



## Alzheimer's disease, the story of two families

**Danielle:** I think seeing my mom go through breast cancer and seeing all of her friends come out of the woodwork to support that and be around to help and cook dinner and come and visit and talk about it and seeing her go through a diagnosis of Alzheimer's and seeing people not know how to react to that and shy away from that was probably one of the hardest things for me.

**Tom:** Deb's sisters in the early days tried to take her overnight or for a weekend or something and, well, what the problem was, Deb would just say, I don't understand. I'd rather be with you.

**Diane:** Welcome to the *Catching Health* podcast, where we talk about all things related to health, physical, mental, spiritual, emotional, you name it. We talk about it. I'm Diane Atwood, a former television health reporter who now produces the *Catching Health* blog and podcast. Today's topics are Alzheimer's disease and the annual walk to end Alzheimer's. Over the next two months, walks will be taking place in about 600 communities nationwide. They are hosted by the Alzheimer's Association to raise awareness and money for Alzheimer's care, support and research around the world. To give you a sense of where the money they raise goes much of it is for research. The association says it is currently investing more than \$250 million in more than 750 projects in 39 countries. One example of the research it invests in is the U. S. Pointer Study, which is a two-year clinical trial to evaluate whether lifestyle interventions that at the same time target many risk factors can also protect cognitive function in older adults who are at increased risk for cognitive decline. It's the first such study to be conducted in a large group of Americans across the United States. Funds raised also helps support families with services such as an online message board, a 24/ 7 helpline for information on referrals and support. The Alzheimer's Association also has a strong voice when it comes to supporting or opposing various pieces of legislation that may impact people with Alzheimer's or those who are caring for them. I have two guests with me today, Danielle Bernier and Tom O'Connor. Both know Alzheimer's disease intimately. Danielle helps care for her mother who has early onset Alzheimer's and Tom took care of his late wife who was diagnosed with Alzheimer's at the age of 60.

Danielle and Tom are both volunteers at the Alzheimer's Association here in Maine, and they will be walking in their communities. Tom is also a board member for the Maine chapter of the Alzheimer's Association. So, welcome Danielle and Tom, and thank you for being here, willing to share your stories. I know firsthand that caring for someone with Alzheimer's can be a very isolating and lonely experience, and by talking about your experiences, I know that you will provide a much-needed connection for many people.

So, I would like to start with you Danielle, because you are presently helping to care for your mother. I wonder if you would share a little bit about your mother's story and your story.

**Danielle:** Yeah. Thank you for having me my mom is 64 years old. Her name is Carol. She was diagnosed about six years ago with early onset Alzheimer's. Looking back there were signs before we got a diagnosis. It was hard to get a diagnosis for her. Living in rural Maine, it was hard to get the referrals that we needed to get to get her, to see some specialists. Ultimately, we ended up going to Boston and got her final diagnosis and we've been kind of dealing with that ever since. My dad is my mom's primary caregiver. He is almost 66. He retired at the age of 62 because Mom couldn't stay home alone anymore. So, when retirement came up for him, he was able to take it. It was hard watching my Mom kind of decline. She lost her speech very early on and her ability to communicate with us, and that was really hard. Back in 2018, she woke up one morning and she had struggled with diverticulitis which is infections that you get in your intestines. And she had woke up one morning with my dad and dad could tell she was in severe pain even though she wasn't able to communicate that to him and ended up taking her to the doctors, and she had emergency surgery where she had an infection that had gone through her intestine into her gut. And so my mom has a colostomy bag now. But when she came out of surgery, the way I think of it, we kind of never got her back. She did not come out of surgery very well. She became completely dependent for everything in her everyday life from eating to personal hygiene and dressing and all of that stuff. She spent almost a full three months in the hospital after surgery. We went home for two days and we ended up back in the hospital again. She had had what they essentially called like a psychosis, and we live in the mid-coast Maine region and our hospital just really wasn't able to deal with it, so we ended up down in Portland where the doctors were fabulous. Social workers were really good, and we were able to get Mom on the right medications to be able to go home. We weren't sure at that point if we were going to be able to bring her home or not, or if we were going to have to put her in a facility. So, we were able to bring her home and she is still home with my dad, who, again, he's her primary caregiver. We have some in-home help that she qualifies through some programs through the state. So, Dad has some help every day that he can rely on. I live probably five miles down the road from my parents so, I

