

## S2\_E4\_Extra.mp3

My name is Lindsey Bongard-Batori. I am connected to Alzheimer's because I had two grandparents who suffered through it and my mother who suffered through it, and two uncles who also dealt with Alzheimer's. So I'm very connected through lots of people in my family. My mom was my person, and I always use that term because nothing explains it better than that. I mean, even at a young age, I remember faking sick in grade one just because I wanted to be home with my mom. I would have done anything to be with her. I have two older brothers, so I think we were each other's people. I just always knew she was there for me. She was definitely my best friend. She was my safe place. And she was just that person always there in the background. She never interfered. She never caused trouble. I don't remember even as a teenager, not wanting to be with her. She was easy. She was kind. She was soft. Being with her was special. And I don't take that for granted. My mom's name was Barbara. She was an avid reader, and I think she passed that down to me. She loved going for walks and just appreciating the little things in life. She loved to travel. And I think if she could have done more of that, she would have. She was a stay at home mom. Her kids were her life. I don't know what she did, but my brothers, sometimes we'd fight over her and, you know, we're happy to be around her and relished being with her and to the point where our friends like to come over and hang out with her and loved her cooking. But again, she never pushed herself into our lives and kind of just thought she'd always be there with me, which she is in a different way. If anything, as a mother myself, that I could be a part of what she was to my kids.

I would say in her mid to late sixties, her and my dad moved to a condo. My older brothers and I were out and all living relatively close. My older brother lived in the States, though, you know, I'd always consider us a close knit family, even though we were, you know, have our arguments or whatnot. So I had kids first and she was very involved. We started to notice her repeating herself a lot. I don't even think it was forgetting things. It was more repeating what she had just said. And we started to get annoyed with that. My dad, my brothers and I, like we depend on you. What do you mean? You just said that? And then I remember feeling the sense of guilt. Like, why am I getting mad at her?

I noticed her slowly drawing back from us. For example, the first time my parents went to Florida and we would go visit. She wasn't coming to the pool with us or wasn't participating as much as previous. And I was like, "What are you doing? Why don't you want to be with us?" I would start to talk about it with my brothers and my dad and nobody else noticed it. We did just very here and there, sort of quietly to each other. It was odd for her. And then she started forgetting things. I remember one day she called me crying. She went to Loblaws and she couldn't find her car, and the parking lot wasn't even that big, but she was hysterical and she was scared. And I had to talk her down and had to talk her through it. And eventually she asked for help, which for my mom, who was a bit of a quieter person, wasn't the most proactive. So if she could figure it out herself, it was just easier and quieter and she didn't want to make a bigger deal about things, so she had to ask for help. That was hard and she was scared. And I think that was like her first realization of this task was a lot harder than we all expected. Another thing that came up was one year at a Passover dinner, there were some prayers and somebody said the prayers. And about 2 minutes later she said, okay, let's say the prayers. And we all kind of looked at each other like we just went we just did that.

It was then that we decided as a family with her involved that it was time to talk to your doctor about this memory issue. And she was obsessed with something called MCI, which is mild cognitive impairment. And we knew we knew we've been down this road before

with my dad's parents and my mom's father. That's when it sort of became real and it started to have an effect on my entire nuclear family, my brothers, my dad, my mom and myself of like, what's to come. And it was scary. It was almost painfully slow, this decline, because when we started talking openly about it to other people, everyone's like, "What are you talking about? She seems fine." I would have to explain, "You don't know her like I do, and you don't see her every day." And it was almost like we had to justify this, this decline I could see in her when we would go to social events. She was quieter. And I remember saying to her one day, "Mom, you were so quiet." And she said, "I don't have anything to offer. And it's hard for me to join in a conversation." And that hit me. I felt really sad for her because I knew she was uncomfortable and she started to not want to go out a lot. And that was hard for my dad, who was near retirement, and my father, who's very active and plays tennis three times a week and is very social and works out and likes to get out and do things.

She started to retreat more and want to stay home and lie down, and she was diagnosed with depression and she didn't like entertaining as much and kind of noticed she was reading books that she she'd read before and she would make jokes about it. She said to me, "Did you read 50 Shades of Grey?" And I said, "Yeah, Did you?" And she's like, "Yeah, I read it twice. You know, my memory is not so good." And I was like, "Well, okay, Mom." So she knew. She knew things were going down. And then eventually her license got taken away and that was a very hard blow. And I remember when that happened to my grandfather, she was very aware of how hard that was for him. So when that happened to her, she could see her independence was being taken away. And we tried as a family and my dad was still working. But we tried as a family to organize. You want to go out? I'll take you this day. Jeremy will take you that day. Dad's going to take off that day. And it just got complicated and hard. And Uber was not even a choice. She couldn't do that. So she was just staying home more and more. We weren't letting her do so much, like, take care of my kids or, you know, go out by herself. And she did go out by herself once and she fell and had to go to the hospital and get stitches. And it was really scary. And that's when we started to have the conversation of what's her next step like? What do we do? How long do we watch her decline before something really bad happens?

