

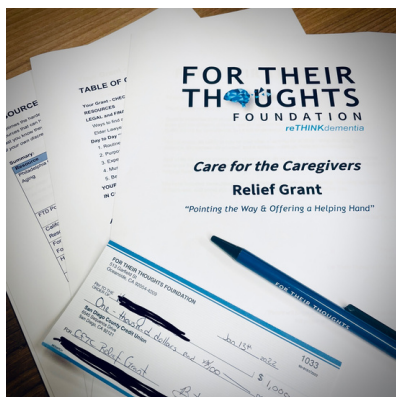
Care For the Caregivers Relief Program

CFTC -Grant Recipient

Diagnosis of loved one - FTD

Age at diagnosis: 50's

Meet Alex and his mom, Debi



“She took care of me, it’s only fitting that I can honor her with taking care of her now.”

But who expects to say that at only 25?

“My mother first

showed symptoms in 2016 when she started cutting with her knife blade up at a dinner and argued to the point of screaming with my father and I that we were wrong when we tried to help her.

“By 2017 she and I almost got into a traffic collision because she forgot how to drive when entering a four way intersection. She was then diagnosed with FTD [frontotemporal dementia] that same year.”

Since the diagnosis Alex has been her primary caregiver. FTD is a rapid brain degenerative disease and within two years of diagnosis Alex left his Master’s program and moved in to provide full-time care as her condition worsened. Debi has lost her ability to speak, use her hands, and walk. When we spoke with Alex we asked him standard questions to understand his situation. His responses echoed **the two recurring themes we find with every family caregiver:**

When asked what his biggest needs were to help him help his mother; he mentioned **finances but he emphasized the need for emotional support.** Having someone to talk out the disease’s evolving challenges without having to over explain or be judged was more important to him than solely financial support. At only 25 years old Alex often goes four to five days without leaving their apartment or talking to anyone else.

Yet he would never have it any other way. Caregiving is an opportunity for him to “give back” to his mother who has always been there for him.

Bringing us to the second theme: Like all the others, putting his mother first is integrated into the very core of his nature, and his “commitment to duty” is reflected in his response to the question, **“What words of wisdom would you like to share to help other families/caregivers experiencing dementia with their loved one?”**

“In the beginning I wasn’t given a manual or any guidance on what being a full-time caregiver was going to be like. It was through trial and error I developed strategies to assist me on my duties.

These are just a few tips out of many, but I hope they aid [others] on [their] caregiving:

- Understand that this is a messy and often an unfortunately thankless commitment; **we do it because they need us and we love them, that is what matters.**

- **It is critical to remember that their actions are not their fault, but the disease.** From dealing with their fits of rage, paranoia, mood swings, extreme change in appetite, and even forgetting who you the caregiver are, give yourself a moment to step back once in a while to take a deep breath. Here are some tips of what I found to help me the most during caregiving...

- **Get yourself disposable plastic gloves** to use for anything bathroom related or feeding purposes. The gloves will save you stress from bodily fluids. Sometimes it's easier to feed by hand than utensils as they may bite down on them and won't let go.

- **A shower bench** for them to sit on makes washing much easier as well as tearless shampoo.

- If your loved one picks at their skin long sleeve shirts and **Dementia mittens work wonders.**

- Having available cheap clothing for them to wear and for you to throw out in case of urination accidents, throw up, or drooling that the washing machine can't handle.

- **Playing music** they know can help calm them down.

- **Create bedtime schedule** around their tendencies and take them to the bathroom before tuck in.

- **Keep a ledger** of what times they wake up at and when they get tired to narrow down a bed time schedule.

- Often times they will wake up in the middle of the night and roll so **bed rails** are paramount.

- Try not to let your loved one stand for too long as their feet can swell or sit for too long as their joints may stiffen. **If their feet swell a warm foot soak helps.**



- Try to **switch pill medication for liquid** if you can so it's easier to swallow.

- A food processor helps get food to a manageable state for their consumption since they sometimes cannot fully open their mouths to eat or drink properly. **Most importantly go with the flow of your loved one, work with and around them, do not expect them to do what you want how you want it.**

Our interview with Alex gave us a better understanding of his current position and resources. Leaving college and a job to care for his mother, but also paying for everyday supplies such as gloves, adult diapers, bed rails, cleaning supplies, and clothes creates financial and emotional strain. FTF has been able to provide Alex with a customized care resource package that includes local support groups and contacts, palliative and in-home care options, and a financial check of \$1000 for relief and respite. **Money cannot change his situation, but we hope that along with the resource package it will bring him some semblance of relief and continue care options.**

Thank you, Alex for everything you are doing for your mom and will continue to do for her. **FTD may have taken away her ability to express her feelings, but she is still your mother; and proud of you beyond all words.**

**Names have been changed at the request of the family to protect their privacy.*