

Episode 086: How Frontotemporal Degeneration (FTD) is Different than Alzheimer's

Christy Turner: I'm very pleased to have a special guest today, Deborah Dolan, who is a volunteer with [the Association for Frontotemporal Degeneration](#). She is a retired professional and also was the spouse, the care partner, of a person living with frontotemporal degeneration. Welcome, Deborah.

Deborah Dolan: Thank you, Christy. I'm very happy to be here.

Christy Turner: I'm thrilled to have you, for many reasons. Number one, because there is a big national conference coming up in May. That will be, actually, May 3rd in Los Angeles, and there is still time to register for that. So I will put that link in the show notes and that is the [National Conference](#) for the Association of Frontotemporal Degeneration. And number two, and more important, I think, to everybody who's listening, whether Los Angeles is a possibility for them or not--so often, we use the broad term of dementia and I have found that people still are really kind of confused about what frontotemporal degeneration is and how that fits in with dementia. And folks are often confused about Alzheimer's and how does this all fit together. So today we're definitely going to have a chance to demystify a bunch of stuff, debunk, maybe, rumors that you've heard and get down to the straight scoop on what frontotemporal degeneration is. And you may know it as frontotemporal dementia. You may have heard that term before, or FTD, but it is frontotemporal dementia. And I'm going to turn it over to Deborah to explain more about that.

Deborah Dolan: Thank you, Christy. I think one of the things that I have realized early on, in test diagnosis, my husband's diagnosis, is that people weren't sure if dementia was the illness in and of itself or you know, just exactly where FTD fit in the whole scope of things. So I'd just like to clarify in the beginning that dementia is really a condition of the mind that's caused by a disease of the brain. Okay? So under dementia there are many different types of diseases of which frontotemporal degeneration is one of those. So that's one of those, I've had people say, well everything's Alzheimer's disease. No, Alzheimer's disease is just diagnosed most often. In fact, at the time that my husband was diagnosed in 2011, I was in Minneapolis, we were living in Minneapolis and no one, none of the doctors in the Minneapolis area, were very familiar with FTD at all. So, we ended--

Christy Turner: How many years ago was that, Deborah?

Deborah Dolan: 2011.

Christy Turner: So not that long. I mean, that's just eight years ago.

- Deborah Dolan: Correct.
- Christy Turner: And there is, unfortunately, there have not been massive medical advances. So just eight years ago, you would think that medical professionals would be familiar with frontotemporal degeneration and yet, not so much.
- Deborah Dolan: Right. It was just hitting the radar. Even at [Mayo Clinic](#), it was just hitting the radar. But let's talk a little bit about what FTD is and then, you know, if you want more specifics we can certainly go back to my experience along the way, you know, with my husband. I think, how I think how it differs from Alzheimer's is really important. I was a, a group facilitator for the [Alzheimer's Association](#) for eight years in Minneapolis. And in that--before my husband was diagnosed--and in that eight years, Christy, no one ever mentioned FTD. There were other forms of dementia that were mentioned, possibly like normal pressure hydrocephalus, Parkinsonian, but never FTD.
- Deborah Dolan: So when my husband was diagnosed, I was as new to it as everyone else was, especially because my husband was 59 years old at the very onset of symptoms. And that's the nature of FTD. It's really marked by a younger onset. I think it was oftentimes misdiagnosed as young onset Alzheimer's. And then as they, the physicians, researchers, started saying, you know what, this is affecting, this looks different. It's affecting a different part of the brain and basically memory [loss] with Alzheimer's, you know, is prevalent. Memory [loss] is not a typical symptom in the early stages of FTD.
- Christy Turner: That's a really key distinction and one that folks should really be aware of. So if a physician is giving a diagnosis of Alzheimer's or vascular dementia or early onset Alzheimer's, what have you, and you're noticing that there are definitely changes, but memory [loss] doesn't seem to be the chief concern, that's a good cue to keep going down that path toward an accurate diagnosis. And along those lines, Deborah, what, what shifted in order for your husband to get an accurate diagnosis?
- Deborah Dolan: Um, actually I said to, um, he was being seen by his endocrinologist, uh, for hyperthyroidism, which is something that is oftentimes, you know, part of the diagnosis process, looking at the thyroid and other issues that would cause behavioral changes. Um, and um, when the thyroid was finally back in its normal realm. I said to the endocrinologist, "Are any of these changes in his personality, in Todd's personality, uh, related to hyperthyroidism?" And the endocrinologist said no. And this is where my

