



“I have dementia, but dementia does not have me”

Interview with Brian LeBlanc



By Jean Galiana

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Elder and Long Term Care
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About Brian LeBlanc



Brian LeBlanc is a national public speaker with Alzheimer's disease. He is an advocate for dementia awareness and education. Mr. LeBlanc is an Advisory Council member at the Dementia Action Alliance. The alliance raises awareness about what it is like to live with dementia. At the Alzheimer's Association, Mr. LeBlanc is a member of the national Early Stage Advisory Group and the local executive committee.

Mr. LeBlanc is also on the leadership board for Covenant Care. This organization develops programs and services for patients with various forms of dementia, such as Alzheimer's disease, and their loved ones. Mr. LeBlanc lives in Pensacola, Florida, with his wife Shannon and their two children.

In this interview, Mr. LeBlanc discusses his efforts to address the stigma of Alzheimer's disease and other forms of dementia. He also shares his experiences of maintaining an active and involved life with dementia.

Interview

Jean Galiana (JG): Please share your personal experience with dementia.

Brian LeBlanc (BL): I am the fourth generation of my family to have Alzheimer's. I am fifty five years old. My great grandmother had Alzheimer's. She had seven children. Of those children, one was my grandfather. One of his sisters had Alzheimer's. That sister had ten children. One was stillborn. The remaining nine all had Alzheimer's. My grandfather and grandmother had two children – my mother and my aunt. My aunt developed brain cancer My mother had Alzheimer's. I am one of five children. I am the youngest. I am the only one that has the disease. My father had vascular dementia. My wife's grandmother passed away from Alzheimer's.

I have been around this disease since the early 1980s. I have seen the effects of Alzheimer's. When I give my presentations about Alzheimer's and other dementia related illnesses, I do not try to paint a rosy picture of it because it is not pretty. There is nothing good about the disease, especially because there is no cure or method to slow the progression.

My friend, who is a local musician, and I sing in senior care facilities. People are horrified when I tell them that I am going to a senior care facility to sing for people with Alzheimer's. They are concerned that I will be in contact with many people with more advanced dementia. My thought is that I hope someone like me will come and sing songs to me when I am in their position. You cannot believe how it lights up their faces! Music transports people to a different time and place. Music takes you away from thinking how you used to be and what your life used to be.

Recently, my wife and I went to see James Taylor. He is almost seventy years old. He still sounds like the James Taylor of old. The music transported me back to the 1970s and 1980s. I sat there with the biggest smile on my face because it was wonderful.

JG: In all the time you have spent around Alzheimer's, have you seen improvements in areas such as treatment, stigma, or prevention?

BL: Unfortunately, no. I will tell you why. If you talk to anyone about cancer, their response is, "Do you mean brain cancer, prostate cancer, breast cancer, pancreatic cancer, or another form of cancer?" They list all the different kinds of cancers because they know about them. They know all about cancer because there are ways to treat and possibly cure the disease. Everyone knows about HIV/AIDS, heart disease, and diabetes. When it comes to Alzheimer's, all they know is that it is the disease that old people get. We need to bring more awareness and education about Alzheimer's and other forms of dementia to the general

population. Hopefully, we can inspire honest conversations and slowly chip away at the pervasive stigma and fear that surrounds the disease.

JG: Is your desire to increase awareness and education what drove you to join the [Advisory Council](#) of the [Dementia Action Alliance](#)?

BL: Yes. I am also on the leadership board of [Covenant Care](#). I am part of the national Early Stage [Advisory Group](#) of the [Alzheimer's Association](#). Locally, I am on the executive committee of the [Alzheimer's Association](#). I do not work anymore. My efforts are all voluntary. This dementia advocacy is what I do as a career. I want to be involved. Do you know who [Sandy Halperin](#) is?

JG: I do. But please share your thoughts about Mr. Halperin.

BL: Sandy Halperin lives in Tallahassee, Florida. Like me, he is an alumnus of the Alzheimer's Association and the Leadership Advisory Council of Dementia Action Alliance. He also lives with Alzheimer's. He has been a committed advocate for living a vital and vibrant life with dementia. He encouraged me to become involved in dementia advocacy and awareness. He has inspired me. I plan to take the torch from him and keep it going when the time comes. In December, I was in Washington, D.C., to participate in a panel discussion at the technical conference for American Association of Retired Persons. I told my story to a room full of guests.

JG: What else have you done as far as education and advocacy?

BL: I am a big social media geek. I have my own Facebook [page](#) strictly for Alzheimer's. It is called "My Alzheimer's Journey." I have a [blog](#) entitled *Alzheimer's: The Journey*. I am also active on [Twitter](#). I give many presentations around the Panhandle area of Florida. Occasionally, I travel to Mobile, Montgomery, and Birmingham, Alabama. I go everywhere that I am invited to speak.

JG: What is the message you convey in your speaking engagements?

BL: Alzheimer's is no longer a disease of the elderly. People should know the difference between dementia and dementia related illnesses. I also speak about the stigma that is associated with the disease. There is rampant stigma around Alzheimer's. People think someone with Alzheimer's cannot do anything. There are many of us with Alzheimer's who live somewhat good lives. We on the advisory board discussed stigma when we were in Washington. All twelve of us have dementia. People were surprised that we were walking around, talking, and sounding somewhat intelligent. People were asking themselves, "How can this be? This person has Alzheimer's. My grandmother has Alzheimer's and she is in a senior care facility. She cannot do anything." I explained to them that one day I will be in the same condition as their grandmother. I do not know when. Right now I am enjoying my life for the most part.

