

# Down Syndrome and Alzheimer's Disease: A Personal Perspective

By: Jane Boyle

My sister Ellen's amazing life spanned 52 years. She lived at home and was a beloved member of her community. She graduated from high school at 21, worked for 20 years, and then attended adult day programs. A Special Olympian for 30+ years, she won countless medals in bowling, swimming, and other sports. She had an enviable social life and circle of friends and admirers. The list goes on.

At age 50 she was diagnosed with Alzheimer's Disease.

When Ellen was born in 1965, doctors said her life expectancy would be about 20-25 years. Medical advances have dramatically increased life expectancy for persons with Down syndrome (DS) and many now live into their 60s and even 70s. For many with DS, aging brings new challenges including a high risk for Alzheimer's Disease.

By the time Ellen turned 50, our parents had passed away and we had been living together for several years. I began to notice subtle changes in Ellen's functioning, cognition and behavior. These grew more pronounced and baffling. As the search for answers began, our family doctor ordered medical work ups, and vision and hearing checks. Many issues were ruled out, but challenges mounted and answers were slow in coming.

When Bev Roberts, Director of The Arc of NJ's Medical Mainstreaming Program, answered my desperate phone call, she listened carefully and understood exactly what I described. Her invaluable suggestions set us on a path to find medical specialists, occupational therapists, behaviorists and other supports specific to DS and Alzheimer's.

One was the *National Task Group on Intellectual Disabilities and Dementia Practices (NTG)*. Each month, the NTG's National Family Support Group brought together DS/Alzheimer's families and caregivers from across the country to share experiences and learn from experts in the field. I learned that while there was no cure for Alzheimer's, it was critical that I become well-informed in order to ensure the quality of life and quality care for Ellen.

The day Ellen was born in 1965, a pediatrician gave my parents simple advice: "Take her home and love her."

That advice endured. Ellen remained at home surrounded by family, friends and her faithful dog Sophie until her death at age 52 from complications of end stage Alzheimer's disease. In-home hospice supported her during her final months.

The support of caring professionals and the generous sharing of others traveling this same road made a great difference in the final chapter of Ellen's beautiful life story.