stop in when I can. I'm married, I have three kids, they're eight, 10 and 12. So, we're busy with school and dance class and all of those fun things that come along with raising little kids. But one of my primary concerns, I like to make sure that I'm there for my dad if he needs anything. He knows that he can call me at any point in time, anytime during the day and if he needs something, I'll, whether it's leaving work, whether it's leaving home, I'll get there to do what I need to do for my dad. To help him through the caregiving process and being able to take care of my mom who requires 24/7 care. So, that's a little bit about our story and how that started, what we've been dealing with.

**Diane:** Wow, your dad must be exhausted.

**Danielle:** He is. My dad, I never knew I was related to Superman. So he is, he has really pulled through and he does a fabulous job with my mother.

**Diane:** Now some people might say, isn't she ready to perhaps go into a facility that cares for people with memory issues?

**Danielle:** She is at that point. Her doctors deem her what they call nursing home care status. So, if we needed to put her in a facility, we could. We prefer to keep her home. Dad prefers to keep her home. She's comfortable there. She does better there and while he's able to do it physically, then he wants to be able to do that. So, we try to stay away from the it's going to be a financial problem, a financial burden if, if we needed to. So, as long as he's able to and I have a brother, my brother and I kind of keep tabs on that if you would. We make sure that Dad's doing well. He's getting out when the caregivers are there and that he's able to go out and do things and hang out with his grandchildren and come up for dinner or play golf or whatever it is that he likes to do with his time. We really make sure that he does that for. COVID threw a loop in it. It made it a little more difficult to leave home, but he came up to our house, you know, he came up five miles down the road to have dinner on Friday nights. So, you know, we do what we can. That's our choice.

**Diane:** I have a ton of questions for you, but I'm thinking that your story probably resonates very strongly with Tom because Tom, you took care of your late wife much in the same way that Danielle's dad is taking care of her mother. Correct?

**Tom:** Yes, yes. Danielle, thank you for sharing that because it's also my experience a little bit different, and it's only a testimony to the fact that there's over a hundred different types of dementia. And several of my friends have had similar experiences to me and some have different experiences depending up on how the disease affects them. But my wife, we used to do, I still do Meals on Wheels in greater Portland on Christmas, and we were doing in Christmas of

2010. I was preparing the meals and Deb and three other friends were packing the meals according to 16 routes to be delivered. And I explained it to Deb about three times, but she just couldn't grasp it, and it was the first indication to me that we have a problem. And then through the first five months she was unable to do her work, her job. I was familiar with it, and I spent many hours on weekends and stuff, helping her get through. And I finally convinced her she had to take some time off, but the organization agreed, and they parted ways, which was fine. Then in September, she had a battery of tests through the summer and yeah, cause there's a 2011. And then in September she was diagnosed with dementia and things were fine. She was still driving for a little while, she started volunteering at Meals on Wheels and other things. As she progressed in 2013, I cut back my work hours and then in January of '14, I stopped completely because she needed 24-hour care. But through those years we stayed active while I was home with her from '14 to '18, we were out every day, volunteering, visiting friends, going for a walk. I didn't want her sitting around the house, watching television all day, and so I had kind of a, I was blessed. You know, our relationship was good, we got to travel, we've done four or five different trips. We went to Puerto Rico for 27 years with a timeshare and when we returned in March of '17, it was very apparent to me she couldn't travel anymore. And then her father passed shortly thereafter in Connecticut and her two sisters are in Maine and they didn't think Deb should go. I said, no, I want Deb to go to her father's funeral. So, the youngest sister was able to drive with us and when we got to Connecticut, she said, Tom, I didn't realize how she progressed, I think you have to start thinking about a residence, which we had been looking into. I took Deb to a couple places. I always wanted to go do things with as much input as she could give. So, in June of '18, she moved to a facility. It was a tough adjustment period, but after a while she was at home. I visited regularly. She was always happy. To interject for a minute, through the Alzheimer's Association, a program called Legacy Storytelling, we got to write our life's history with some UNE students. And we had a couple of OT students and a couple of nurse students, and they just fell in love with Deb, naturally. I mean, that was her. Well, one of them still walks with me and there's a couple others that may walk again this year, but they have stayed in touch. And they visited Deb and they just made her so happy. Oh, quick example, the walk of '18 Deb was in the facility and three of the women who walked, Deb's sister walked, her BFF from Connecticut came up with her sister and we all walked and then headed back to the house for a barbecue, and Christine, the BFF, and I went and picked Deb up, we brought her in, I walked Deb into the backyard, she saw the three young women, they started smiling, hugging, dancing. It was just, it was beautiful. And that went on for about a year, and then that slowly went away. We couldn't dance anymore, but we always had nice visits and she was always a pretty good mind, played music for her, brought cinnamon chip muffins, some apples, and then September 29th of '19, she and I were having a good time with some staff and then through

