

The Alzheimer's Podcast: Navigating Rough Terrain with The Dementia Sherpa
[Episode 104: I Call it a Gift](#)

Jamie: And you know, I call it a gift. And people will tell me, will say, *That sounds like a strange gift to me.* And I say, “You know what? God gives you gifts that you may not recognize until you open the box.”

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. Our guest today is Jamie Tyrone, who was first on the show in episode 100: Enjoy Us in the Moment, where she used her own experiences to offer some creative, real-life examples of how to hit it out of the park as a care partner.

A trained nurse and former marketing executive, Jamie's now a full time advocate for Alzheimer's research. She 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.

Jamie is the CEO and founder of [Beating Alzheimer's by Embracing Science](#), or B.A.B.E.S. for short. 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 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.

And on top of all that, she's co-authored a new book with Dr Marwan Sabbagh. It's called [Fighting for My Life: How to Thrive in the Shadow of Alzheimer's](#).

Several years ago, Jamie was exhibiting symptoms of MS, and was given the diagnosis. But something still seemed amiss. She was determined to unravel the mystery, and that's where we pick up Jamie's remarkable and inspiring story in today's episode.

Christy: *So, did the diagnosis of MS turn out to be correct?*

Jamie: Well, so after a few years of me still exhibiting symptoms, my MRIs were always negative. So, I was told by one of the neurologists--in fact, it was at UC Davis--and he was saying, "No," he said, "I think this might be some sort of mitochondrial issue, that the powerhouse of the cells aren't functioning correctly."

And so when you get extremely fatigued, that's when I would start walking funny. We even moved from a two story home to a single level because I was just not able to recover from going up and down stairs. So, the diagnosis was still elusive.

There's a part of me that can't help but think it may be related to my genetic status because there is some mitochondrial defense, dysfunction, but it's usually just in the brain and not the rest of the body. So I, you know, we don't, I mean that's what one neurologist has said, so, you know, I don't know. I have no idea. And actually that's what kinda got me in this trouble to begin with, because it was a missing piece of my health puzzle.

And so, how I found out my genetic status in detail was I participated in this study that said, *If you knew you were at genetic risk for certain diseases, would you change your lifestyle?* And so one of the tests on the panel was MS. Alzheimer's wasn't even on my radar screen. Even though it should have been. But you know, I was 49 at the time, and even though there was a family history, I was in what I call healthy denial, that I could put that off. I'm like, *You know, it's not going to happen to me.* And it wasn't even on my radar screen.

When my results came back one night, eight o'clock at night, I'm on my computer and my email and it says, *Oh, your results are in,* and I'm like, "Oh my goodness, I'm so excited. I can't wait to see if I have, if MS is one of my risk genes."

So I opened it up and I actually was below the risk for the normal population. But then, way over to the side, it says, *Oh, by the way, you have two copies of this gene. It's called the ApoE-4, and that puts you at this huge risk.* And the results came back and it said 75%. And so I was dumbfounded.

And so what do we do when we want answers? We go to Google. So I went to Doctor Google, as I call it, and I started looking at the research. I mean, this all happened in one night.

Duke University had put my risk at 91%, with the average age of onset, like, around--well, in that particular article, I don't know if it talked about average age of onset, but further discussion and further investigation, it showed that, I think, the average age of onset, like 63, with this genetic status, but that's average age. I mean, people can get it in their 50s, with earlier diagnoses. So, you know, who knows?

I'm 59, I'll be 59 in a couple of months. And I keep thinking, *I'm kinda like waiting for a time bomb to go off.* But then again, I can't, I can't be obsessed with it anymore, like I was. I mean, I have to realize that I was given this information for a reason. And that was to tell my story about genetic testing, caregiving, and research participation.

And that this, writing the book, is what I was supposed to do in my life. And you know, I call it a gift. And people will tell me, will say, *That sounds like a strange gift to me.* And I say, "You know what? God gives you gifts that you may not recognize until you open the box."