training really came into being helpful, because I went right back, we went right back to his primary care doctor and I said, "You know what, we need some neuropsych testing because this person is not my husband and not the man that I've been married to for 20 some years. So we need to get to the bottom of it. " And for that, I'm very grateful for my education and my training because otherwise, I don't know where we would have been in 2010 and 2011. It would have been a difficult road.

Christy Turner: Right. So what was the gap between the original diagnosis of early onset and the correct diagnosis?

Deborah Dolan: Uh, what was the shift?

Christy Turner: How long did it take you to, how long did it take you to get that correct diagnosis?

Deborah Dolan: Um, once, I'm going to say five years.

Christy Turner: Oh my gosh!

Deborah Dolan: And that's not unusual. It sometimes takes three to seven years to get the correct diagnosis. I think it is a little bit faster today than it was back in 2011 because it's just like, it was described as a, a psychiatrist, I believe, is putting a large amount of rocks on the table. You've heard this comparison or metaphor--and then removing all the rocks that weren't applicable. And in the end, the last rock on the table is the diagnosis. And so they, it's a process of elimination. The primary variants of FTD are found in behavior and in language and or motor skills. Okay? So Todd's, um, certainly his, his behavior was changing. He was very apathetic, didn't want to talk to me about anything as far as, you know, the future, retirement, grandchildren, anything such as that. His language was changing. He was not nearly as well spoken and he certainly couldn't track sometimes what I was saying to him. And I thought, this is just strange, you know. And motor changes, he didn't have any real, you know, a stumbling or tripping and falling, anything like that. What he had was his motorcycle he rode. He could no longer shift it into first gear. And so that's a sequential act that you know, is, mind and feet. And, um, he started having trouble with his motorcycle to the point where, um, I refused to ride with him anymore because I was scared.

Deborah Dolan: So that's, you know, what kind of took place along the way over the five years. And we're saying, you know, changes in behavior, very apathetic, changes in his abilities, changes in language and um, certainly, um,

because he's in sales, change in language certainly meant change in income level.

Christy Turner: Oh yeah.

Deborah Dolan: Then so when you put all those symptoms together, you go, "Wait a minute. There's something drastically wrong." FTD, especially variant, behavioral variant, is oftentimes misdiagnosed as a midlife crisis, or other type of behavioral issue. That is really unfortunate, because it creates a lot of of sadness as well as working with them, the disease.

Christy Turner: So what would you--I think your story, and thank you so much for sharing it, is definitely one of persistence and going, "Wait a minute, this doesn't seem right." And as you mentioned, your professional training really helped you understand that and know that. What advice would you give to people who are listening right now going, "You know, I've wondered about this diagnosis that my person has. That just didn't seem right. I know somebody else with Alzheimer's, I know a few other people with Alzheimer's, and I've read about Alzheimer's, and this just doesn't seem like that." What would you advise them to do as far as pursuing a correct diagnosis?

Deborah Dolan: Well, [I would certainly try to educate myself](#). That's one of the things that I always tried to do. And going to the AFTD website, going to the Alzheimer's Association website, will give you [symptoms that you can look for in your loved one's possible dementia](#). Other than that, I think talking with your family physician, being a really strong, good advocate. Making good notes of the changes of behavior. That's what the primary care physician really needs to hear. And then if you're referred on to a neurologist, which is what I would ask for, to take those same notes and say, "These are the behaviors, and we're not just looking at memory loss. In fact, my husband or my wife has very little memory loss. My loved one has little memory loss. So it is, you know, what else could it be?" Because there are over a hundred as I understand, different forms of dementia that have been found today. So there's a whole lot of dementias to look at, the primary, three being Alzheimer's and [Lewy Body](#) and FTD at this point in time.