October, she lost 30 pounds and the end of October, she had a bad fall. Three days later, she had another bad fall, went on hospice and was gone November 21st. So, in a way it's a blessing for her because this disease, there is no cure. Right now, it's really, you know, you get this disease, it's not a good, and, and Deb wasn't going to recover, and we had a good life together. All of our family had a good life together, and so, I've adjusted to her being gone.

**Diane:** I suspect you're still adjusting. Yeah. It's hard to adjust, I mean you lived a lifetime together.

**Tom:** Wonderful lifetime, you know, we did everything together and I'm glad we had a lot of similar interests. Well, she used to read a lot and that ability disappeared, but we kayaked biked, hiked and over the years, those things, it was funny. I've had my knees replaced, and one year Deb started, oh, we can't kayak anymore, your knees, you can't kayak anymore. So, I got in and out of the kayak on the grass in the backyard, I said, I can kayak. Oh no, you can't kayak. Finally, I realized she didn't want to do it anymore. She had lost interest in it, but she didn't want to say that. So, but I have many great memories and she was well loved by her family, my family, and we always talk about her.

**Diane:** I have a question for both of you. I'll start with you Danielle, it sounds like your mother has progressed to the point where she can't really engage, but in the beginning, did she understand what was happening to her?

**Danielle:** In the very beginning, I think there was a lot of denial. My mom was laid off from her job in 2013, basically, for lack of ability and having problems functioning with her day to day stuff that she is, she worked at her job for 23 years. So, having those what's the fax number questions and not knowing the fax number, that's been the same for 23 years. So, some of those smaller mistakes turned into larger mistakes, turned into an issue with performance. So, when she got laid off is when we really started pushing for appointments at the doctors without really talking about it as a family because she was 55 years old. My mother is also a stage four breast cancer survivor. She was diagnosed at the age of 40, so she had been on monthly medications for 15 years and her primary care physician said, you know, it could be chemo brain, we don't see anything wrong. So, we kind of pushed again and we still don't see anything wrong, but if you're noticing an issue, we'll try to get you into a neurologist. We saw the neurologist and the neurologist said, well, you know, it could be this and this and this, but I really don't think it's dementia or Alzheimer's because you're so young, and that's when we pushed it a little bit more and got further into Boston and getting into some specialists and that's when we got our diagnosis. My mom and I never really talked about her diagnosis. She talked about it with friends. She talked about it, obviously with my father, never really talked about it with me. I never really brought it up either. It was one of those unspoken

