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Living With Alzheimer's Disease

By Tom Doyle

Editor's Note: This excerpt is from a presentation done by a panelist at the Intercompany Long-Term Care Insurance Conference Association closing session in Chicago in March. We can never fully express our thanks to the Alzheimer's Association and Tom Doyle for the courage to share his moving story and optimism for the future.

It is great to be with you today. I don't know if you can tell but I am shaking. I am not shaking totally because of nervousness—although speaking to a group of almost 1,000 participants can be nerve-wracking, especially for a person living with Alzheimer's—but the shaking is because I have also been diagnosed with Parkinson's.

My name is Tom Doyle and I am living with Alzheimer's. I live with my husband, Levi, on the north side of Chicago. We have been together for 15 years and have been married for nine years. He is not only my husband but also my care partner. I also have three children, two boys and a girl, from a previous marriage, as well as four grandchildren.

Professionally, I have been a teacher, principal, superintendent and university professor.

I had an incredible career as a professor and university administrator. I was chair of the teacher education department, served as a faculty senator and was on the senate negotiating team working with administration to create a new contract for faculty. I loved my students and received almost perfect scores on my student evaluations. My life had purpose, meaning and joy.

But then, my world was turned upside down. At that time, I was seeing a psychologist and one day he commented that he had noticed I was losing words and forgetting what I said. I was repeating myself. When I heard this, my anxiety started to increase. At home, my husband confessed he had also noticed I was losing words and forgetting things. He also added that I had become disorganized and could not follow through on simple tasks in my home office as I prepared to teach and during the teaching of online classes. I too began to notice these changes.

The most devastating thing that happened though is that I was no longer able to remember lectures I had given for years. During class, my students would ask questions and I couldn't recall the answers. I remember trying to cope and hide the symptoms by instead asking the students if they thought they knew the answer to questions. I could no longer grade papers efficiently. I would get lost in the middle of grading a paper and have to go back and begin again. Though I had always been extemporaneous, I started to script my classes so that I could read verbatim my lecture. Shortly after these symptoms began, my student evaluations began to go down. All of these changes increased my anxiety. Before I taught a class, I would become so nervous that I would sometimes have a panic attack. I knew I couldn't go on like this; I needed to talk to someone about the changes in cognitive function.

I spoke to my neurologist, who I was seeing for Parkinson's, and shared the problems that I was having at home and at work. He gave me a short memory test and said it indicated I had mild cognitive impairment. Later testing indicated a diagnosis of Alzheimer's disease. My psychologist, neurologist and husband all agreed that I could no longer function on the job. I met with the chairs of my department and told them what was happening and I didn't think I could continue on the job. They each touched my arms as a gesture of love and said that I didn't need to come in anymore. So, on Aug. 9, I was employed in my dream job and, on Aug. 10, I was on full-time disability and retired.

I was devastated. I couldn't believe what was happening to me. This was probably the darkest hour of my life. This disease robbed me of my sense of purpose, meaning and joy. I began to go through the stages of grief that first year and a half. I considered my work peers my friends, and, when I was no longer



working, it felt like I had lost them. I was embarrassed because when I would get into a conversation, I would often get lost. I would lose words. I started to lose my ability to comprehend reading materials. I began to isolate myself from other people. My husband was going to school so most days I would just sit at home. I was so lonely. At first my colleagues from the university would call but that stopped after about the first six months. They had moved on but I hadn't and didn't believe I could.

About that time my incredible husband, Levi, asked me if I would experience more support in Illinois since my family—father, brothers, nieces and nephews—lived in the Chicago area. I said yes even though I was leaving my daughter and one of my sons in southern California and Levi was leaving all of his family. What a sacrifice he made!

Throughout this time I was still searching for purpose and meaning for my life. I decided that since I found so much purpose in working that I would get a job at Walmart. Well, I lasted three days. I was working the cash register and it would ask me for my employee ID number before every transaction. I couldn't remember it. I had to put it in my phone and with every customer who waited in line I had to pull out my phone to remember my ID. This was so frustrating for me and definitely the customers. My line would grow because I was so slow. On the third day seeing my line almost half way down an aisle, I walked away from the register, went to the assistant manager and said I couldn't do the job. I literally left my cash register and went and clocked out. I was a failure at Walmart.

I had to find a sense of purpose elsewhere and, luckily, my doctor put me in touch with the Alzheimer's Association. I reached out to my local chapter and became very involved with their programs. I attended both younger onset and early-stage support groups. I began to tell my story of living with Alzheimer's to groups of people in a variety of different organizations including second-year medical students at the University of Illinois-Chicago.

Then I was nominated for and selected to serve on the Alzheimer's Association National Early-Stage Advisory Group. This role has given me the opportunity to share both my story and the incredible work of the Alzheimer's Association with a nationwide audience. Additionally, I was recently nominated and elected to serve on the board of directors of the national Alzheimer's Association. From the very beginning of my relationship with the Alzheimer's Association, they have given my life purpose, meaning and joy.

The work of the Alzheimer's Association is amazing. Research is being done to find a cure for this terrible disease. We are close. Great strides have been made in research to find ways of

stopping the disease even before the symptoms begin to show. The association is finding more and more means for early detection of the disease and treatment that will stop the progression of the disease, eliminating the tragic effects of the disease.

Now that I've outlined some of the major successes I've experienced since my diagnosis, I do have a regret that I must confess to you today. I regret not knowing more about the importance of having long-term care insurance prior to my diagnosis. Like many others, I never thought ahead about what the consequences would be if I was diagnosed with and suffered the debilitating effects of a chronic or terminal disease. I wish I would have known more about this field when I could have planned for my financial future. I do not have long-term care insurance, and therefore am left with only Medicare and its supplement to pay the cost for my treatment. I worry what will happen if something changes and Levi cannot take care of me. It's possible that we may need to access government assistance for future care, which could result in fewer choices and a diminished ability to select care options that appeal to my values and preferences.

It is so important that a person has a plan for long-term care, whether they can imagine a future where they would need to use it or not. Based on the financial plans and decisions Levi and I now navigate, I have stressed to my children that they do not know when a calamity may strike and they may need long-term care. I have suggested to each of them that they purchase long-term care insurance now before they get into a situation like mine—which we know can happen to anyone! I admire your work and the services you offer and advocate for, in order to help people who may need long-term care have more choice and less stress.

So today we celebrate! I have reason to celebrate because I live a life of purpose and joy. I serve as a spokesperson for people who need to hear about Alzheimer's, what it is like to live with Alzheimer's and, most importantly, how to live well with Alzheimer's! We also have reason to celebrate all of you and your incredible work, which can connect people with benefits that will enable them to live well—even if they find themselves needing long-term care.

My name is Tom Doyle. I have Alzheimer's but Alzheimer's does not have me. ■