Christy Turner: Yeah, excellent advice. [I would strongly encourage people to keep a notebook](#). Um, even though we as primary care partners do not have cognitive impairment, often getting into an appointment, especially when you've been waiting and waiting for [it], you can get tongue-tied or the thoughts fly out of your mind, and it is so helpful, as you mentioned, to

have those notes right there. Like, "Here is the actual evidence of what I'm witnessing. Here's the log."

Deborah Dolan: Right. And those thoughts do fly--even the most crucial moment in time--that memory will fly out of your mind because you've had 50 since then, or you've had 20 since then.

Christy Turner: Right.

Deborah Dolan: Then, another thing that I like to do is before I go to, went to, a doctor's appointment with Todd, um, I would sit down and I would make notes for the doctor to review. Hopefully before he actually saw Todd; oftentimes the day of they would read it while, you know, we were in the appointment. So that things that, changes that I'd seen in Todd, whether it [was] behavior, language, whatever it happens to be, in his abilities, in his recognition of what's--his insights, let's use that word. That's the best word. His insight into what was happening around him. Um, and with that information, I think it put the primary care physician on the right path, seeing this as a neurological disorder that we needed to investigate further. Yeah. So that letter is important, each and every time.

Christy Turner: Absolutely. Absolutely. So, for folks who are driving or in the gym right now listening to this, no worries. We're gonna get links to all of the resources that we've talked about so far and whatever else we will talk about during this episode in [the show notes](#) so you can go back and look up these resources. Another thing that I wanted to ask you about, Deborah, is based on your professional experience then versus your personal experience, would you say that there are significant differences for care partners of people living with Alzheimer's versus living with frontotemporal degeneration?

Deborah Dolan: Yes. And I would say that probably the most glaring difference is the age of onset. Um, you know, the typical age of onset is somewhere between 45 and 65 years of age. It can run from 21 to 80, but the average age of onset is between 45 and 65. And so, as I said, my husband's, his symptoms were at age 59. That is peak earning years. You know, you may have a young children in your home, or college aged children. Um, we happened to have grandchildren who--our home was like a revolving door, every weekend somebody was there to spend the night. And it was wonderful and then Grandpa didn't want it anymore. Um, so, you know, I think it really hits hard when you are a spouse or a care partner in any capacity because it's younger onset. You don't think of dementia. You think of dementia with someone who is elderly.

Deborah Dolan: We think our grandparents because, um, that's what Alzheimer's is. You know, you get older and the chances of you getting Alzheimer's increases. But this kind of sneaks up on you. Because it is young onset, and that's the biggest difference right there. And people need help. [They need to figure out their money](#). They need to figure out insurance, [they need to figure out doctors](#) and they need to figure out [who's going to support them](#), the care partner, you know, during this journey, because it's not short. It's a fairly, usually a fairly long, oftentimes a very long journey.

Christy Turner: Yeah. Talk about that a little bit, would you? Because I think that often--well, hopefully not as often as I'm thinking of--but too frequently, I'll say that, I see families who sort of adopt the, "I'm going to grit my teeth and suck it up and just get through this" [mentality]. And I often equate it to trying to sprint through a marathon, which is great for getting yourself injured, but not useful for completing the marathon. You just get hurt in the process. So can you speak to the typical period of time and, and then circle back as to all of the supports, where you mentioned people need help, how they would access that help?

Deborah Dolan: You bet. And the mean duration, or the average duration, of the disease is anywhere from seven to 13 years after diagnosis. So my husband's went from 2006 to 2017, from symptom, not from diagnoses, but from first symptoms. And those first five years, I would say we're probably every bit as hard as the next few years, you know, during the disease. So, um, finding a support system as soon as you possibly can, for you and for your loved one, becomes really, really important because of the long duration. For me personally, we had, because of the profession I was in, we had bought long-term care insurance, and that was a blessing in the fact that Todd, um, I was also caring for my mother who had age-related dementia and my father was 90 and so they were all ready in an assisted living community.