things where I knew it was happening and she knew what was happening, but we were going to leave it unspoken between the two of us. I was there for her, with what she needed. I had her grandkids. She babysat for us for a little while until that became where she couldn't, and it wasn't safe for the kids. But I mean, she same with Tom's wife, she drove for a while. She stayed active. She loved to walk. We live near a family-owned-campgrounds, so she would walk up and down that camp road all the time, go down and visit the campers, sit down at their campfires and talk with them and then walk home. She turned into a very big walker. That was one of her things that she did, and we were fine with her doing so because there were enough people that live near my father who knew who my mom was. So, if they noticed that maybe she was wandering and didn't quite know how to find her way back, that they would help her. So, you know, I think that where my mom was young when she was diagnosed with breast cancer and she hit that head on, I'm going to beat it, it's going to lose. And it did. I feel like the diagnosis of Alzheimer's was just like that one thing too many that she just didn't want to deal with, and she just kind of let it take its course and do its thing. And unfortunately, when she had her surgery, we kind of lost what we had, you know. She would dance. My brother got married about two months before her surgery and she danced it up on the dance floor. She couldn't really have a full-blown conversation with you, but she got her point across. She was extremely happy. She was very happy that he was married and that we were there, and we were all together. And you could tell. We didn't need the communication. We just knew Mom, so.

**Diane:** It's interesting. My mom had Alzheimer's and in fact, Tom, I'm pretty sure she lived for a couple of years at the same facility that your wife lived in. Only my mom passed away in 2016, so you didn't cross paths. But I learned a lot of lessons and one of the lessons I learned was that you really need to seize the moment. I learned that she would enjoy things in the moment. In fact, a couple of times when she'd go on an outing and I'd say, how was the outing and she said, well, I have no idea where I went, but I know I had a good time. I thought that was really neat. So I really tried to, in the moments, even if it was just a smile, that later happy, but I'm curious about how other people treated both your mom or your wife, you know, people who aren't living with Alzheimer's either as the person with it or the family, the caregivers they kind of don't know how to act. Did either of you find that and do you have any advice for people who might be in that situation who don't know how to act?

**Tom:** I was surprised a few years ago when I became an advocate for the association, and I was preparing some information to take to Augusta. I fortunately worked at Southern Maine Agency on Aging for eight years before I had to stop work to be with Deb, and so I had great support throughout this whole time, the good social workers, dementia experts, et cetera, and they all knew Deb and they all loved her. In fact, I had Team Deb. Three people that

have since retired, but they were with me. They're still with me, which is great. But I reached out and one of the people said to me, you've got to talk about the stigma of Alzheimer's. And I had never thought about that probably because of the support that I had from the beginning and the fact that it just kind of flowed. I never felt any stigma. I was pleased to explain to people that my wife has dementia. I usually said Alzheimer's because then they oh, okay. But what I've learned in stores and well, we were trying to get her some clothes for a 40th high school reunion and suddenly, well, my wife had breast cancer, her hair hadn't come back yet, and all of a sudden, everybody in the store is helping us pick out clothes for Deb and stuff. It was wonderful, but I have many stories like that, but that stigma thing and Diane, you asked me before about Deb, I think knew what the process was at least in the beginning. We went to, well, it was the Steward Adult Daycare Center and showed pictures from our France trip. And it was my first time doing it and it was too long, but we got very little reaction from the attendees and I could tell Deb was getting a little anxious about the whole thing and when we left, we were walking out of the building she says, I'm never coming back here. And I think what it was, she saw herself in the attendees. And so, she was grasping that this is my road. An aside to that, Deb went to the Stewart Center for a while. She used to fight me like crazy to go. She wouldn't say goodbye to me when I dropped her off and then she'd go in the secured area. I think she was fine. She was going around hugging everybody, saying hello. She was just giving me a hard time.

**Diane:** Huh, my mom did the same thing. If you don't mind, I'll tell a quick, funny story. So, my mom, after my dad died, lived alone in the family home, which was quite large, and we did have caregivers who came in and I have three sisters who live here in Maine so, we tried our best to take turns doing things. But I took her to another adult daycare center, and she seemed to have a lovely time when she was there, and when I was there with her. Very social, but she too didn't want to go, and I remember one time taking her and we'd barely left her street and she demanded that I stop the car and she said, I can't go, I don't have my bra on. I said, well, let's go home and get it. But, there's this line. There are boundaries. You're trying to do the best as a caregiver and yet imagine what it must be like for them to understand that they're losing their independence, and so, to be able to put your foot down about, I don't want to go, I don't, you know, I'm not dressed properly, that's a statement and I think it's important to pay attention to those.