And the gifts that I was given was that everyday I wake up with a purpose. And that purpose, hopefully, is to help people decide whether or not they want to know their genetic risks. What, again, the pros, cons, and pitfalls. What would you do with this information if you knew it? For me, it was very anxiety-provoking and it took away my healthy denial. I could no longer deny that I could get the [sic] Alzheimer's disease.

I can no longer say, *Nah, it's not going to happen to me.* Every day, when I have a brain hiccup, or every day I misplace something, or every day that I get confused about something, when I can't multitask, I have that printed on my forehead. I have 4-4. ApoE-4-4. And I can't run from it anymore. I can't; it follows with [sic] me every day.

So the question is, do you want to know? And if you do want to know, make sure that you put your financial house in order. Make sure that you get your long-term care insurance, if that's something that's in your financial plan. Make sure you get

your life insurance and disability insurance in place. Because once it's in your medical record, there is no going back. It is now in your record and it will be with you forever.

So, people say, “Yes, I can take this information and I can change my lifestyle. I can eat better, I can diet, you know, eat better and exercise.” Well, but you can do that anyway, without knowing your genetic status. Anxiety is not good for the brain. Now, there are people who have different personalities, and there are people out there that may say, “Eh, it's no big deal.” So then maybe genetic testing is okay for them.

But it's not something to be taken lightly. And I recommend genetic counseling. And then to me, the only reason for me to know, that's quite actionable, and that is to be a research participant like the Phils [Phil Gutis, our Assistant Sherpa] of the world and the Jeff Borghoffs the world. I mean, you know, they, they participated in a study that they thought was going to be hope--you know, that there was some hope behind it, and it didn't turn out that way.

But they gave their, their life, their body, their soul, their commitment to find a cure to Alzheimer's disease. And people, sometimes people will say, “Oh my goodness, that's so altruistic of you.” And yes, we do. And I am a research participant and we do do these things because we want to help the next generation.

But I also feel like I get something out of it. And that's a very strategic plan for me or anybody that may be at risk, which is actually anybody, everybody, you know, age is a risk factor.

But I have my finger on the pulse of what's going on in research as do you know the other people in the, in [the Biogen study that was closed](#), is that they now know the next studies because the researchers are on top of it. Therefore, you will be on top of it, studies that people, the general population, doesn't even know about.

But if you are a research participant, you are going to be close to the studies. And, as [George Vradenberg says, from Us Against Alzheimer's](#), is that the first person that will be cured of Alzheimer's is a research participant. So, I think that's a very strategic plan.

Christy: Mm hmm. So, if you had it to do all over again, would you--

Jamie: You know, people ask me that question, and it's a very good question.

Christy: *Yeah, I'm sorry. I know it's not an original one.*

Jamie: No, no, no, no, no, no. I think it's a good question, though. So, because I think you're asking the question that everybody's thinking about. My answer is that I would have preferred not to know.

Christy: *Mm hmm.*

Jamie: Because it did cause great anxiety for me. On the other hand, I'm now a research participant because of it. And that's not such a bad thing. That's what I can do to help mitigate my risk, is to be a research participant.

And I have to tell you, my niece--my niece!--so you know, she knows the family history. She knew that I was writing this book. And what does she go and do? She goes to [23andMe](#), she signs up, and I'm like, *Oh, my goodness!* So, she comes back with one copy of this gene, puts her at increased risk. Not like I do, but you know.

She called me and she says, "You know," she goes, "I thought it was okay because I knew my family history. But I'm looking at the results and it's kinda hit me in the face that this is a reality and I really should've thought about this more."

And I'm like, "What? You should be listening to me!" But it doesn't really matter; she made that choice. But here is where it does matter: is now my sister, her mother, will now know what her genetic status could possibly be. And my sister is very upset, 'cause she didn't want to know.