Deborah Dolan: And so probably sooner than what a lot of families would have, I moved Todd into an assisted living community. And not everybody was happy with, you know, my decision to do that. But I had to keep our insurance going. I had to keep money rolling in. My job was a 24/7 one. And um, I, I couldn't do it with Todd. Um, you know, I couldn't leave him by himself. He loved the assisted living apartment. The first 24 hours, he loved it. And I really believe, Christy, it was because his world became easier for him to organize and comprehend, because it was smaller. Yeah. People coming in and out, you know, his routine was the same day in and day out and he really thrived, uh, for more than a year there, um, before he actually started wandering. And when it was very cold outside.

Deborah Dolan: But so, you know, um, doing, figuring out--whether it's a popular decision or not--what is most important for you, in order to be able to maintain your life is, um, certainly very, very important. Um, maybe you have, if it's younger onset, maybe your, your partners parents or siblings or someone that lived nearby, even your adult children or college age children, older children can certainly help you. As long as they understand what's happening, and what's at risk. And that's Dad's safety or mom's safety, you know, the loved one's safety. Um, and then from there I really worked on, "Who do I want to be in this equation?" And I wanted to be his wife. I wanted to be Todd's wife. And so that's how I approached caregiving. And that was an important decision for me because I was able to maintain my job, like being a grandparent, being a daughter, and being Todd's wife at the same time.

Christy Turner: I'm really glad that you mentioned that, because that is so huge. And especially for professionals, I think. Um, you know, we're so good at what we do professionally, sometimes we need to take that step back and make that conscious decision of, "How am I going to navigate through this?" And I think it's always different when it's your own family.

Deborah Dolan: Oh, very definitely!

Christy Turner: I mean I, obviously, yeah, it's not that you don't care about your clients, um, but it is very different when it's your own family. And--did you use another professional?

Deborah Dolan: To navigate through the system?

Christy Turner: Uh huh.

Deborah Dolan: Um, not, not really. Well, I'm not going to say that, because I did. I have a very good friend who own several memory care residential communities or homes. And I oftentimes would call her and just say, you know, "This is what I'm thinking. Do you think it's the right thing to do? You have other thoughts around it?" Yes, I didn't employ them, but I certainly leaned on my colleagues within the elder care community in Minneapolis, which we happen to have a very large, very well organized community in the Twin Cities, which was very fortunate for me. Oh yeah, I did, certainly to that degree. But you know what else I used was just, uh, my, um, and I'm going to say this politely--I hope we can say this--my gut. You know, what was the right thing to do? What would I do for another family member? What would I do for a client? Is this the same thing that I want to do for Todd? And I have to say it was a little more emotional with Todd, and

more emotional with my mother, because I love them, because they were part of my life. But at the same time, I was able to get past that emotionally and get to the common sense of my gut: "This is the right thing for Todd's dignity. This is the right thing for Todd's well-being. And this is the right thing for your well-being." That's really important, because you can't just like you, the metaphor, the marathon, you can't reach the end. If you get tripped up and beat up, you know, at the beginning of the race, you're not going to make it to the end.

Christy Turner: Absolutely true. And I wish that it was a smaller group of care partners that have both a spouse and a parent that's affected. But I think it's actually a fairly significant chunk of care partners. That's a lot to juggle. Even just one person, really, you know, loving one person who's living with some type of neurocognitive condition is tough. Um, and then when you, you add in multiple people to that, and the different roles too, right, being a daughter versus being a wife.

Deborah Dolan: Right. Exactly. Yeah. My friend used to say, "Man, you, you switched those caps out quick. You got on the wife hat. Now you've got on the daughter hat." So sometimes my head's spinning with that.

Christy Turner: I bet.

Deborah Dolan: But life, life went on. During Todd's progression of the disease, we had a grandchild who was diagnosed with type one diabetes, and then all of a sudden Grandma's giving shots. You know, there are a lot of things Grandma didn't know she was going to be doing. And then later on, we had another grandson who was diagnosed with cancer and he survived. And he's in college and doing well today, but a lot went on. You can't cut off the rest of your life, especially when you're younger. The work, the family, the extended family, the people that you love, your friends too. So, um, it is very important to make an assessment that doesn't just look at the dignity and well-being of your loved one, but at the dignity and well-being of yourself as well. So that you can come out at the other side of this, at the end of that marathon, and you're still whole.