**Tom:** I used to not tell her, and we'd get in the car and we'd turn left out of the driveway toward the center. She'd say are we going to that place? And I'd say yes, but once we got inside, she was fine. Well, six months later I be waking her up. I don't want to get up. You're going to the Senior Center. I never called it the daycare center. You're going into the senior center. Oh. She'd jump out of bed, get dressed. She loved going. So things change.

**Danielle:** I think seeing my mom go through breast cancer and seeing all of her friends come out of the woodwork to support that and be around to help and cook dinner and come and visit and talk about it and seeing her go through a diagnosis of Alzheimer's and seeing people not know how to react to that and shy away from that was probably one of the hardest things for me. It was very lonely. It was lonely for the family. I can imagine that it was lonely for my mother and lonely for my dad. And I just think that talking about this and having open discussions, my hope is that it helps people that aren't dealing with it day to day that have friends that are diagnosed think about that and think about it may make you uncomfortable, but think about the person that's going through it, and if you shy away, because you're uncomfortable, how that feels for them and how lonely that must feel. And I think that that's really important. I know speaking for myself and I would assume speaking for the rest of my immediate family, it was very lonely. We had friends in our lives that we had had for dozens of years, decades that weren't talking, weren't visiting, weren't calling weren't checking in and it would be in passing. It would be meeting up in the grocery store, oh, how's your mom, you know? But not really being present. And one of our very good friends, one of my mother's very good friends finally talked to us and he said, you know, I haven't been there for your mom because I haven't known how, and it makes me so mad and so, I just don't come around because it makes me sad. But I've realized that you and your dad need me. And that was a turning point, you know? It's like, yeah, we do. You haven't just not dealt with Mom and her illness, but you've kind of left the rest of us to deal with it on our own, too. And I'm really hoping that with the Alzheimer's walks and with all of the information that's out there now, and hopefully bringing more awareness to what happens in a family that's affected, that hopefully that will help people, that don't deal with it day to day, be present for the people that are their friends.

**Diane:** I love that he was able to say how he felt. That I don't know what to say.

**Danielle:** I don't know what to say. What do you say? How do you say anything? I mean, you get a diagnosis like that and we all know how it ultimately ends. So, how do you acknowledge that and how do people acknowledge it and come forward with it and be able to be there for people when it's hard for them, too.

**Diane:** Did both of you reach out to the Alzheimer's Association at some point to find out about resources or services?

**Danielle:** We learned about the Alzheimer's walks through a friend of ours that wanted to walk in honor of mom. So, this is our third year walking and that's how I kind of became more involved. We raised quite a bit of money as a family/friends team and my mom was honored at the Mid-Coast Walk. On our

first walk, Drew Wyman had reached out to me to see if that was okay, and he and I keep in touch and I try to do what I can with volunteering and getting sponsors and fundraising and stuff. We didn't know that it had existed. We didn't know that the support was out there. We'd call the local hospitals; do you have a support group? And I think it's different maybe in our situation. I mean, my dad's 60, 62 years old, and to go to a support group where most of the peers that are going to be, they're going to be quite a bit older was hard. So, he shied away from it as did the rest of us because it's hard to listen to it and everybody's story is a little bit different, but having Mom at the stage that she's at, at her age and having people that aren't even there yet. It was harder for us to reach out and do that because we didn't know about the resources early on. My dad relies on his family for support. He has my brother and I, and my brother and I find our support in other areas.

**Diane:** And Tom, you are now a board member for the Alzheimer's Association, and your career was at the Southern Maine Agency on Aging?

**Tom:** I was there eight years, Diane, the last eight years of my work, I was Finance Director. I moved to Maine 23 years ago when I got into nonprofit finance and general management work. So, I worked with Larry Gross and Debbie DiDominicus, who you know well.

