



## Our Journey with Alzheimer's Disease

A Conversation with Michelle, daughter and caregiver of her mother

### **1. Tell us about your journey as a caregiver.**

Being a caregiver started even before my mother's diagnosis. My mother was an independent and bright person who lived out-of-state. We talked on the phone regularly and I began to hear things that just didn't sound right. She was good at covering things up, so at first it was hard to tell what was happening and how serious it was. I became increasingly concerned and went with her to see her doctor where we first learned of her diagnosis. Although the diagnosis of Alzheimer's Disease was not a total shock, I remember leaving the doctor's office with very little information, feeling unsure about the future.

### **2. How did your role as a caregiver change over time?**

My role as a caregiver changed slowly from being a concerned daughter to directing my mother's care. In my case, my mother agreed to move to Massachusetts but wanted to live independently. Involving her in the early decisions about her care was very important. As the disease progressed, my role became increasingly larger. I was regularly presented with complex decisions and didn't always know the right thing to do, even if I had a general idea of the options.

In caregiving, there are good times when things are working well, and also unpredictable difficult times; it's not a smooth road. For example, Alzheimer's is not just the forgetting and loss of abilities, but it also affects judgment. Paranoia and delusions are not uncommon, and the reactions of your loved one can be accusatory and hurtful. Even though you know it's the disease talking, it's still hard. Understanding the progression of the disease can help you be prepared for the different stages.

Eventually my role as a caregiver meant carving out a big section of my week. Things would pop up very quickly and it was hard to know if it was a major or minor issue. I often had to drop plans to deal with a problem. It can be emotionally draining and physically challenging. It's all part of this journey and why it's so important for caregivers to try to find a balance in the daily uncertainty and take care of yourself, so you are able to take care of others.

### **3. Did you have planning discussion with your mother regarding her choices for care?**

My mother had always told my siblings and I since we were children that she did not want life prolonging measures. If she couldn't live her life to a certain standard, she wanted us "to pull the plug." She never thought it would be her mind that would fail. She did not have planning documents in place, but was still competent at the time of diagnosis to do a Health Care Proxy and Durable Power of Attorney. In hindsight, it would have helped to have her planning documents in place long before the diagnosis so we



could have had more in-depth discussions about her preferences for mid-stage care and made sure the Durable Power of Attorney was acceptable to financial institutions. However, I felt my mother gave us a gift in that she was clear about her end-of-life wishes. When the time came and she couldn't speak for herself, my brothers and I all independently came to the same conclusions and believe we made the decisions she wanted. This made a very difficult journey much easier.

#### **4. What was helpful to you in your role as a caregiver?**

Information is key not only at the time of diagnosis but at every step in this journey. I needed both good medical information about medications and treatments, and practical information for what the medical changes would mean for my mother's safety, health, and daily support. For example, we had to change my mother's living arrangement from independent living to assisted living, and then, to a more skilled nursing environment. Moving can be very difficult for a person with Alzheimers. My mother would feel a great sense of panic and fear. The Alzheimer's Association has a caregiver's hotline that offered some wonderful advice on how to move my mother with the least amount of trauma. Also, my local Council on Aging was a great resource for practical daily living information.

The one thing that helped me personally was a caregiver's support group. It's people just like you caring for a loved one at all different stages of the disease. It was very helpful to hear other people's experiences to know what was coming down the road. Their support helped me feel more in control and I was able to plan better for my mother.

#### **5. What were some of the challenges toward the end of life?**

Alzheimer's is a terminal illness and at some point the care goals changed from curative care to keeping my mother comfortable in her everyday life. Finding the right doctors who understand the end-stage of the journey can make a big difference. Too often, caregivers find themselves at odds with treating physicians who are still prescribing mammograms, colonoscopies and preventative medications. I had to be a strong advocate for my mother and refuse unnecessary treatments that would cause her undo trauma, pain, anxiety, and worsen her cognitive condition. It's a very emotional time for families with incredibly difficult decisions. It is made worse when a doctor or nurse doesn't read a chart or you are placed in a position of having to defend your goals for care.

#### **6. What would you pass on to other caregivers starting this journey and their doctors?**

I am so thankful to the caregivers who helped me along the way just by listening and sharing practical strategies. I would say to caregivers starting this journey, think about a support group and find places that offer good information to help you prepare for the upcoming steps. Changing medical culture is not easy. Understanding the difference between helping people maintain a comfortable life verses prolonging life is a challenge and key to providing good care. For doctors and care providers, I would hope all would read the charts as they approach a new patient, and ask the caregiver/agent a very simple question- **"What are your goals for care?"** What a relief it would be to start a discussion with that mutual understanding of the goals and to work as a team to get the best possible care for your loved one.