn't a weirdo, 'cause he passed the *I'm not a weirdo!* test. He's kinda like a, I wouldn't say caretaker. Yeah. He, I mean, he loves giving. He loves taking care of people. And it's so funny if he wants to do something for me and I don't think it's necessary, he gets like, he gets a little pout on his face, you know, because that's his, that's his personhood. He likes to take care of. He's a great man. I'm very fortunate. And there's a good possibility that I may get Alzheimer's, but, um, who knows what the future's going to bring? And we're just going to embrace it day by day and he's getting ready to retire and we're going to enjoy life and just be happy and laugh.

Christy: *And that's our show. Thank you so very much for being with us today. Resources mentioned in this episode are in the show notes at DementiaSherpa.com/Episode100.*

You've been listening to The Alzheimer's Podcast with Christy Turner, wishing you a blessed and easy week ahead. Be sure to check out the show notes and subscribe by going to DementiaSherpa.com/podcast.