

## **A Portrait of Unconditional Love**

Caring for a loved one with dementia is not for the faint of heart. Witnessing someone you love deeply slip away is painful, particularly when that someone is your spouse. The mutual support, communication, shared memories, and romantic intimacy that define a committed relationship gradually fade.

It takes a special person to care for a spouse as dementia erodes the foundation on which a marriage is built. According to a 2017 report from the Alzheimer's Association, thirty-three percent of spousal caregivers in this situation are men. Norm is among that minority who care for a loved-one with dementia in the home, and his story paints a portrait of what true love and devotion look like.

## **Confronting a Devastating Diagnosis**

Several years ago, Norm began to see changes in his wife's behavior. She had become unusually temperamental, but Norm thought maybe she was just depressed. She had survived a bout with breast cancer 20 years earlier, and the cancer had returned. As Norm says, "because a lot of us are getting older," he thought the changes in her behavior came with the territory –perhaps she was having difficulty at 60 adjusting to age-related change and a renewed health challenge. He convinced her to see a psychiatrist.

After several visits, and drug treatment, Norm saw no improvement. He also noticed that her speech was becoming slurred. That's when he decided to take his wife to a local hospital for further evaluation. Ten hours and multiple tests later, the doctor decided to perform one final procedure - a brain scan. The results were not good. Norm recalls the devastating news the doctor gave him, "We're not dealing with depression or psychosis - we're dealing with a neurological disease. Your wife's brain is deteriorating."

Norm goes on to say, "As a lay person, I didn't know what this meant. The doctor advised us to see a neurologist who could better explain the situation and boy, did I get woken up." Norm decided to get a second opinion from a top neurologist at a leading Boston hospital, which confirmed a diagnosis of Frontal Lobe Dementia, also known as Frontotemporal Dementia or FTD. FTD is caused by progressive nerve cell loss in the brain's frontal lobes.

There is no cure for FTD, or treatment to slow disease progression. Norm uses the image of Pac Man to describe what's going on to his friends. "Pac Man is slowly consuming her brain, and there is no way to slow down Pac Man - it's just doing its thing."

The lifespan for someone with FTD is normally eight years from when the disease first presents, but Norm doesn't really know when FTD began in his wife. The behavioral changes that he observed before diagnoses, and which were inexplicable at the time, were probably symptoms of FTD, but he didn't recognize them as such. Norm guesses that he may have only a year to a year-and-a-half left with her.

## **Changing Roles from Companion to Caregiver**

Norm's wife is turning 64 in two months, and he describes her as "having the brain of a two-year old." Picture the behavior of a child that young, and you can start to imagine what Norm is up against. The tragic difference is that a normal two-year old can expect to cognitively progress as time goes on. Norm's wife will continue to regress. Her eating skills are deteriorating, and she lacks the ability to maintain proper hygiene on her own. "My wife doesn't know how to keep herself clean and groomed,

and doesn't want to," says Norm. "She doesn't speak much anymore because she doesn't know how to formulate words. It's very difficult."

Norm holds onto, and is grateful for the vestiges of his relationship with his wife that remain. She seems to still recognize him. "When I say good night to her, she'll roll over and give me a kiss," he says.

That's not the case with her sons. According to Norm, "Our son, his wife and two grandchildren came for a visit. We all went to the daycare center where my wife spends time to pick her up. She had absolutely no idea who our son was, and that was very hard for him."

Despite the heart break and physical challenges involved with the care of his wife Norm is determined to stay the course. "It's a comfort when people who've gone through a similar experience offer help, and when I thank them, they reply that I'm doing a good job," says Norm. "I've heard that other people just give up and put their spouse in a care facility. I've been married for 36 years. I'm not just going to give that up. She may not know what's going on, but I do. It's like anything else – you stick with it to the end."

### **Seeking Support**

Norm needed support in his new caregiver role. As so many other family caregivers report, sharing the experience with others in the same boat helps ease the stress, and the sense of feeling overwhelmed with fatigue, emotions, and isolation. His HR department sent him information about the Savvy Caregiver program, which was being offered nearby and Norm decided to give it a shot.

Norm reports, "The Savvy Program was so helpful because it prepared me for what's going to happen as my wife's condition worsens. I wanted to get as much information as I could about resources that are available to help family caregivers like me. I'm basically in this by myself."

After completing the training, Norm offers the following advice:

- **Get as much support as you can.** "Elder Services of the Merrimack Valley that sponsors Savvy does a wonderful job of locating services for you. Try to utilize them as best as you can."
- **Learn about the disease itself.** "Understand why your loved one behaves the way they do. You can't get mad at them. They've lost the ability to analyze, and they can't relearn the skills needed to remain independent."
- **Cultivate patience.** "Patience has never been my strong suit! Caring for my wife is teaching me patience one way or another."
- **Take care of yourself.** "Learn how to keep yourself healthy. It's like being a mother – you're not going to lie in bed when your kids are up and need you. Discover ways to take breaks and find time for yourself."
- **It's an emotional rollercoaster, so look for bright spots.** "Because of my wife's disease she doesn't show emotion. How do I tell if something is wrong? I try to make things as comfortable for her as possible and make the best of the time we have left together."

The Savvy Caregiver Program is an example of the evidence-based programs offered by Elder Services of Merrimack Valley'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 Elder Services of Merrimack Valley's Healthy Living Center of Excellence, 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.