**Diane:** I was going to say, I bet you worked with Debbie D.

**Tom:** Debbie D. Is a very good friend. She lives down the road and we get together regularly. She's part of the senior group we developed. When Deb had breast cancer, they had a Pink Out Day. Everybody wore pink. They were always very supportive through that process, and then when the dementia started, I had great support and information and all, and sometime through that period, Deb and I stopped at the Alzheimer's Association and got briefed about the association, and then, she has two sisters, one here in Westbrook and went up north and a brother in New York state, and they contacted the association that they didn't understand what was going on. They didn't understand that there was no cure. They didn't understand anything about the disease, and so the executive director very nicely came in on a Sunday when her brother was in town and we had a nice gathering of us, and so they got pretty educated about what we'll expect going down the road, and so from there, I never got into a support group though. I either just missed one that started or there was one that was starting for people with early onset when Deb had already been past that. And was always trying to tie in a support group, but where I was at that point in time, and where Deb was at that point in time. But we did a lot of, they had activities. They did walks in forests and stuff. They went to concerts. They had this legacy story telling with the UNE students. We did a coloring thing with fourth graders with one of the Portland grammar schools. These little kids were

terrific. We had two little kids with a nursing student from USM and Deb and me and these young kids, they were, I think, trained. They just knew what to say when to say it, and I was like, this kid is 25 years old.

**Diane:** Little kids, they don't have any filters. They're not afraid to say things or ask things. It's marvelous. And somewhere along the line, we put up all these little filters and blinders.

**Tom:** And that's why I find the association is obviously a first stop, but Southern Maine Agency on Aging for everybody over 60. They're there to help people improve the quality of their life in their older years and all the different services available, including a lot, there's support groups, there's dementia, they have a savvy caregiver course, which is about being a caregiver. It's just another wealth of information at Southern, well at any Area Agency on Aging. There's five in the state.

**Diane:** I did the savvy caregiver course, and I had the same experience with the Alzheimer's association as you did. I come from a large family and there were also nieces and nephews around that were helping out with care, and they were very helpful. We did a conference call. We had an in-person meeting with some family members and then we did a conference call with family members who were out of state so that everybody could ask questions because you're right, there's this great deal of lack of understanding or misunderstanding. And so they were extremely helpful for getting my family on kind of the same page about what was happening. I have some other questions I want to ask you. Caregivers need support, and oftentimes they're kind of overlooked. Everybody's grateful that you exist. But what kind of support in order for you guys to do and your father to do, Danielle, the best job, to deliver the best care possible to your loved one, what kind of support do you need? And I'm talking about support beyond support from other family members, although that is important. Is there good support available for caregivers?

**Tom:** No. Danielle, I applaud your family for getting your father out to play golf and do things. Deb's sisters in the early days tried to take her overnight or for a weekend or something and, well, what the problem was, Deb would just say, I don't understand. I'd rather be with you. I don't want to go, you know.

**Danielle:** That was my mother as well. She would rather be with my dad.

**Tom:** Yeah. Yes. And then everybody's still working, the local friends and family and so I found, you know, that respite part's important. That's why the daycare center was kind of my relief for a while. And then when Deb went to a facility, I just kind of looked at it as an extension of daycare, but it isn't. There were very few days she was very happy and all of a sudden it struck the, I think

that I don't like it here, but then that evolved, and she was most happy. I remember one of the aides one time telling me after dinner they were sitting on the couch, watching television, and she had her arm around and that put her head on her shoulder and said, Tom, I love you.

**Diane:** Ohhhh.

**Tom:** So, a lot, a lot of memories and the things that can happen. Everybody knew her by name. We'd be walking and hi, Deb, she'd smile. Probably a week later, and they all knew my name. It was a very friendly at home feeling.