Christy Turner: I'm so glad that you're talking about this, Deborah, because I think so often, that's a piece of it that gets lost. And I don't know, I think as professionals, I think we're getting better at including families, but I think historically, we've kind of sucked at that: where the focus is entirely on the person with the diagnosis. Which makes sense. Of course we need them to be safe and well cared for and, and have a max quality of life. But one question that I often ask families is, "If you don't have a plan for

yourself, if something happens to you, if you go down, what happens to your person?"

Deborah Dolan: Yeah.

Christy Turner: And that often is the kind of little jolt that people need to hear in order to go, "Oh...yeah...." I always tell families, "You're kind of a big deal. Like, you're the center of the universe, you're the ring master. Um, and it's okay to have assistance. That's totally fine."

Deborah Dolan: Yes, and you need to educate your family. You need to educate people around you: what's happening, what you're experiencing, what your days are like, what your nights are like, so that they can really be empathetic as well. Because without that conversation, the empathy may or may not develop.

Christy Turner: I think that's a great point too. And I find that most folks really, genuinely want to be helpful, but when they feel like they're kind of operating in the dark, and don't really have any direction, aren't sure what to do, that's when people will shy away, rather than stepping up.

Deborah Dolan: Mm hmm, if we don't tell people what we need, they can't read our minds.

Christy Turner: Oh, thank you. Thank you. Thank you. Yes. I know a lot of times families get really stuck in that, "But my sister should know!" or "My son should see!" Yeah, you're right. They should, but they don't. That's not a super power they have. So we're going to have to give them a clue. We're going to have to help them out, shine a light on kind of what it is that we need and that will be supportive. So is there anything in particular that you found was really useful for you as a care partner?

Deborah Dolan: Besides AFTD?

Christy Turner: That would be kind of the centerpiece, right there?

Deborah Dolan: Yeah, because really the Association, uh, really became the source of my education. It became the source of my support. It became the support or the, you know, education awareness, um, advocacy. They really were there when I needed them, either to call the 800 number [[HelpLine: 1-866-507-7222](tel:1-866-507-7222)], 24/7, to talk with someone when you know, that hamster gets on the wheel in your mind and it goes around and around and you feel desperate and you can't get it to stop?

Christy Turner: Right!

Deborah Dolan: And it's always at 2:00 AM, Christy. Or when you just feel lost. And I think, I think the times that I really felt lost was when I would get started thinking about this is [a progressive, degenerative, terminal disease](#). Oh my goodness. Aren't they ever going to find an answer to this dreaded, awful disease? And so understanding the research and doing what we can through the registry, um, [the AFTD registry](#) where anybody can sign up and give their input as a caregiver, as a person with the disease, um, as a professional, um, so that we learn more and more and more about the symptoms of the disease. And going to the conference, which is coming up here, as you said, you know, May 3rd. I always gleaned a lot of information from the stories of others as well as from, um, the research. Didn't always understand it, the big words, but the researchers that spoke and the healthcare professionals that spoke, I think that they gave me a lot, but you know what, I walked away feeling, "You know what, I give them some information as well, because I'm the reality." I'm one piece of the reality of this disease.

Christy Turner: And that is so huge. So you still work with the AFTD now, today?

Deborah Dolan: I do. I do.

Christy Turner: And what do you do?

Deborah Dolan: I speak every time I can find a forum to speak, a soapbox to stand on. And that's what I do most often. Um, two years ago, um, well my mother passed in 2015, my dad in 2016 and then I knew when those dominoes started falling that they were going to tumble quickly. And I moved from Minneapolis back to my roots in Iowa, to be close to my daughter. And because I really knew that I was going to need her, a very physical presence as we, you know, headed down the last part of this journey with Todd. So, when I arrived here, I stopped facilitating a support group. I was really pouring all of my efforts into advocacy for Todd within the healthcare environment where he was. Because caregivers don't necessarily know, well and it's, there's a new behavior every day just about, they, they can't be there 24/7 and recognize everything that's associated with FTD. I couldn't either, but between the two of us, the partnering of the caregivers at the facility and myself, then I could advocate for Todd's well-being to the highest degree.