So it not only affects you, but it affects the family. Because if someone is a 4-4? And I don't have any biological children, but my child, if I had a child, would definitely have at least one 4, because how this works is that you get one gene from each parent. So I got a 4 from my father and a 4 from my mother. So we know that because I'm a 4-4, that I would be passing down one of those genes to

my children. So it doesn't just affect the individual who's doing the testing; it affects the family.

Christy: Right. And this is where genetic counseling comes in.

Jamie: Absolutely. Yes. Absolutely. And with genetic counseling, the counseling is supposed to be [before] the train leaves the station.

Christy: Right. But I think a lot of people don't know that. I think they think it is after. Like, you get the test and then talk to a genetic counselor. They're thinking of genetic counseling as like therapy, right? So you have a problem and then you see a therapist.

Jamie: Yup. No, and you speak to the genetic counselors and their profession is helping someone decide whether or not they want to know--and in several meetings, not just one meeting. And now they're having to deal with the aftermath. And they're like, *Wow, now what do we do? This is going to change our profession here.*

And you know, that's not what they've been trained to do. And they're fielding calls all day long now about people who are saying, "Gosh, you know, I'm at this high risk of Alzheimer's disease. What do I do?"

And it's like, *Ugh!* Now they're having to deal with that. And, and that's, part of the book is talking about the brain health and the different types of diets and what that means and what inflammation does to the body and how it contributes to possible Alzheimer's disease and different types of diets.

And [Dr Sabbagh](#), who is the director of the [Lou Ruvo Cleveland Clinic in Las Vegas](#), is the co-author of the book. So he goes into all the different, you know, the different explanations between each diet and what it means, but it's written in such a way that people understand it.

And it's so funny because I thought, *Oh my goodness, is a researcher gonna be able to write it in a non-academic way?* You know, because they, you know, they communicate very high level when they talk about this and that, that I can't even keep track of.

But it's written in such a way that people can understand and go, *Oh, now that makes sense. Now I understand the principles behind the diets that are all being discussed.* There's a lot packed into this book, but it's very exciting to see how it ended up bringing everything together and tying it into a nice package.

When I was going through this period of time in which I felt like I was stranded and didn't have, that people didn't understand, I happened to be at a conference. And we were sitting together on a panel discussion and Dr Sabbagh was sitting next to me and it was like the first time I was talking about my genetic status. I was putting it out there because I'm like, *You can discriminate against me. I don't care. I need to talk about this.* I had just gotten through telling my story, my genetic status, and he covered his microphone and he leaned next to me in a very private moment, and he said, "I am so sorry." And I thought, *Wow, this is a very kind, empathetic, and compassionate man.*

Christy: *Was it through the process of writing the book that you came to a place where you've made some kind of peace with having the information and the anxiety that that was causing you?*

Jamie: It was definitely part of the healing process. Because part of what I was experiencing was that no one would listen. You have a subgroup of researchers who feel like medicine is being too paternalistic and that people can handle this information well and that we need to go ahead and let everybody have access to it.

And so when I would see that or hear that, it would trigger me. The PTSD would start to get triggered and I'd be like, *You don't understand: there's a person behind the DNA. It's just not the DNA. There's a person behind the DNA.*

And so writing this book, my hope was not only therapeutic for myself, just to be writing, but it was also about, *Wow, now I'm being listened to.* Harper Collins, who published it, they're listening. They want--we all want--everybody to hear a message.

The day that the book was released, I thought it was going to be a busy day, a rushed day. And I literally sat all day long, with some tears in my eyes and did nothing other than just to feel that moment of, *Gosh, my voice is being heard.*

Christy: *That is so powerful. It's a simple thing and it's so often overlooked. And so it can be somebody--you know, you, in the position you were in, and certainly people living with Alzheimer's or other dementias that so often people are not listening to them. And as human beings, we all need to be seen. We need to be heard, we need to be connected with on that human level. If that doesn't happen first, we're not going to be very successful with any other types of help or so-called help or assistance that we're there to offer.*

Jamie: You know what? That was so beautiful how you brought that. Because as I was talking, the light bulb went on, just what you were saying, that I had never drawn that line between my personal experience of not feeling, like I wasn't listened to, to the experience of those who are living with dementia, and listening. And not necessarily listening with your ears, but listening with your senses, your eyes, how the person reacts. That's your way of listening.