**Danielle:** I think that our experience was a little bit different because of mom's surgery and how she came out of it. Because she lost all independence, just like that. We didn't have that slight decline. We had where we were at and then we had like nothing, and when we took Mom to the hospital for the second time after her surgery and we ended up down in Portland, we weren't sure that she was coming home. We weren't sure that she was coming home at all because we weren't sure where she was going to recover from her surgery, but we also weren't sure that she was going to be able to be home because of the care that she was going to need. And when they said it's really your choice at this point, and dad, he really wanted to bring her home. That was something that they had talked about and she wanted to be at home and he wanted to be able to do that for her and my brother and I said we're okay with that but we need to get you in home health because I work full time and my brother works full time. I said, you can't do it by yourself all day and all night by yourself. And I think that this is something that's really important. It took us going to see a lawyer to be able to apply for the proper program in the state to qualify for being able to take my mom and take care of her at home. It took us a lawyer to help us navigate all of that. It was very difficult to navigate. We got denied a couple of times and I couldn't get through my brain like how were they denying? I don't understand, like, just come spend two hours with us. How can you deny that she needs at home care? I don't understand why, how you are denying this claim.

**Diane:** On what basis did they deny it?

**Danielle:** We didn't really get bases. We just got a letter back that said you've been declined, whether it was in a financial level, an income level, the right people hadn't talked to the right people to actually have her cognitive state evaluated. It was a very, very hard process for us as a family.

**Diane:** are you today in terms of any kind of resources?

**Danielle:** We were finally approved through the state to get Mom in the, they call it an at home waiver program. We're waiving our nursing home status to be

able to keep Mom at home. So, she qualifies for in-home help. It took us from when we got approved for it, it took us almost a full 12 months for the state to be able to staff that. So, the caregiver shortage is incredible. We had a couple of staff lined up that never showed up, so in the meantime, for this year, we went to a private facility to have at-home care where we paid for it out of pocket, and that's a financial burden as anybody can tell you. But it took about 12 months for them to be able to staff my mom. My mom qualifies for 54 hours of help a week, which sounds like a lot when you're saying 54 hours. I mean, 54 hours is a lot, right? Because a 40-hour week in the job and that's kind of what you equate it to, but when you figure 24/7 care, 54 hours doesn't really equate to that much. So that's what Mom qualifies for through her program, and we were lucky enough and we've had the same caregiver for about 18 months now. And my mom's oldest sister lives right next door to my mom and dad and she is a tremendous help. She picks up the extra hours that the other caregiver can't do and she picks up any hours that Dad might need to go to the grocery store because he ran out of milk, or she picks up the milk for him or whatever it might be, she's been instrumental in being able to keep Mom at home. So you know, that that's another issue that I think it would be nice if it could get fixed someday.

**Diane:** Someday. I mean the tremendous burden of stress that you're already under. And then trying to get help.

**Danielle:** Just trying to get help and the stress of trying to get help was incredible.

**Diane:** And most people probably wouldn't have the perseverance that your family

**Danielle:** My father has said that if it had been just him, he probably wouldn't have been able to do it. He said if it hadn't been for myself and my brother, that to be able to kind of take those reins and make sure that all of the paperwork that they needed got filled out and sent to them and kind of navigate him through that, he probably wouldn't be able to do it himself. makes me feel for the people that, I mean, what do people that don't have family support? What do they do? You know, and that's what the Alzheimer's Association is all about. That they're there to help these people that can't navigate through on their own.

**Diane:** Was there anything about care giving that you didn't understand until you're actually in the thick of it?

**Tom:** I call it on the job training. It's like every day you get up, what's new today and you adjust to that. And it's kind of what makes it, well, my case taking care of my spouse, the woman I love dearly, it was being with her and

doing these things and adjusting to her life was easier, I guess, cause I wanted to be with her. I wanted her to be happy, and so when she didn't want to kayak anymore, several things along the way, I finally realized she just didn't want to do them anymore. I guess you just have to be ready for whatever's going to come your way and it never quite sure what that's going to be. And hopefully, the loved one is at peace in their mind and not agitated and not angry, and you can kind of follow their lead. And as long as they're going in the right direction, let them lead and you follow and make sure and I, I say we're safety officers, we take care of their hygiene, we feed them. Some months ago, I came up with this analogy, which is either good or bad. We have a six-year-old granddaughter, and when she was born in March of '15, we watched her go from the hospital to diapers, to crawling, to walking, to talking, to eating and over a similar period.