JG: You seem perfectly functional.

BL: Today, you are seeing me on a good day. I also have plenty of bad days. Those days are difficult. My wife is helpful on the bad days.

JG: What are the characteristics of a bad day?

BL: My brain does not work well on a bad day. For the past two mornings, I have had difficulty getting started. Sometimes the difficulty lasts a little while. Sometimes it passes quickly. I can take a long time deciding what to wear. Having this appointment to talk with you helped me, because I knew that I had to shake it off and be able to talk intelligently to someone.

JG: Does getting your message out help you to focus, and therefore give you something back?

BL: Yes. Absolutely.

JG: What other benefits do you receive from all your advocacy and awareness efforts?

BL: The feedback. People come up to meet me after I speak. It makes me happy. Their comments amaze me. They regularly tell me that I am brave and speak with such passion. They are surprised I can share my story and help to dispel the stigma. I have the same response every time. I look at them and say, “How could I not do this? If I did not advocate and share my experiences, I would be sitting at home in my recliner – probably having my brain go to mush. This allows me to remain active. If I can educate and make people aware of Alzheimer’s by talking to them and answering their questions, it benefits us both. It likely benefits me more than it benefits the audience.

JG: Do you think that the public is not taking dementia seriously enough?

BL: Yes. I do not mean any disrespect when I say this, but I get angry in November during football season when the National Football League is all wearing pink. I understand they are trying to raise awareness about breast cancer. But I ask myself, “Where is the purple for Alzheimer’s?” With all the heads that get damaged in football leading to cognitive issues, I would think they would be wearing purple some seasons. I am going to make that my mission.

JG: Please tell me more about your [blog post](#), “The Angry Side of Alzheimer’s,” for the Dementia Action Alliance.

BL: That blog post was inspired by an interaction I had with my wife Shannon. One evening, Shannon and I were driving back from one of my presentations. I asked her how I did. She knows when I ask a question, I want an honest answer. She just started crying. I thought, “What did I say or what did I do?” She said, “People get to see the polished you. They get to see who you used to be. Why do they not get to see the angry, confused, frustrated person that I see every day?”

Why do they not know that every morning you need migraine medication and a warm compress before you are able to speak?" I used to work in marketing. I appeared on radio and television weekly. I cannot explain how or why, but when I get in front of an audience, the public relations guy that resides in my long term memory comes out and takes over. I have no control over it. It just happens. It is like a light switch.

When a local news station interviewed me a couple of months ago, I told them I wanted them to follow me throughout my journey with this disease. I did not want them to report only on the good days. I wanted to show people the whole picture. My wife Shannon inspired that choice.

JG: Have you have become a perfectionist?

BL: Yes. I always have been. Now it is amplified. Something as simple as getting dressed can be laborious. I spend too long thinking about what to wear. There are things that I used to do with ease that have become difficult. It recently took me almost a whole day to trim a bush. It used to be easy. Now I've become meticulous about every single thing. It is almost like I am super focused on the task at hand. That is not good for my family because sometimes I am too intense.

JG: Is there anything else you would like to share with our readers?

BL: I saw this quote last night on Twitter. It said something like: "My eyes can still see, my ears can hear. I am still me inside. Just know that I am still me. Do not forget me." I have lost friends, and family has become distant because of my Alzheimer's. I believe that is because they do not know how to talk to me. I guess they worry that they may say something I will not understand or ask me a question that I do not know the answer to. They do not realize that I can still function. I think that was also part of the inspiration for the "The Angry Side of Alzheimer's" blog post. My sister is the only one who communicates with me. My three other brothers do not. Maybe it is because they saw what the disease did to my mother. When my mother was in a more advanced stage of Alzheimer's, she stopped talking. She loved music. She would look at us and start to sing, but with no words — only sounds. She forgot the words, but not the tune. The tune from "The Sound of Music" meant she was happy. We had to try to make sense of a different kind of communication. I wonder if that is what my brothers think I am like now. They do not know because they do not talk to me.

JG: Have you have found other social outlets through your advocacy, education, and training activities?

BL: Yes. The other members of the Alzheimer's Association Advisory Board and I talk. We all have the disease. It is comforting to talk to someone and know you can ask a question like, "When you are standing up, do you just suddenly start to fall?" Everyone will start laughing and say, "Yes, it happens to me once or twice a day." Imbalance is a symptom that we did not realize was associated with Alzheimer's. All of us have experienced it, yet we never talked about it because we

did not have anyone to talk to about it. It helps us not feel so bad about everything.

JG: Did the members on the Alzheimer's Association Advisory Board become a support group?

BL: Exactly. We have similar challenges and experiences. We serve a one year term with the advisory group. It started in July. It is going to end this June. Some of the members are already suggesting that we have a monthly conference. Hopefully, we will continue to talk to and support each other. We can schedule our own conference calls and just meet every month or so. It does not have to be the end of everything. We can keep going. We just have to remember to call each other.

JG: I hope you will. Thank you for this discussion and for all your advocacy efforts.

BL: Thank you, too.

END