



May 9, 2023

We are the parents of three daughters. Mia was our middle child. She had Down syndrome and lived a full, independent, vital life.

From a young age Mia was blessed with articulation skills and 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 both independently and with the National Down Syndrome Society took her to communities across the country. She was impactful. When Mia was 41 years old, she was diagnosed with Alzheimer's Disease. 41. She progressed from mildly forgetful to confused. We took her to a clinic that specialized in disabilities and voiced our concerns. After a thorough evaluation we were told Mia did not have Alzheimer's. Later that year our fears were confirmed when a neuropsychologist examined her. She said not only did Mia have Alzheimer's; she had "fallen off the cliff."

Mia's social skills had masked it. We were shocked! Mike and I quickly moved 80 miles to Des Moines to provide support, eventually moving into a house the three of us could share. Despite the understanding and support from her employers, we could tell other employees were covering for her confusion at work. We encouraged Mia to retire. The three of us embarked on Mia's Retirement Tour, traveling from one end of the country to the other visiting the people who loved Mia while she could still have conversations with them. We tried to do everything right. We followed a Mediterranean diet, exercised regularly, but failed in attempts to practice meditation. Mia and I became involved in a research project to explore the Down syndrome/Alzheimer's Disease connection with the Linda Crnic Institute for Down Syndrome in Denver. As the disease progressed we acquired things--a stair lift, a custom wheel chair, a wheel chair ramp, and a specialized van. When the pandemic hit, Mike and I became Mia's sole caregivers. Our independent daughter became totally dependent on us for all aspects of daily living. Mia developed a seizure disorder that required frequent tele-medicine (remember COVID) appointments with her neurologist and her memory care physician. We prepared mashed sweet potatoes and fresh fruit and vegetable smoothies with protein powder. We crushed her pills to make them easier to swallow.

Hospice came into the picture when we needed more frequent advice on daily care. They provided a nurse and a bath aide. At the nurse's urging we acquired a hospital bed to put in our den and stopped taking her upstairs to her bedroom. Mike began sleeping on a mattress on the floor by Mia. It was a struggle coming up with activities to engage her when Mia could barely communicate. We showed her pictures of family and friends and familiar activities from her amazing 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. Her sister, her brother-in-law, and nephew made COVID era visits standing on the porch and talking to Mia through a slightly opened window. Her sister from Portland made several masked visits. Her boyfriend from California called frequently. Hospice services expanded to a music therapist and social worker. We were doing pretty well, but we panicked when Mia stopped eating, even more so when she stopped drinking. The hospice nurse came daily, her sister several times per day. 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.

Through it all, Mia knew us. Perhaps she continued to know us because COVID's isolation allowed us to spend every minute of every day caring for and engaging with her. A vivid memory Carol has is of sitting with Mia on chairs at the dining room table. Mia had mostly lost the ability to talk, but clearly said to Carol, "I'm lucky."



Over the course of the next couple minutes, she said it four times. Carol wanted to tell Mia she was anything but lucky, but in her heart, Carol knew Mia was trying to express gratitude. It was so very Mia.

This is ONE story. In recent years we have become aware of how frequently this story repeats itself. Four people with Down syndrome we know intimately 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 with Alzheimer's Disease.

Because 80-90% of persons with Down syndrome will be diagnosed with Alzheimer's disease, the work NAPA does affects our community, the Down syndrome community, in profound ways. Because there is a known significant connection between Trisomy 21 and Alzheimer's Disease, we propose professionals from the Down syndrome community should be part of NAPA Council subcommittees, so we can more readily help each other.

It is very common that people caring for Alzheimer's patients in their homes are children caring for their parents. With Down syndrome the opposite is the case. As shared earlier, we were able to provide for Mia's needs in our home. We were old enough to be retired, but young and strong enough for the very physical work of caregiving. That is not always the situation. Many parents caring for their children with Down syndrome and Alzheimer's are significantly older care providers. The caregiving experience is more likely to be detrimental to the health of more senior caregivers, unlike what we experienced as the relatively young care providers for Mia. We have a request. Please recognize the full-time nature of older parents caring for their adult children. Provide these caregivers support and respite services.

We have additional concerns:

People with Down syndrome make up the largest group of early onset Alzheimer's disease patients. Therefore, it is important for research and treatment studies to include persons with Down syndrome. It is important for clinical drug trials to include persons with Down syndrome. It is important to include professionals with knowledge of Down syndrome in all aspects of the Alzheimer's disease conversation.

As for our story, while we were aware people with Down syndrome could develop Alzheimer's as adults, it wasn't really on our radar. Mia was so vital and so healthy--and so young.

We appreciate the opportunity to be heard. Thank you!

Carol and Mike Peterson
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