
Down Syndrome and Alzheimer's Disease: A Personal Story

Carol and Mike Peterson, parents of Mia Peterson



WE ARE THE proud parents of three daughters. Mia, our middle child, was born with Down syndrome – and she lived a full, independent life. From a young age Mia was blessed with a personality that made others want to listen to her. She wanted to help people with their struggles. She wanted to be a teacher. She wanted to be a friend. Mia was all of these. Her advocacy work took her to communities across the country.

When Mia was 41, she was diagnosed with Alzheimer's Disease. She went from mildly forgetful to confused. We took her to a clinic that specialized in disabilities and were told Mia didn't have Alzheimer's. Later that year, our fears were confirmed when a neuropsychologist examined her. She said not only did Mia have Alzheimer's, but she had "fallen off the cliff."

We tried to do everything right. As the disease progressed, we acquired things —a stair lift, a custom wheelchair, a ramp, and a specialized van. When the COVID-19 pandemic hit, we became Mia's sole caregivers. She developed a seizure disorder that required frequent telemedicine appointments with her neurologist and her memory care physician. Hospice came into the picture. We acquired a hospital bed to put in our den and stopped taking Mia upstairs to her bedroom. Mike began sleeping on a mattress on the floor by her side.

It was a struggle coming up with activities to engage Mia when she could barely communicate. We showed her pictures of the family and familiar activities from her busy life. We showed her pictures in cookbooks and talked about foods we might prepare. We played a game of tossing a balloon around the house. Every smile we got was treasured.

On the last day of her life, June 8, 2021, Mia struggled to breathe. With her family surrounding her and her Oregon family on FaceTime, Mia passed away. She was 47 years old. It was gut-wrenching and sad, but it was also a relief.

We remember one day, after Mia had mostly lost the ability to talk, she clearly said, "I'm lucky." Over the course of the next couple minutes, she said it four times. We wanted to tell her she was anything but lucky, but we knew she was trying to express gratitude. It was so very Mia.

Ours is ONE story. In recent years, four people with Down syndrome we know well have been diagnosed with Alzheimer's disease and passed away before the age of 50. All of them were amazing people, living healthy, impactful lives before they were diagnosed.

Since up to 90% of people with Down syndrome will receive an Alzheimer's diagnosis, our community needs to be included in all aspects of the Alzheimer's conversation. We are grateful to the National Down Syndrome Society (NDSS) for their advocacy, and we urge you to learn from them and work with them to improve outcomes for the Down syndrome community. Mia was an advocate all her life. We hope that, through sharing her story, her legacy of advocacy will continue. Please remember her and do what you can to advance legislation that will help families like ours.



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