Christy: *On the heart level, too. Yes, exactly.*

Jamie: And that was beautiful, how you absolutely brought that experience in relationship to those with the disease, and the light bulb went on. So, thank you.

Christy: *Where have you settled now, Jamie, as far as the future? Is that something that is still very present for you, that you think about a lot? Or do you feel more grounded in the fact that you have this book out--congratulations!--and you're a research participant and really an advocate and an activist? Or is it a mix?*

Jamie: I'm sorry, what was the question? "Or is it a mix?" Is that what you asked?

Christy: *Mm hmm, yeah.*

Jamie: It is a mix and I--you know, you used the word grounded and I think that I am at that place now where I feel very grounded. May 7th, when the book was released, I think is the day where my feet were firmly planted on the ground, that everything has come full circle.

And that my advocacy continues. And the book has been a confirmation that the advocacy needs to continue and that everyone, everyone who is an advocate, their voice needs to continue on. Because we do need to find a prevention or cure for this disease. And I'm not going to stop, but I'm not going to have the ups and downs like I had before. You know, the frustrations, the tears.

I feel just like you said: grounded. Like it's just now a nice, even pace. I'm looking forward to be able to continue on but not have that fear. I mean, a lot of what I've done has been based in fear and now it's based in optimism. Now it's based in, *Okay, let's get our boots on the ground!* Like Phil. Oh, he's so cute.

I kinda got off the subject. But I guess I'm moving forward with more levity, with more hope and excitement and that there's a message. And that because of the book, people have an opportunity to read it and see the experience and help decide whether or not they want to know their genetic status and what you can do for brain health and decreasing your risk and consider research participation.

That's kind of the three main themes of the book, is genetic status; do you want to know? Here's what you can do; and then, demystifying the research. So I think if I had to sum it up in a nutshell, that is really what this book is about.

Christy: *Mm hmm. And it sounds like there's a lot of hope in it, too.*

Jamie: Yes. I mean, look at the subtitle [of the book], *How to Thrive in the Shadow of Alzheimer's*. I mean, I am living in the shadow of Alzheimer's, but this is what I'm doing to thrive. And I truly feel excited about the future.

And, you know, I'm not perfect in my diet, but I know the principles behind it and I have the control. And so pretty much, I try and stick to it as much as I can, but it doesn't mean that I have to be so obsessed with it like I had in the past.

And that I've come to the point of drawing balance in my life and enjoying life and enjoying the journey. I mean, when I got to the point where I could say, *Okay, God, why me?* But when I was able to flip the fear and say, *Well, why not me?*

That I was kind of groomed all my life, from being a nurse to business development, hospital administration, in public speaking, that I was kind of groomed. And when I was able to flip that fear and say, *Okay, this is what I was given, and this is what I've been prepared for all my life. And now the moment has come.* And you know what? That's a blessing. I know people are thinking I'm probably crazy, but it's a blessing. I wake up every morning with a purpose. How often is that?

Christy: That's exactly what I started to say, was that is a strong sense of purpose.

Jamie: Yeah. So I'm the fortunate one. Last time, Christy, that I did a Google search, no one's getting out of here alive. Now, my husband thinks he is going to be the first one to do it. But that's not the case. But it's what you do here, while you are alive. Isn't it awesome?

