Courage in Dementia Caregiving A PERSPECTIVE FROM A FORMER CAREGIVER

Honoring **Diane Beckley Milner**Milwaukee

Navigating the Caregiving Journey

November is National Family Caregiver's Month. A caregiver's burden is great, especially for those caring for a loved one living with Alzheimer's or dementia. I know first-hand the challenges of caregiving. In 2000 I moved from the Twin Cities to Milwaukee to care for my mother, who was living with dementia. My journey with my mom was short. It was just 3 years before she lost her battle. While it was difficult, I will always cherish that time.

Recognize the Signs

There is huge stigma attached to dementia and many families don't want to acknowledge it. Dementia is not a normal part of aging and it will not go away with time. Caregivers need to be prepared for the progression of the disease and the impact it will have on their lives.



Early diagnosis isn't easy, especially for adult children caring for their parents or grandparents. My mom went to multiple clinics and was seeing different doctors, so the signs of dementia weren't detected. I could see it right away though and quickly found a geriatric doctor to get her officially diagnosed.

Let's be truthful. A parent may not want to go to the doctor and their adult children don't feel comfortable pushing back. But mom isn't the parent anymore and caregivers need to take control and push the envelope. You must make decisions and become an advocate for your loved one.

Importance of Self-Care

When I moved to Milwaukee, I left a successful 20-year real estate career to become a full-time caregiver. It was very overwhelming and I had to learn so many things. I was what you'd call a "sandwich generation" caregiver, as I was also caring for my 3-year old son at the time. I learned quickly that I could not deplete myself. I had to balance two age groups – a high-energy child and a senior with dementia.

Caregivers must be adamant about self-care. I had a friend whose mother was caring for her father, living with dementia. The mother also had diabetes and wasn't taking care of herself. She wore herself out to a point she couldn't be an effective caregiver.

For the three years I cared for my mom, Thursday was always my day. I dropped my mom off at a day center and did things I enjoyed. That's the way you love the person you're caring for – you feed your own soul. I always ask caregivers, 'what have you done for yourself lately.'

Finding Caregiver Resources

Today there are many excellent programs in place to support dementia caregivers. The Alzheimer's Association offers free information and resources for caregivers, including care consultations, education programs, support groups and 24/7 Helpline support at 800.272.3900. Many tools, tips and online education can also be found at alz.org. Twenty years ago, I had to find resources and available services on my own. I joined two support groups – one at the Alzheimer's Association and one at our doctor's office. In that setting you can just be yourself, ask questions of others on the same journey, and there's no sugar-coating the discussion.

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