

Dad Got Dementia When He Wasn't Old, Neither Was I

By Christina Gebel

I always thought I'd plan a wedding before a funeral.

At first glance, they have a lot in common: getting the venues, choosing the food for the reception, sending out an announcement, printing the program, choosing readings for the Mass or service, asking friends and family to fill positions of honor, and writing thank you cards. I remember one of three "hitting rock bottom" moments I had in July of 2014. I was at the post office to mail over 200 thank you cards, small cards in envelopes stamped with white roses.

"You must have just gotten married!" said a well-meaning man in line to the counter.

"No," I said, "My dad died."

My father passed away on June 20th 2014 at the age of 68 from [Frontal Temporal Dementia \(FTD\)](#), a rare form of dementia. That's how the textbooks and doctors describe it. I just say it's a horrible disease.

We first started noticing something was wrong the moment he woke up from his second open-heart surgery to replace an aortic pig valve (the first surgery having been 10 years earlier). We were told for one year that it "takes about a year for the surgery anesthesia to leave a person's body" and told by his primary care provider to wait a year before pursuing any further tests. After a year of my dad not quite acting like my dad, we saw a neurologist who did one MRI and confirmed a diagnosis of FTD. Many people with FTD ([nearly half](#)) are [misdiagnosed with depression or a mood disorder](#) and told to go home and take anti-depressants, so we were lucky it was diagnosed properly. At the same time, it's hard to say we were lucky.

FTD is a seemingly hopeless disease. No matter when you're diagnosed, there's no good news or rays of hope that follow. There is no cure. There is no treatment. There are no tough decisions to weigh. There are no surgeries. No therapies. No chemo regimens. No PET scan that might bring some good news, at least for a bit. No pills to take to slow the progression. In short, no options. We were told how it would go and how it would likely end (slowly losing many abilities, including his ability to communicate – something we already noticed – until in his final days he would lose his most basic functions, like his ability to swallow). You are basically told to go home, make arrangements, and try to get the best care you can to make the years ahead as good as they can be.

All of this started when I was 24 years old. For five years, I learned a lot about things I thought I'd have at least two more



Christina Gebel, left, pictured with her father and mother. Her father, diagnosed with FTD, passed away in June 2014.

decades before I worried about: long-term care; nursing home wait lists; adult day care; Medicaid "spend down" ([which is a euphemism for depleting the assets a family has worked and](#)

[saved](#) a lifetime for); Medicare; [Do Not Resuscitate orders](#); a variety of drugs that work for a couple weeks or couple hours, then don't work at all; [advance directives and a power of attorney](#); [elder law lawyers](#); death certificates and cemetery plots; choosing a casket; military burials and 21 gun salutes; Catholic burial; and cemetery rules for grave markers, including what can be placed on graves seasonally.

I envied so many of my peers. They were thinking about save the dates, wedding bands, honeymoons, bouquets, dress fittings, songs to play at the reception, cake tastings, buying a home or condo, remodeling a fixer-upper, how they would post the announcement of their first pregnancy on Facebook, which baby carrier to buy, and when it was time to conceive baby number two.

Those were things I would have rather worried about or picked out. I told my counselor so many times that I felt as though everyone was at a fun reception on a party boat, and I was treading water, vigorously signaling to the boat. I wanted to get back on. And my family was in the water with me.

What my dad was going through was only half of it. This disease affected everyone in the family, particularly my mom who cared for my dad tirelessly, all day and all night. *(continued on next page)*

"...we were lucky it was diagnosed properly. At the same time, it's hard to say we were lucky."

(continued from previous page)

During the night, he would wake up once every 45 minutes and pace and run into the wall and start putting on his clothes at 2:00 AM, as if it were morning. He paced all day long. Once a social man who loved parties, he would get somewhere and want to leave right away. It tore my mom's heart to pieces to watch her partner and best friend of nearly 45 years of marriage and five years of dating become a stranger of sorts. My brother took care of him, too, sometimes staying overnight just so my mom could get two straight hours of sleep. Everyone grieves. You start grieving the loss of your loved one while they're still alive, and you grieve years before they die. And years after.

Even with having the best friends in the world, I spent many days those five years feeling alone – the type of alone you feel in a room full of people. On top of that, FTD is not a disease that is easily understood by the general public. To them, and to me before all this, it was an "old person's disease." Only old people get dementia and Alzheimer's. Alzheimer's and dementia: same thing, right? [\(They're not\)](#). It means they just forget stuff and don't know where they are. [\(I so wish those were the only two symptoms!\)](#). Well, there are nursing homes to help, right? I can't tell you how many well-meaning people told me they were "so glad" my dad got into a nursing home so my mom could get some relief. My mom was utterly depleted and sad, and my dad was alive yet living in a nursing home. Trust me; there was not much to be glad about. But, you could keep him home and get help, right? [\(few can afford it!\)](#) I had many conversations about nursing homes with people more than twice my age. They were putting their moms and dads in one, as well. Sometimes, I seemed to have more in common with people in their 40s, 50s, and 60s than with my peers. This was not what I signed up for. I never thought things would go this way.

I always thought my 20s would be marked by only the happy milestones you dream of, like launching my career, getting married, having kids, and bringing them to grandma and grandpa's house to be spoiled. However, I seemed to be behind on happy milestones and way ahead on unhappy ones.

In truth, though, I wasn't entirely alone. There were many good people along the way. I was blessed to have a friend in my graduate school class whose dad had FTD and passed away, who reached out to me, even when I didn't have the



Author Christina Gebel's parents, pictured above, were married for more than 45 years. Prior to living with FTD, the couple enjoyed many social opportunities together.

*"In truth...
I wasn't entirely alone.
There were
many good people
along the way."*

energy to reach out to her. I became a lot closer with my friends whose parents were sick or had died. While it was still a nursing home, I maintain the home that accepted and cared for him was the best one I have ever seen. The staff was exceptional, and they honored his dignity in caring for him.

The same friend whose dad had FTD started a private group for young adults in their 20s and 30s on Facebook, who have or had a loved one suffering from FTD; I realized I was part of an invisible group of young people that was gradually becoming visible. One member had a [spouse who died from FTD in his 30s](#). His 30s. And even though they couldn't fully understand what I was going through, my friends who had the courage to sit with me in my emotions and just let me be sad or cry were a blessing. A group of friends dropped everything and flew or drove in for the funeral. I was sent cards and messages by people who didn't know what to say, and a lot of times there wasn't anything to say except, as one good friend who had lost her mom years earlier from cancer put it: "It just sucks."

I always thought I'd plan a wedding before a funeral, and I always thought I'd plan a wedding with my dad in it – to have that moment where he walks me down the aisle, beaming, and gives me away to my husband. I always thought dementia was an "old person's disease." I always thought people in their 40s and 50s, not their 20s, had to struggle with putting their parent in a nursing home. I have always thought FTD is a hopeless disease, but maybe, someday, there will be hope.

Christina Gebel holds a Master of Public Health in Maternal and Child Health from the Boston University School of Public Health. She is a birth doula and certified Lamaze Childbirth Educator as well as a freelance writer, editor, and photographer. She currently resides in Boston working in public health research. You can follow her on Twitter @ChristinaGebel

*This article is being published by
The Association for Frontotemporal Degeneration (www.theaftd.org)
with the permission of the author.*

**AFTD is a non-profit organization with a mission to improve the quality of life of people affected by FTD and drive research to a cure.
For more information about FTD, email info@theaftd.org or call 1-866-507-7222**