I watched Deb go just the opposite. And that's kind of the way I see in my case, how the dementia progressed, the going backwards from birth, where you can't do anything for yourself. Deb was so independent and so she was educated to the corporate management and everything else and to watch all that go away, but at the same time, maintain her beautiful smile and loved kids. I mean, she hugged everyone. It was always dangerous in the grocery store. Some mothers would, why are you hugging my kid?

**Danielle:** I have a quick story about hugging. I had taken my mom Christmas shopping one year and she had left her purse in the cart when we left and we had gone across town and we couldn't find a purse at the next store so we went back and there was a man standing outside of the store that we had been in that had her purse and she had just bolted into the store. Have you seen anything? She came out to me. She was close to tears and I said, Mom, it's okay, this gentleman has it and he's going to give it back. She hugged him. was horrified. He's like, she's hugging me. Thank you for finding her purse, I said, you know, she has dementia, I said, but thank you for finding her purse. But yeah, she hugged everybody, too. She was a very big hugger.

**Diane:** I do want to make sure that we get in the walk, so you both are walking and why do you walk?

**Danielle:** I walk for two different reasons. I walk because it helps me to raise awareness. And it makes me feel like I'm doing something in kind of a situation where you can't do anything. You can't fix it. You can't make it better. The most you can do is deal with it and live with it and be patient with it and get through it. It's like a day by day process. My Mom, when she was diagnosed with breast cancer, became a very big advocate in the local breast cancer walks. So, the second reason that I walk is kind of, if she was able to, my mom would be walking, my mom would be doing this. She would be raising the awareness.

She would be telling people, her story. She would be listening to other people's stories, just so that people knew that they weren't going to be alone. It's what she did with her cancer. It's what she would be doing now, so I like to think that maybe she's proud of me.

**Diane:** Your mom was an example to you and now you and your family are examples to other people.

**Danielle:** Yeah, we try.

**Tom:** I like to walk to raise awareness and to help raise money. You know, so many people as we were talking about, aren't familiar with the disease and they just don't understand it, and as we progress through research and the funding the government gives and the fundraising that we all do, I think hopefully, more people are getting aware of things. In the earlier days of Deb's disease, we generally had a half, a dozen, eight people walk with us and that's kind of dwindled over time, particularly with her passing, but I am glad most of them still make donations toward the walk. I've been committed since before Deb died. I knew it wouldn't help her really, but to help find a cure and I'm not a doctor or a scientist, but I try to do whatever I can to raise awareness. So, by being an advocate, by walking, participating in The Longest Day, in these different things, I'm hoping in my small way, someday before I'm gone, we'll hear about a cure.

**Danielle:** I second that, Tom.

**Diane:** I third it. I appreciate so much your willingness to tell your stories and allowing me to share a little bit of mine too.

**Danielle:** I appreciate the platform for it. It was very nice to be able to, so.

**Tom:** Yes. Thank you, Diane.

**Diane:** Well, it was my pleasure. If you want more information about Alzheimer's association or would like to participate in the walk to end, Alzheimer's go to ALZ.org. You can put in your zip code to find out where there might be a walk in your community, and you can walk from home, in your neighborhood, or you can attend a local event, and yes, there will be COVID protocols in place. You have been listening to the *Catching Health* podcast. I am Diane Atwood, host and producer. If you would like to read my blog *Catching Health*, listen to more episodes of the *Catching Health* podcast, or find a transcript of my conversation about Alzheimer's disease with Danielle and Tom, go to [catchinghealth.com](http://catchinghealth.com) That's it for now. Stay well, and I hope you

have a great day and maybe we'll see you at an Alzheimer's walk in your community. Make sure to say hello.