

Things Don't Always Make Sense

Written by Kevin Dinstell for Health Stories Project

At 26 years-old, Anna Brancheau was fulfilling one of her lifelong dreams: living abroad. She had moved to Berlin after finishing college, established a great circle of friends and had a good job. She had even learned German well enough to envision a life there.

In late 2009, Anna traveled home to Edmonds, WA for her brother's wedding. It was a joyous occasion, but she and some of her relatives noticed that her mother, Nancy, was behaving unusually and was having trouble remembering certain people and events. Those who didn't know her very well may have chalked it up to excessive celebration, but Anna had a feeling there was something else going on with her mother.



Upon returning to Berlin, she began to grow more and more concerned about her mother with each phone call. "We're really close, so I knew something was wrong with her," says Anna.

Although she had noticed changes in her mother's speech, it was the frequency with which 57 year-old Nancy, a high school art teacher, told Anna she was being called in for disciplinary meetings with the school board that really alarmed her.

"All of a sudden, she was forgetting to do routine things like take attendance, turn in grades, and return phone calls from the parents of her students," explains Anna.

Realizing how out of character this was for her mother, Anna contacted the school principal to let her know she feared there was something seriously wrong with her mother. Soon thereafter, Nancy went on paid medical leave. Anna returned home to Washington and over the next couple of weeks, she and her mother went to see three different neurologists to try to determine what was happening. After the possibilities of a tumor or stroke were ruled out, Nancy was diagnosed with both Frontotemporal Dementia (FTD) and early onset Alzheimer's Disease.



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While both of these are forms of dementia, a general term for loss of memory and other intellectual abilities, there are some key difference between them. Most people with FTD are diagnosed in their 50s or early 60's and rarely beyond, whereas Alzheimer's grows more common with increasing age. Memory loss isn't a prominent symptom in most cases of early FTD, so Nancy's neurologists attributed hers to early onset Alzheimer's. One of the most telling signs that Nancy was experiencing FTD was how rapidly her speaking abilities were declining, an unusual occurrence in most Alzheimer's cases.

"One of the hardest parts was that my mom kept forgetting the diagnosis," says Anna. "I don't think she ever really understood but eventually I just let it go because it wasn't that important. The last doctor was very up front about how it was going to impact our lives and what I needed to do to prepare. I still wasn't ready for how

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it would change me and my family. I mean, how can you be?"

Anna moved back home to take care of her mother in February of 2010. It was clear that Nancy wouldn't be able to return to work, but it fell on her daughter to explain this to her. "It was really hard because she couldn't really understand," says Anna. "But I was afraid that if I didn't intervene, she would have been fired and then she wouldn't have qualified for disability benefits. She had worked for the district for so long and had disability insurance so we had to act."

The transition that Nancy faced over the following weeks and months was very difficult. She quickly began to lose her ability to safely perform everyday tasks like cooking and driving, as well as more complicated matters like managing her finances.

"I had to slowly take these things away while trying to preserve her integrity," explains Anna. "I had to put a hold on her accounts because she would withdraw money and over-donate to charities. Other times I would find it under her mattress and have to deposit it back in the bank."



For Anna, taking on this new role was abrupt and left her feeling conflicted.

"You go from being somebody's daughter to being their caregiver," explains Anna. "One day it just transformed. People told me I was so great to do it, but at times I would hate it. I would get mad. She couldn't dress herself properly and started to become incontinent. It was like having a 60 year-old child. Somebody becomes completely dependent and it can be frustrating but you can't blame them because they can't control it. I had to learn to be patient but it was really hard."

The hardest part, though, was when Anna's own mother looked at her and didn't remember who she was.

"It happened on a train, when we traveled back to Germany together to collect the belongings from my apartment there. She asked me who I was and wanted to know where I was from and where my family was. You can't react shocked because that will make her feel confused and frustrated and scared. So I just told her about myself like I would to a stranger. Even then, she kept saying that I wasn't in any of the pictures and would often confuse me with one of her sisters."

Writing about her experiences has been helpful for Anna. For several years, she shared her journey through a blog called "[Mama Forgets](#)." In addition to allowing her to vent about her frustrations and keep friends and family updated on Nancy's health, it's been a place where she can capture some of the more lighthearted moments that she and her mother share.



"One time we were walking around a lake and she was so engrossed with the flowers and the trees, like a child seeing the world for the first time. And then she'll go and do things like put ketchup in her iced tea," Anna says with a smile.

There are also situations that have been absolutely terrifying. Although Anna would lock and alarm the door to their house to prevent Nancy from wandering outside, there were times when her mother slipped out unnoticed. On one occasion, she ended up in a Seattle park about 13 miles away, sitting on a bench in the cold, with sores on her feet from walking so

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far. That was where the police found her. That was also where Anna and some family friends found her several months later, when she wandered back to that exact same spot.

