



The holiday season is a time of giving. At the same time, the joy of putting others first sometimes overshadows the need to take care of yourself. The following timeless story reminds us that we need to be gentle with ourselves during the hustle and bustle that comes with holiday activities - particularly if caring for a loved-one living with dementia. It's not a personal failure to feel overwhelmed, and reaching out for support is the best thing you can do for yourself and those you love.

Joanne's Story

Joanne participated in the Savvy Caregiver Program, which provides training and support for those actively caring for friends or family members with dementia. This program is generously supported by the [Harvard Pilgrim Health Care Foundation](#) whose leadership understands that families play an important role in caring for individuals living with Alzheimer's and related dementias.

Devoted Daughter

Caregiving seems to be in Joanne's DNA. She was a loving and committed daughter who would never dream of putting her mother in a nursing home.

Joanne's mother, widowed for 30 years lived down the street from her. Joanne had a brother who was involved and always eager to help, but he lived a town away. It seemed only natural that she would keep an eye on her mother. "Throughout the years I always went down there and made sure she had company because she secluded herself," Joanne recalls. "She was happy in her own home so I made sure she was OK."

As Joanne's mother grew older, Joanne began doing more chores for her. "I did her food shopping- took her to the doctor – cleaned her house – raked her leaves – you name it. I was her everything," says Joanne.

It was Joanne's brother who first learned that their mother showed signs of cognitive decline. Feeling overwhelmed by caretaking duties, Joanne asked her brother to take their mother to a doctor's appointment. "One day he came and told me – just in passing – that the doctor said she showed symptoms of the beginning stages of dementia – nothing more than that," Joanne remembers.

This memory stands out to Joanne because she was given so little information that would prepare her for what she was about to face as her mother's disease progressed. Like many families, Joanne thought that dementia was a normal part of aging.

New Signs that All was Not Well

As time went on Joanne's mother started falling. "She gave me crazy reasons like this flashing light came in and knocked me over. That was the beginning of hallucinations, but I didn't know it," says Joanne. "I thought, she's not being careful. We blamed her."

As the falls became more frequent, Joanne found herself at her mother's house more, and less at her own home. Eventually Joanne was sleeping over at her mother's house, struggling to fulfill all of her work and family obligations and somehow make it all work. But something had to give, and eventually Joanne's mother moved in with her, where she lived for four years.

At first everything seemed fine, and Joanne continued to go to work. But by the third year she had become more vigilant, calling her mother every day to check on her. A turning point came when Joanne discovered one day that her mother had not eaten lunch even though she professed otherwise. As Joanne realized that her mother required closer supervision it became impossible to work outside the home.

The Diagnosis

It was also around this time that visits to the emergency room became more frequent, and Joanne first learned about Lewy body dementia (LBD). LBD affects brain chemicals that can lead to problems with thinking, movement, behavior, and mood. LBD is the second most common form of progressive dementia after Alzheimer's disease.

According to Joanne, "During one trip to the ER I told the doctor that my mother was walking, and all of a sudden she couldn't put one foot in front of the other."

Although only an autopsy could confirm his diagnosis, the doctor felt that Joanne's report and past records pointed to LBD as the cause of her mother's symptoms. Armed with a diagnosis, Joanne hired an aide to come in three days a week to help out. But now, Joanne was starting to suffer as well. Dementia is often referred to as a family disease for good reason. She was coping with her own symptoms of stress and felt very alone.

"I found myself getting really burnt out," says Joanne. "I was scared more than anything else, because I'm not a nurse or a doctor and didn't know how it would go. I was taking it one day at a time."

Finally, the disease progressed to the point where Joanne could no longer care for her mother at home, and she put her in a nursing home where she lived for a year and three months. Looking back Joanne can now see that the disease had presented four years earlier, when her mother started to fall in her own home.

You Don't Have to Go It Alone

Joanne first learned about the Savvy Caregiver Program from another family during one of her mother's rehab stays. She confesses that she enrolled in the program primarily for herself. She needed to be with people who were going through the same thing, convinced that no one could understand what she was feeling unless they shared a similar experience.

Joanne had her husband and children for moral support, but she didn't want to burden her children. According to Joanne, "I wanted my daughter to have her life and go out, because she would have stayed home if I needed her to, and I didn't want that."

Joanne's struggle to care for her mother in the early stage of LBD stands in stark contrast to the support and tools she received as a participant in the Savvy Program. Through educational workshops, Joanne came to understand that her mother's behaviors were symptoms of the disease and gained new skills for managing her relationship with her mother as the disease progressed.

"The Savvy Program helped me embrace the remaining time with my mother and enjoy it because I understood the personalities that were coming out were symptoms of the disease," says Joanne.

But perhaps the most profound benefit Joanne received from Savvy was the support she received from other participants who could understand her sense of “going it alone” as a caregiver.

“The only thing I ever wanted from anybody was – how are you doing? How’s it going? That’s it. Not even do you need my help, but how are you? That’s all you want,” says Joanne.

Joanne has become a champion of the Savvy Program and eagerly shares what she learned with other families who are caring for loved-ones with dementia.

“Every doctor should know about Savvy,” says Joanne. “That way caregivers can understand before the disease progresses that they can be a comfort to their loved-one who is living with dementia.” And they learn the importance of taking care of themselves.

The Savvy Caregiver Program is an example of the evidence-based programs offered by Elder Services of Merrimack Valley and North Shore’s Healthy Living Center of Excellence, which means their benefit has been proven or informed by research and evaluation. These programs are designed to promote healthy aging among older people.

A grant from Harvard Pilgrim Health Care Foundation supports two evidence-based programs offered by including the Savvy Caregiver and Matter of Balance Trainings in Massachusetts, Maine and New Hampshire. With this grant the programs aim to train 40 Master Trainers, who in turn will train community-based coaches to implement workshops for close to 750 program participants.