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Submitted electronically to: GUIDEModelTeam@cms.hhs.gov.

Dear Ms. Johnson and GUIDE Model Team,

Thank you for taking the time to meet with us and the Lewy Body Dementia Association on August 23rd and hearing our concerns regarding how the GUIDE Model will serve people with frontotemporal degeneration (FTD).

The Association for Frontotemporal Degeneration (AFTD) is the only non-profit organization solely dedicated to improving the quality of life of people affected by frontotemporal degeneration (FTD) and driving research to a cure for all FTD disorders.

Frontotemporal Degeneration is the most common form of dementia in people under 60. It covers a group of disorders caused by the loss of neurons in the frontal and/or temporal lobes of the brain and includes behavioral variant frontotemporal dementia, primary progressive aphasia, corticobasal syndrome, progressive supranuclear palsy and overlaps with amyotrophic lateral sclerosis (ALS). The symptoms of FTD vary according to where in the brain the disease starts and where the loss of neurons is most concentrated. While behavior and personality changes are the most common symptoms, it also involves the loss of language and communication and impaired movement and muscle control. Memory loss is not a hallmark symptom of FTD. The age of disease onset ranges from 21 to 80, but most FTD cases occur between ages 45 and 64. This means many people with FTD are too young for Medicare and struggle to access care and services while they wait to qualify.

For Medicare beneficiaries who have FTD, the GUIDE Model offers several valuable services. Care coordination and management are needed services for people with FTD who often receive services from a range of different providers. Caregiver burden, as measured by the Zarit Burden Inventory, has been shown to be higher for people caring for someone with neuropsychiatric symptoms of dementia¹ and research has shown that FTD caregivers have a higher burden compared to people

¹ Besser LM, Galvin JE. Perceived burden among caregivers of patients with frontotemporal degeneration in the United States. *Int Psychogeriatr*. 2019 Aug;31(8):1191-1201. doi: 10.1017/S104161021800159X. PMID: 30398132.

caring for someone with Alzheimer's disease². Therefore, respite care is an important and valuable service for FTD caregivers. The annual per-patient costs (both direct and indirect) in FTD are nearly 2-times greater than reported costs in Alzheimer's disease³, which means any care or services covered by public benefits are valuable for people and families impacted by FTD.

The Association for Frontotemporal Degeneration (AFTD) has identified three key issues where the GUIDE Model may not meet the needs of people with FTD and their caregivers.

- The dementia screening tool used by the GUIDE Model; The Clinical Dementia Rating Scale (CDR) is not as effective for FTD as other screening tools.
- The importance of FTD specific training and educational resources.
- The importance of data collection and analysis for different types of dementia

Dementia Screening for FTD

The Clinical Dementia Rating Scale (CDR) is not as effective for assessing FTD as it is for Alzheimer's disease. The CDR does not include language and behavioral domains which are highly relevant to assessing FTD and understanding the severity of needs. As a tool, FTD experts find the CDR is more well suited for use in research settings than in clinical care. An alternative screening tool, that is more sensitive to FTD is the Quick Dementia Rating System (QDRS)⁴. AFTD suggests using the QDRS, in addition to the FAST, at least for people with non-Alzheimer's dementia.

FTD specific training and educational resources

The GUIDE Model should require participants to provide training and resources that educate professionals in the care of people with FTD. Such a requirement is an important way to ensure providers are aware and attentive to the needs of people who are younger with different clinical presentation, care needs and family support needs. Resources contained on AFTD's website and material such as [AFTD's Partners in FTD Care](#) or resources like the [Healthcare Webinars](#) are critical for providers to understand FTD and serve individuals and caregivers impacted by the disease. AFTD is pleased to partner with the GUIDE participants to provide FTD education, resources, and supports to better serve their patients.

Data collection and reporting

AFTD urges the GUIDE model to require all participants to assess and track dementia type, rather than a general diagnosis of "dementia." The goals of the GUIDE Model; to improve quality of life for people with dementia and their caregivers, delay avoidable long-term nursing home care and enable more people to remain at home through end of life, must be evaluated according to dementia type

² Huang W-C, Chang M-C, Wang W-F and Jhang K-M (2022) A Comparison of Caregiver Burden for Different Types of Dementia: An 18-Month Retrospective Cohort Study. *Front. Psychol.* 12:798315. doi: 10.3389/fpsyg.2021.798315

³ Galvin JE, Howard DH, Denny SS, Dickinson S, Tatton N. The social and economic burden of frontotemporal degeneration. *Neurology*. 2017 Nov 14;89(20):2049-2056. doi: 10.1212/WNL.0000000000004614. Epub 2017 Oct 4. PMID: 28978658; PMCID: PMC5711509.

⁴ Galvin JE. THE QUICK DEMENTIA RATING SYSTEM (QDRS): A RAPID DEMENTIA STAGING TOOL. *Alzheimers Dement (Amst)*. 2015 Jun 1;1(2):249-259. doi: 10.1016/j.dadm.2015.03.003. PMID: 26140284; PMCID: PMC4484882.

because of potentially significant differences in type and level of services needed, as well as family supports. The lack of data collection and analysis at the level of dementia subtype in federally funded dementia care programs does a disservice to those without Alzheimer's disease dementia. This level of assessment is critical before the model can be considered effective for FTD and other non-Alzheimer's dementia. People with FTD rely on the same professional networks that serve people with Alzheimer's. However, the needs of those impacted by FTD fall through the cracks of care and services because they are pushed to the margins by the far greater number of people with Alzheimer's. When the quality of care and services are assessed without attention to the type of dementia, there is a risk that important information about accessibility and appropriateness of interventions will be lost. This enables provider reimbursement for all types of dementia because they meet the needs of only of the majority. On behalf of everyone living with or caring for someone with FTD, please build in elements in assessment, training expectations and data collection that recognize the needs of those with non-Alzheimer's dementia.

Conclusion

AFTD appreciates the care with which the GUIDE Model has been developed and for the opportunity to provide input on behalf of those impacted by FTD. The GUIDE Model offers important services and resources for people with dementia and stands to improve care if implemented by providers. However, the GUIDE Model must consider the needs and disease symptoms of FTD and non-Alzheimer's dementia in the program to ensure the greatest opportunity for success.

Respectfully Submitted,

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