Fortunately, Anna hasn't had to go at it alone. Soon after moving back to Edmonds, a family friend named Pattie moved in to help take care of Nancy, sharing the daily tasks of bathing, feeding, entertaining her. She lived with them for about two years and "was an absolute blessing who cared for my mother like her own family," according to Anna.

Her brothers have also stepped up to help share the responsibility of caring for their mother. "Sometimes having a sick parent can really damage relationships between siblings," says Anna. "But I think it's brought me and my brothers closer. It's strengthened our relationship. If my mom could understand how they're doing now, she would be so proud."

As the diseases have progressed, Nancy has lost the ability to display much emotion through her facial expressions. Anna has found creative ways to get through to her and make her smile.

"We were raised Catholic and my mother is very strong and passionate about her faith," she explains. Although Anna is not a practicing Catholic anymore, she still remembers many of the prayers that she would recite next to her mother in church.



"When I whisper prayers in her ear, she sort of comes to life. I think it gets to the far reaches of her memory. To get her to smile is a big achievement." Anna has also found that playing music and dancing around her, two other things Nancy has always loved, can bring out a smile as well.

Since her diagnosis, Nancy has taken two medications continuously, Aricept and Namenda, in hopes that they would slow down her cognitive deterioration and decrease the severity of her symptoms. Without anything to compare to, Anna can't really say how much it's helped, though.

After Nancy suffered two grand mal seizures and became very sick, Anna realized that it was no longer within her capabilities to manage her mother's medical care on her own. She made the difficult decision to move Nancy to an adult family home, where she now lives with four other residents and receives 24-hour care from professional caregivers. Anna and her brothers visit her a couple of times each week, but she still deals with constant feelings of guilt that she can't do more to help the woman who raised her.

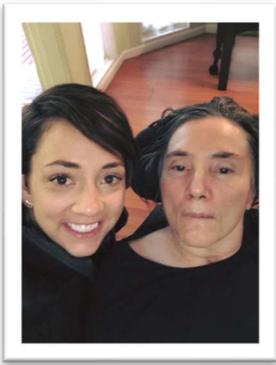
Getting Nancy the professional care that she needs has also allowed Anna to attain more balance in her own life. She was able to become certified as a yoga instructor, something which has really helped her come to terms with the realities of losing her mother to this disease and changed the way she reacts towards life's hardships.

During those first few years, one of her main sources of strength and inspiration came from a support group she discovered through the [Western and Central Washington Chapter of the Alzheimer's Association](#).

"It was a breath of fresh air," says Anna. "This was for young adults with parents with early onset Alzheimer's. I remember going there and meeting these two brothers whose mom had the same symptoms as my mom. I was so excited to share stories and experiences with people who got it - in an open, honest, and trusting place. You feel so alone and wonder why this happening to you, but then you realize it's happening to other people as

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well. It helps you come to terms with your new reality.”



Finding humor amidst the pain was a critical part of the support experience for Anna and some of the other group members. They even created a “GUILT” jar – every time someone said the word “guilty,” (a word used all too often by caregivers to describe how they feel) that person would have to pay into the jar. The money would be later used for the group to do something fun together, like have a pizza party.

In addition to support groups like this, the Alzheimer’s Association offers a number of other resources for caregivers, such as [24/7 Helpline](#) that people can call with questions about symptoms, medications, professional care, and advice for making legal, financial, and living-arrangement decisions. They also feature a [Caregiver Center](#) where people can find all kinds of different resources and connect with others

who are in similar situations.

November is both **National Alzheimer’s Disease Awareness Month** and **National Caregiver Month**. It’s a time to recognize the devastating impact this disease has on Americans, well as the amazing people who step up to help take care of those who suffer from it.

So just how big of an impact does Alzheimer’s have? Here are some sobering statistics:

- Alzheimer’s is the 6th leading cause of death in the United States
- More than 5 million Americans are living Alzheimer’s
- Every 67 seconds, someone in the United States develops Alzheimer’s

That’s why it’s so important to spread awareness about Alzheimer’s – people can make a difference by supporting vital research and essential programs and services to fight this disease. If you would like to make a donation to the Alzheimer’s Association, please visit their website [here](#).

Anna hopes to make a difference of her own by sharing her story with others. She also has some advice for people who are caring for someone diagnosed with Alzheimer’s or another form of dementia:

“Try to take care of yourself. You can’t do it all. People wanted to help me and I would push them away because I thought I could do it better. But accept help and don’t worry if everything doesn’t go exactly the way you would do it. Read books about it, but you can’t compare your situation to others because every situation is different from the next and everyone deals with it differently.”



Although the experience hasn’t been easy, Anna believes that it’s humbled her and made her grounded, leading her to be able to have a healthy relationship with her boyfriend and get a great job in Seattle.

“My mom is the most amazing, compassionate, unselfish person, and I hope that I can be half the woman and mother she is. I am heartbroken that she won’t be part of my next chapter in life, or get to know her granddaughter, my niece. She would have been an amazing grandmother. She of all people didn’t deserve this, but things don’t always make sense.