Deborah Dolan: And that gave me satisfaction. And it gave me hope that he was in a good place, you know, as best as he could be. And as soon Todd passed away, I

was on the phone with AFTD, and I was on the phone with the Alzheimer's Association here, and I said, I'm yours. Let's go out and educate and bring awareness to FTD, as well as other dementias along the way, you know, you can't talk about FTD in isolation. So that's what I primarily do for the Association, is anytime a speaking engagement comes up, anytime that I can fill in somewhere for a facilitator, a group facilitator, I'm happy to do that.

Christy Turner: That's awesome. Thank you so much for continuing to share what you've learned and the lessons you've picked up along the way to inspire and encourage others. That's huge.

Deborah Dolan: Thank you, Christy. I think one of the things I am oftentimes asked is, "How did you get okay with it [with my husband's disease]?" I was never okay with it. Um, I'm not okay with me getting old either, but I can't do anything about that, either. So, uh, what can I do? I can accept, I can educate, and I can give a voice where people can't, you know, they don't have their own voice to be able to say how they're feeling, what they need, uh, what we can do to make their life journey the best it can be. And so that's my goal. And, um, my forum is AFTD and my forum is the Association, the Alzheimer's Association. Here. We don't have a local chapter here of a FTD. We have one support group in Des Moines, Iowa. So, but it's going. We're getting a lot more recognition by, by doctors here, um, and able to diagnose FTD.

Christy Turner: Wonderful. So you're speaking at the conference. What is your topic?

Deborah Dolan: I'm not speaking at that conference in Los Angeles.

Christy Turner: Whaaat?!

Deborah Dolan: You know why? Because I'm going to be in Italy. I have a milestone birthday this year, at the end of April. And um, one of the, uh, guest I'm Todd gave me gifts every year. He just may not have always known what gifts he was giving me for my birthday and for Christmas, but I always had something under the tree or on my birthday from Todd. It really did help. Um, and this year he's giving me a trip to Italy on my milestone birthday, so I won't be in Los Angeles. And I'm very sorry to say that. Um, I know that there are many wonderful speakers there, including, I think our keynote speaker. I'm really interested in hearing her story because I'm a long time soap opera watcher. I love "Days of Our Lives." And Martha Madison, who is, her role is Belle Black on "Days of Our Lives." Her mother, Barbara, has been living with the behavioral variant of FTD since 2008. And so, um, Martha has become a spokesperson for FTD and um,

she has, uh, a big voice. She has a big audience, so that's wonderful. Um, she will be our keynote speaker, but then we also have multidisciplinary panel discussions going on with, professionals, people living with FTD, care partners. They're focusing on the, you know, the three areas that we have to focus on. One is research. We've got to find some way of treating this disease. Or stopping it. Care, you know, how do we best care for our loved ones? Like I said, I was blessed with long-term care insurance. Um, I don't know where I would be today if, you know, if I, well I, my life would not have been the same. I would have had to bring my children in. And, you know, done less, probably, for my mom and dad. And then support, where do people find support, especially in the rural economies, you know, the rural areas.

Deborah Dolan: It's one thing to be part of a big city in a, in a big medical group, but you get out into the rural areas and there isn't the support to offer to families either medically or, you know, just um, emotionally. So those are some of our speakers. Those are some of, I digress and I apologize for that, but it's always something new there to talk about. Let's see what else. We have Mario Mendez, who is the director of neurobehavioral, behavior, excuse me, at the Veterans Administration in Greater Los Angeles. And he's also a professor of neurology and psychiatry, um, at, um, UCLA. And we are seeing, you know, PTSD and um, FTD may have some links there. And that's something that they're starting to talk about. Um, so by him working at the VA and he sees a lot of our veterans that are coming back and develop FTD, whether it's part of their PTSD or not.

Deborah Dolan: Uh, we have an, I'm just gonna slaughter her name, and I apologize. Kimiko Domoto-Reilly. She's an assistant professor of neurology at the University of Washington School of Medicine. And we have Mary Guerriero Austrom, who is a professor, as well, at the Indiana University School of Medicine. And then Jamie Fong, who is a genetic counselor. And I want to say, if I can just take a second to talk about the genetics part of it, of FTD, because when Todd was diagnosed and his sister was with me during the conference that we, a couple of early conferences that we went to at the Mayo Clinic, they were talking about FTD but not being very, uh, genetically connected or familial connected. Well, that has changed, um, over the last few years and now they're, the percentage is about 40%.

