

## AFTD Comments for NAPA Council Meeting October 24, 2022 - Melissa Fisher

Good afternoon. My name is Melissa Fisher I live in Oregon and our family's long term care access experience represents the disease of frontotemporal dementia and finding LTC care for my dad on the island of Maui. I am also the Oregon State Ambassador for The Association for Frontotemporal



Degeneration and have been sharing our story far and wide in the hope that we can improve access, experience, and create training and more inclusive care for this lesser known dementia.

After 10 years of observing increasingly odd and uncharacteristic behaviors and another 3 years of actively seeking a diagnosis, in March of 2018, at the age of 70 he was diagnosed with behavioral variant FTN – that is severe frontal and temporal lobe atrophy, his

MRI also showed vascular dementia.

The incidents that led up to his diagnosis would take a lot longer than two minutes to explain, but he went many times to the ED, six times to county jail in less than a three month timeframe, stealing alcohol from stores with an eventual lifetime ban from Costco, wandering for miles, breaking his tibia on one walk -- not believing his doctor it was broken and refusing care, had several delirium induced episodes - jumping out of a moving car and attempting to “enter” the bathroom in the 9<sup>th</sup> floor of a hotel that was actually a balcony while my mom desperately held him back, are just some of the more horrific experiences, mostly faced by my mom dealing with my dad.

Being that Maui county is rural, placement options for my dad were not many. Like just two – both run by the same company. She attempted to hire in home care, but he would not allow it, she tried adult day care to get even a short break, but on the very first day, he was able with no tools to dismantle the locked gate mechanism, alluding security and get several miles away before the staff discovered he was missing. They had assured her that they knew what FTN was and would not have any issues. In reality they were wholly unequipped to manage my dad for even a few hours. He was still strong physically, but his brain was selectively broken. He retained all of his professional mechanical capabilities, but he had no ability to control impulse, understand time, short term memory, empathy, or awareness of the impacts of his actions on everyone around him. He still managed to be a kind loving father, husband, and person that he always was, but it took everything we had to keep him safe. My mom could not even get help from the only 5 bed psychiatric ward on island, even for temporary placement while she tried finding medications that would help – citing he had a brain disease not mental illness.

A year into his diagnosis, my mom simply couldn't do anything more and the situation was dire, so she reached out to the one privately owned place that had a “memory care”, and sharing her story, they denied her flat out, citing liability. He was too young, too active, and yet even with dementia they wouldn't take him. A year later a new administrator came in, someone my mom knew, and so she tried again, desperate for help. This time they said yes, sharing that they knew what FTN was, their staff trained in it, and capable of meeting his care needs. My dad did not have Alzheimer's, and I knew Alzheimer's well as my maternal grandmother had it and at the end of her life died alone in a geriatric psych ward in Oregon – a week after placement, moved because they said she was combative at her care home. That memory haunts me to this day, and what happened next for my mom is not acceptable either.

In February of 2020, my family placed my 72 year old dad. The enormous stress of caregiving for many years for my dad, left my mom physically and emotionally spent — in fact several days after placement

she fell and broke the top of her femur off and had to have emergency hip replacement surgery. She was no longer able to continue to manage him at home.

We also looked off island for help and told multiple times that my dad would not be accepted anywhere without an exam by an LTC, and of course we couldn't get him placed. The only option one healthcare system in Oregon gave me was get him to the mainland, transport via medical transport to an ED, where he could be kept for months until a bed opened at a geriatric psych ward opened up. And how would we "hold" him? Drug him, lash him to a bed? Where is our humanity? Why are there no humane transitions in care solutions for this dementia?

When I visited the LTC before he was placed, I brought FTD educational materials and offered my help in training the care team. The facility educator blew me off saying they knew all about FTD and were trained to it. I didn't believe her, but she refused my offer. I also looked around and realized that several of their security gates were broken and the keypads were visible to the residents, and I knew that my dad would quickly figure them out – which he did. Escaping on two occasions early on. I told them they needed immediate fixing, but they did not. They actually had for a short period used a staff member to "guard" the door down from my dad's room that went directly to the outside.

Within days of placement, I was told that he needed more medication to deal with his agitation and I worked with his geriatric psychiatrist almost daily to try and find a dosage that would work to help make him more compliant. I was also told that we must hire an outside agency to provide 24/7, 1:1 care, I have heard from many other FTD families that supplemental care is not uncommon an ask.

The agency we hired to provide an additional level of 1:1 care at a price of \$4,000 a month. That is in addition to the \$11,000 a month mom paid to the facility for a shared room and board. Two months in, my dad was transferred to another facility run by the same company due to his rapidly deteriorating physical and cognitive state. He was able to walk and talk when we placed him. Within a couple of months, he could no longer do either. His deterioration was rapid and irreversible.

We desperately need improved staff training, expanded awareness and education of the other dementias, inclusive facility design – beyond memory, and most importantly safe and adequately staffed LTCs. I thank you for the opportunity to share our family's story and hope that it will inform and improve the experience for individuals with FTD and their families.



Thank you,

**Melissa Fisher**