Unique Care Considerations in Frontotemporal Dementia

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Caring for someone living with Frontotemporal Degeneration (FTD) can be challenging and unique care considerations must be employed. While FTD falls under the *umbrella* of dementia, the presentation, symptoms, and implications are quite different than what most family and professional care partners encounter with other forms of dementia, including the most common form of dementia, Alzheimers disease.

Starting with the diagnosis process, the journey of those impacted with FTD can differ in many ways from the journey of other forms of dementia. It is estimated that it takes an average of 3.6 years to obtain the FTD diagnosis versus 2.8 years for Alzheimers disease. During this time, misdiagnoses are common and families struggle with significant, sometimes dangerous, changes in behavior and language. These changes can also lead to damaged relationships, termination of employment, and even involvement with the legal system. With the average age of onset for FTD between 45-64 years, the employment, financial, legal, and caregiving implications on the family system also differ greatly from more common late onset forms of dementia.

For the family care partner of someone newly diagnosed with FTD, it is important to formulate a plan. The first step is to create a care team which could be comprised of family members or professionals, determining goals for care, learning about FTD, and a plan for how to support the person living with FTD as well as those involved in their care. Seeking out and utilizing caregiver support resources can help care partners learn coping strategies as well as feel a sense of community in what can otherwise feel like a very isolating journey.

Professionals who are involved in the care for individuals living with FTD must understand that FTD is not Alzheimers disease and a *one size fits all* approach to care will not work. Creative, person-centered approaches are required and change is constant. Individual versus group engagement is often more successful and individuals living with FTD will often relate more to care staff (who are closer to them in age) than others living with dementia. Structured, *failure-free*, low demand engagement activities are generally more successful. As risky and impulsive behaviors may occur as a part of the disease progression, accommodations must be made for safety issues. Additionally, since those living with FTD tend to be younger than others living with other forms of dementia, they tend to be healthier, stronger, and more active. Care and engagement plans should reflect this difference.

As with other forms of dementia, it is important to remember that personality, behavior, and mood changes can be symptoms of disease. Thus, offensive behaviors should not be taken personally. While this is true, it is also important that those involved in care for those living with dementia not simply attribute all behaviors to disease progression. Care partners should always consider unmet needs as a potential cause of behavioral

expressions and assist accordingly. The danger of attributing all behaviors to symptoms is that we miss the opportunity to assess and address unmet needs.

Finally, those involved in care for someone living with FTD must take care of themselves. This includes being mindful of physical and emotional self-care. FTD care is challenging but there is help available. While there is still so much unknown about FTD, there are fellow family members and professionals who are walking similar journeys and there is comfort in connecting with others. Those living with FTD are our greatest teachers and we must learn how to support them by involving them in the process.

View Rebekah's bio here.