Christy Turner: Wow!

Deborah Dolan: Yeah, people with a neurodegenerative disease have some form of family history of it. And so, um, that's, that's a scary, that's a pretty scary high or a high percentage.

Christy Turner: So that's very significant.

Deborah Dolan: Yeah, the genetics of it is very important and that's part of what that FTD registry, uh, is helping to develop as well as understanding, you know, the family lines up itself. So I think that describes our conference and I can say that I just received an email this afternoon that they're talking about live streaming the conference. So with people, some of your audience can't quite get to um, to Los Angeles, they, FTD is looking at, AFTD, excuse me, is looking at live streaming some of the conference and I would certainly watch their website, um, to learn more about being there without, you know, physically being there. At least being able to listen and to, um, you know, some speakers and some of the discussion panels and what have you. That'll be very helpful.

Speaker 2: Absolutely. And so in addition to all of the speakers that you mentioned, the big shots, there will also be breakout conferences, or breakout sessions, within the conference. And I am speaking with, shoot, I can't remember Mary Ann's last name and she's a very big deal. I can't believe I get to share the stage with her, but I will be sharing the stage with her during one of the breakout sessions and I'm so pleased and honored to be asked to work with the AFTD support group facilitators the day before the conference starts. So, that's all very exciting. I am so looking forward to being there. My only beef with this conference--and it's a beef I have at pretty much every conference I go to: Why, why must sessions be concurrent? Can't we make it a marathon conference? I always want to hear everybody. I want all the knowledge. I want the whole experience. But so, so the live streaming would be fantastic if that does happen. Hopefully that will give people the opportunity to see things that maybe they're not able to catch, either in person or because they're in a different session. I will say though, for those who are able to attend in person, I would strongly encourage you to do that. Number one, this is probably the most affordable conference I think I've ever seen. Seriously. It is amazing. I about fell out of my chair when I saw the registration fee. I was like, "Really?!" Um, and then number two, number two is you always, as a participant, you get such a different experience when an event is live versus when you're watching something in a livestream or you know, some video later. And it's not that the content isn't still great, it absolutely is.

Christy Turner: But, um, as a care partner coming into a conference, being around the energy of all the, all these other people who are also care partners, who know exactly what you're going through, who can completely empathize with your experience. And then in a conference like this, which is going to

have just a bunch of professionals also, to just be surrounded by the love. You know, we are there to support you and to offer our knowledge and again, in an effort to support you and to make life as great as it can be for you and your person. So when you're not able to attend a live event, you miss all of that yummy energy headed your way, or as I call it, the Good Stuff. Respect, kindness, love, empathy and compassion. And, and that's just one of the massive benefits. Plus, you get to actually know people and you know, make some friends and really important stuff. So I would encourage everybody who could possibly be there to come on to the conference in Los Angeles. That is on Friday, May 3rd, and [a link for the registration](#) is going to be in the show notes. Any final thoughts?

Deborah Dolan: I just want to say, I apologize for not getting to the breakout sessions, 'cause you were down here in my notes and I was--

Christy Turner: Oh, that's okay.

Deborah Dolan: From, we are professional, but, um, but at the same time, you know, we're not the doctor who's only looking at the disease. We're looking at the big picture. That's what I always tell families. You know, there's so much more going on than just the disease itself and you need help in every way. And if you are a seasoned partner, one of the things that you can do, especially at this conference, is to introduce yourself to the person you're sitting next to in some of these sessions. Last year I was in Chicago and, I had this lovely lady sitting next to me, and she was young and she appeared to be alone. And I introduced myself to her and just gave her a little bit, a little snippet of my story and she just deflated like a balloon. And she said, "I am so happy to meet someone who's walked this journey because I feel so alone." Her husband had just been recently diagnosed. And so, you know, um, don't be afraid if you're there at the, at the, um, conference to reach out and especially, you know, if you're so inclined, if you're an introvert, that's okay too. But, um, to bring your story. It brings hope and, uh, it brings, um, a support that can't even be defined by you, because it's really coming from the other person's eyes and perspective.

