

AFTD Comments for NAPA Council Meeting October 24, 2022 - Dawn Ducca

Good afternoon, my name is Dawn Ducca, and I am from Michigan. I would first like to say thank you to each of you on this committee for the work that you are doing.

Dementia is very personal to me. I lost my husband of 20 years, Jim, to Frontotemporal Dementia in May of this year. Throughout his 8-year journey with FTD, we experienced many obstacles with regards to his care.

Facilities in Michigan and all over the country are faced with both a lack of employees and a lack of knowledge about FTD. What may work for someone afflicted with Alzheimer's, may not work for someone with FTD which can lead to potential problems with care. I believe educating workers on the different types of dementia is badly needed. There needs to be continuing education programs for workers that cover other types of dementia besides Alzheimer's. I toured several facilities when looking for respite care that did not have any knowledge of FTD, or if they had heard of FTD, they had very little actual experience with it. Additionally, more facilities need to be equipped to handle younger residents with cognitive impairment who are still mobile, like many people with FTD are.

Hospice acceptance guidelines should also be more flexible. Jim did not qualify for Hospice until he stopped walking, 2 months before his death, despite me performing all his ADL's for him. More access to social workers and programs is needed as well. While looking for a day program for Jim, I reached out to my Area Agency on Aging to see what was available for him. Because he was under the age of 60 at the time, I was told no program would take him because he was not considered geriatric. Not all types of dementia's affect people late in their life. We need to do more to help those families that are struggling to navigate diseases such as FTD that afflict people at a younger age. We need support for navigating Medicare, Medicaid and long term care. Our children need help watching the changes in their parent or grandparent. While this disease has changed my family's life forever, we are committed to helping those newly diagnosed walk an easier path in our footsteps.

Thank you for allowing me to speak today.