We started looking into homes for one day because I said to my dad, "I don't want it to get to the point where it's time to put her in a home because we can't care for her and there's nowhere for her to go or we don't know or it's an emergency." Luckily for me, I have a friend who runs a home for people with Alzheimer's called One Kenton, and it's only devoted to people with dementia. And we knew that one day this is probably where she'll end up because we did hire somebody to come a few days a week and it wasn't enough. And my dad, he really tried. He tried with her medications. It just became too much. And he retired and he thought he was going to devote everything to her. That was his plan. And it just came to the point where her speech pretty much declined completely. And I remember her lying in bed one day, and I whispered to her and I said, "Mom, get it together, because if you don't, you're going to be going into a home. And I know you don't want that." So please, like, I was like, begging her, don't do this. But obviously, you know, that was more my issue than her issue. She couldn't help it.

And a few weeks after we had seen the home and gone into the home and decided she got into a habit of going through her jewelry. Just quietly like this habit of sorting. My dad was in the other room and he heard her fall. And he ran into the hall and she had fallen. And he was hysterical finding her like that. And that's when we knew that this can't go on any more at home. Luckily, she got a room at One Kenton, probably three days later. That was the hardest part. I went over, I packed her up and we went over. My brother and my

dad and I. And I unpacked her, made her room as nice as possible, and she never even said goodbye. She didn't say, "Where am I?" She didn't say, "Take me out of here." Like nothing that you would expect a healthy person to say when you're being dropped off.

They say with Alzheimer's, you mourn twice. And I understood what that meant. My parents were married just over 50 years. It really hit him. I mean, they had a very interesting marriage. He was a lawyer. He had his own practice in Markham, and she was the housewife and raised the three kids. And we grew up in Unionville. And I mean, I look back and I think my brothers would agree we had a wonderful childhood and they did everything for us that we could have wanted. I think they had plans when he was to retire. They were going to travel. And, you know, my dad depended on my mom for so much stuff, like he wasn't the easiest person to be married to. And the joke was my mother deserved a medal. That was the joke. And everybody would laugh about it. You know, she would plan these vacations and he would say, I don't want to go. We're not going. And of course, he went and came back and had the best time of his life, and he needed her to push him and do that stuff like we all needed her. We all kind of got that gene from my father. If I'm nervous, I don't want to go. I don't want to do this. And it was her who would always sort of push and say, You're going to be fine. You're going to be okay. It's going to be amazing.

It was very hard for him to watch this. My mom was young to be in a home like she was 72 when she went in. You know, I would go to the home and visit and see people my age visiting their grandparents. So I think for my dad this was opening up a whole new chapter that he was not prepared for. And I think he still battles that today, even though he is moving on and doing things, but this disease really affects. More than just the person. It really affects the entire family.

When my mom first went into the home, she had a great team working with her and I was there every day. I mean, it wasn't even an option. I would be nowhere else. And I remember on the second day, everybody would leave their room and go down to this great room where, you know, it was like morning activities and she had to do this, like, I'm going to call it an aerobics class. But they basically sit in chairs and do these activities. And she wasn't wearing the right shoes. And they said, "Oh, could you go get Mrs. Bongard her running shoes?" And I'm okay. I'm so sorry. And I went into the elevator and I just I lost. I, I cried so hard. I was like. This is not where she's supposed to be right now. And she would not be happy if she was here. She was so sophisticated and just aware of, you know, where she wanted to be and didn't want to be. And she was not fighting this. So it really hit me in that elevator. And that was a very hard moment. And I remember a few weeks later, the psychiatrist said to me, this really nice doctor, and he said, "You know, you coming every day, she doesn't know, so you know who you're coming for." And I said, "Yeah, this is for me. I need to be here with my mom and know she's okay and see her every day."

And my mom did everything for us. You know, the roles were reversed now, and there was no question that I would do everything in my power to make sure she was comfortable. And satisfied. And just to see her and. There was no question where I was going to be. What do I miss about my mom? It's like those little things where something will happen in my kid's life. Or in my life or just that little thing. And I just want to call her. I mean, I would speak to my mom on the phone about four times a day, even if it was just like, oh, hey, you know, I just wanted to tell you this. Or as much as it's the big stuff, the big things. My daughter going away to school or, you know, my younger daughter got her first job or even Grandparent's Day at school where she used to go to and get so excited about. Obviously,

those are the things I want to call her about, but it's also the little things like just being alone and just being like, "oh, hey, Mom", or "Oh, I just read this great book," and I mean, I don't reach for the phone anymore, but I think about her and I think how I was too young, my kids were too young, she was too young. And in my mind I yell out to her and I'm like, Mom, I need you.

There are times when I will go to the cemetery just to be alone and like, I don't want to go with anybody. And I actually sounds a little cheesy, but I have these rocks that I keep by the computer. So if I'm on a zoom or just board and I have these acrylic markers and I just paint them like I just again, it's kind of cheesy, but I just sort of, you know, make these rocks. And then when I go to the cemetery, I leave these painted rocks for her or my kids will. And it's something I feel like she would have appreciated. She likes doing little crafts and stuff, and I just feel like so much has gone on. She's missed a lot and what life is like without her. I just wish she could see it because it's hard. It's hard without your mom, especially when you have a relationship the way I did. We all depended on her for so much and we are still trying to figure out how to continue on without her.