I mean, look at what you're doing and look at the imprint that you're leaving in the world. I mean, and you get up every morning and you have a purpose. And your purpose, you're doing a pretty darn good job. And I mean, excellent job. And I've been reading, you know my emails [from Dementia Sherpa] and every time I'm like, *Where does she come up with all this content? This is so awesome.*

And you keep going. You wake up every day and what a gift you are to all the caregivers and those living with Alzheimer's, and those who are at risk for Alzheimer's. So--

Christy: That's very kind. Thank you.

Jamie: Well, it's true. So, it's true.

Christy: I do feel very, very blessed that I have had an awareness for quite some time, and very strong core belief and conviction, that this is why I'm on the planet, is to do the type of work that I do. That said, I always hasten to add I am okay with this being cured and finding a different core purpose in my life. I can live with that.

Jamie: Yeah. Well, and as Dr. Sabbagh says, he says, “I hope to be put out of business.”

Christy: *Yeah, exactly.*

Jamie: I hope, I hope, you know, and I'm thinking, yeah, wouldn't it be wonderful if we no longer had to have an Alzheimer's Association? Wouldn't it be nice to say that? “You know what, Christy, you're fired. We don't need you anymore.”

Christy: *Yes, absolutely. Yeah, I look forward to that world and I'm totally okay with that.*

Jamie: If I am out of line, please let me know. So I'm going to ask you the question and you do not have to answer it. Would you want to know your genetics? I give you permission to say no because you've asked me this question. Did I want to know, if I had to do it all over again. And I asked this of people that I have this discussion with, you know, would you, would you want to know? And if you would, what would the reason being? Or if you don't, what would the reason being?

Christy: *Okay. So, actually I have been asked this question. I was asked by a newspaper reporter, several years ago, who was doing a story on genetic testing. And I have, part of my story is I have five grandparents who died of some form of dementia or another. Alzheimer's, vascular dementia, and Dementia with Lewy Bodies. So I, in fact, am only genetically related to one of those people. And it was the one who had vascular dementia. And that is quite easily traceable to lifestyle.*

Jamie: Yes, it is.

Christy: *But my quick, easy, super easy answer was, "No." And my reasoning behind that is because of the type of work that I do, I--and my mom's a nurse, and so I started going into long-term care communities probably when I was, you know, like seven, eight years old, because that was part of the programming at the time, was bring your kids to work during the summer.*

So, I have been aware of dementia for most of my life and I have been aware of what long-term care looks like. And I started off working in long-term care and I've done this work for so long and of course had people impacted in my family. So not just the five grandparents, but I actually have nine experiences within my own family, including those five. And I've worked with probably over 1,500 people living with dementia. It's probably closer to 2,000 at this point.

But my point being, to me, genetic testing would seem entirely superfluous. Number one, I don't have biological children. That's one thing, and that may change everything. I would assume that would change everything in my life. I just don't know what all those everythings are. So that's my disclaimer right there.

The second thing though, and most present for me on this issue in the life that I have, is I feel like I have a very good understanding of how people living with dementia are treated, where things in the system, however you want to define that, work well; where the wheels completely fall off the bus.

And so as much as I love doing the work that I do, there is always some extraordinarily selfish part of it, where everything that I am doing, all the time, is trying to make the world a place where, if this is what is in my future, that I will be treated in a way that's okay, that I will be treated with respect, kindness, love, empathy and compassion.

And so I, you know, God bless the researchers. I really appreciate the work that they do and I'm all for a cure. My conscious choice about 15 years ago was the best way that I can serve, and my purpose for being on the planet, is to take care--in the way that I do it; not in direct, hands-on care, because I don't do that. But to take care of the people who are living with dementia right now. And their families. And the professionals who support them. So I'm kind of like the support staff for people who are having the experience right now.