Speaker 2: That is so true and so important. And introverts, it's okay. You don't have to say a whole lot. Even just making eye contact, even a half smile, can be a really big deal. I personally, if I'm on stage, if I'm the speaker, uh, it's like I have a different personality 'cause I'm like a ham bone. But in real life, in real life, I am quite introverted and I remember several years ago, it was probably about 10 years ago now, um, I had just come off stage and the talk was well received but I just was kind of making a beeline for the bathroom because I hadn't done that before I got up on stage. And

this lady, I kind of caught her eye, you know, and she said that was, that was good, and I just had this sense, like I needed to stop. And that was all she said, was that, "That was good." And I said, "Oh, thank you so much." And then she, she said, "My husband has Alzheimer's," and she was young. She was probably like 45. And I said, "Oh my gosh, I am so sorry to hear that." And she burst into tears and grabbed my hand, squeezed it and said, "You're the first person who's ever said that to me." And, you know, that's just one of those things that anytime somebody tells me, you know, they have a person in their life with the diagnosis, I always say that. And it's genuine. I do mean it. But that's the first time I ever heard that response. And so I was just so glad that I just took that moment to connect with her because it, it meant something to her, you know? And, and the release of tears is always good too. I know sometimes people are afraid to interact with other care partners because they're afraid that they will start crying. And you know, tears look different under the microscope. Those tears of sadness or anger or frustration, they look different under the microscope than the tears we cry when we're watching people we love get married, or when there's a new grandbaby in the family, those happy tears. And, and the sad tears and angry tears and frustrated tears are ugly under the microscope. That's why it's called an ugly cry. So get those things out of your eyeballs. You don't need those in your eyeballs. It's okay to cry. It's okay to be genuine. It's okay to be who you are because you are going to be surrounded by people who get it and are there to support you. So that's, that's my pitch and appeal for, "Please come to the conference. We want you there!"

Deborah Dolan:

Absolutely. And along that line, what I heard when you were telling that story is it may have been the moment when that lady accepted not only her husband's illness, but also the fact that she was overwhelmed. And I have a friend, after Todd was diagnosed, that said, "How are you doing, Deb?" And I said, "You know, I think I'm doing better." And she said, "What made the difference?" And I said, "Acceptance. Acceptance, that this is our life journey. Not one I chose. Not one I would have signed up for voluntarily, but it is our life journey and now I have to figure out how to walk it with the greatest amount of dignity and love that I can muster up. And a part of that is accepting that I'm not going to be perfect and sometimes I'm going to feel really sorry for myself." And I did, and I still do sometimes today. I absolutely do, wishing that my husband was going with me on this trip to Italy. He'll be with me, but just in a different way. Yeah. Yeah. So that's what I would say. And I concur with your appeal for people to be able to come or to, you know, um, take the time to go to the conference if there's one, if it can't go to La Watch every year, there's a conference about this time for AFTD, or sponsored by AFTD. It's very affordable and it is worth every minute that you spend there.

Christy Turner: I haven't even done it yet and I already agree. I think it's absolutely going to be. And so we're going to put the link in the show notes so you can go there. Check out the agenda because they've offered the full conference agenda there so you can see exactly who's speaking and what they're talking about. And all of the opportunities you'll have throughout the day during the conference. And you can go ahead and register too. So Deborah, thank you so very much for coming on. To my recollection, I don't think that we have ever talked specifically, or had an episode specifically about FTD here on The Alzheimer's Podcast. Uh, which makes sense, right? 'Cause it's called The Alzheimer's Podcast. And I do think that people, you know, they find The Alzheimer's Podcast and are interested in lots of different things. They may not even have a loved one--I think often they don't have a loved one who has that diagnosis of Alzheimer's, but it's maybe the closest thing they could find that they think might be helpful. So I would love for you to come back with us and continue sharing information about frontotemporal degeneration as often as I can get you to come back as a guest. I would love for you to do that.

Deborah Dolan: Thank you, Christy. I would be honored to return.