Jamie: *What a beautiful purpose to have, really. I mean, the impact. And I think that's something that we're really understanding now, is that it's really the behavior of us in relationship to our person.*

Christy: *Right. And so, you know, as important as the cure is, to me, here's the superpower. This is the super power right here. This is why I have the best job on the planet. Because somebody living with dementia can be upset, can be anxious, and I can step into that moment with them.*

Meet them where they are right there, manipulate that reality. Let them know, I've got you right now. You're safe. I'm on your side. I'm on your team. And help them feel safe, secure and loved. And when you can take somebody from a state of high anxiety to a place where they can exhale? I don't know what better job there is. If there is one, I don't know what it is. That's it, right there.

Jamie: *Talk about God's work. I mean, that is amazing. And it's so true. It is so true. And you know, I get caught up in looking into the future but yet it's the here and now I have with my family.*

But it is very important, the work that you're doing. And I've seen it, and I've seen it happening. I mean, I've seen before my eyes, what you share with everybody, that you can make a very beautiful, connected moment at that moment.

Christy: *Absolutely. And really what does life come down to, other than a series of moments? That's really all we have. We have no idea. You know, I don't know if I'm going to make it to dinner. I assume I am, because I have experience saying I will.*

But you know, there's gonna come a day when that won't be true. I think for me, this is, you know, like part of my life lesson, like a recurring theme in my life, because I love to look around the corner. And I help people put plans together for looking around the corner and figuring out what are you going to do when X, Y and Z happens.

But it is extraordinarily important for me to slow down, to be in a moment and to appreciate the moment. And just one little example is [when] I got on that cruise ship [for the Inaugural Connecting Circles of Care & Building Bridges of Hope Dementia Cruise & Conference], walked into the reception area. I'm an introvert by nature. Looked around, saw a bunch of people I didn't know, and would have happily turned around and walked out the other direction.

The only reason I didn't is because I knew by virtue of the fact that I was there for a dementia cruise and conference, that there were people living with dementia in that room. Which meant I was going to have a comfort level, because I genuinely like hanging out with people living with dementia. And they can tell. Whether they can verbalize it or not, they feel it--

Jamie: They do.

Christy: *--which means I'm then in a fantastic feedback, right. Because we all like to be around people who like us. So again, it's very selfish. So I thought, okay, maybe I'll have an entree that way. And I looked around and I didn't see anybody, and then there was this guy like right there, and I was like, Okay, he looks friendly, nonthreatening, cool.*

And there were three empty seats by him and I said, "Can I sit here? Is that okay?"

And he said, "Oh, sure." And then I'm thinking, Okay, what's the next thing, Christy? Okay, "Hi, I'm Christy," you know?

And he's like, "Hi, I'm Phil." And I said, "I'm kind of an introvert," and he's like, "Me, too." And then boom, it was on and cracking. And so I was like, Whew!

But you know, I would have completely missed that if I hadn't been like, Okay, this is something that doesn't feel natural to me. This feels kind of scary. It's a room full of people I don't know. Just one moment to the next. That's all you gotta do, is just one moment to the next. And then look at the--I mean, talk about a pot of gold at the end of the rainbow. There was Phil! That's how I met Phil.

Jamie: I love Phil! Phil is such a great guy.

Christy: *I love Phil, too. He's fantastic.*

Jamie: He is.

Christy: *And a couple of moments later, his husband Tim up and Tim is amazing. That guy's got just a massive heart and a soothing presence and a DJ voice. So I met great people, but for me, just that being in the moment is really important and kind of trying to keep it reined in to be in the moment and appreciate what's what's right in front of me and what's happening in this moment is--it's important, because we don't get it back.*

Jamie: No. No, we don't.

Christy: *So, that was a super long-winded answer to your very simple question!*

Jamie: But that's okay; I loved it.

Christy: *Jamie, thank you so very much for your time. You've been so incredibly generous with it; we really appreciate it.*

Jamie: Thank you, Christy. You have a beautiful day.

Christy: *And that's our show. Thank you so very much for being with us today. Links to resources or programs mentioned in this episode are in the show notes at DementiaSherpa.com/Episode104.*

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.