



Talking Points: FTD Economic Burden Study

On October 4, 2017 the scientific journal Neurology electronically published “The Social and Economic Burden of Frontotemporal Degeneration,” a study funded and co-authored by AFTD. (The study will also appear in Neurology’s Nov. 14 print issue.) The following are talking points that you can use to guide your conversations about this important new study.

FTD is the most common dementia for people under 60. Because it forces patients – and, typically, their family caregivers – out of the workforce during their prime earning years, it has a dramatic impact on a family’s finances and imposes a disproportionate economic burden on society. A survey of 674 FTD caregivers – the first of its kind – found:

The annual costs associated with FTD are roughly double those of Alzheimer’s.

The average annual costs associated with Alzheimer’s disease are around \$64,000. Data from the Economic Burden Survey, however, shows that average annual costs associated with FTD are about \$120,000. Much of the difference can be attributed to loss of productivity due to the younger age of onset in FTD. Unlike with Alzheimer’s, a person with FTD and their spouse are likely still working at the time of diagnosis.

Household income falls by as much as 50%.

Twelve months prior to diagnosis, overall household income ranged from \$75,000-\$99,000. Twelve months after diagnosis, income declined to the \$50,000-\$59,000 range.

One in three caregivers stops working after a loved one’s FTD diagnosis.

An FTD diagnosis severely compromises a caregiver’s ability to maintain a job. Nearly 40 percent of caregivers surveyed said they were no longer employed following the patient’s diagnosis.

Caregivers still working report losing seven work days in the most recent four weeks.

Caregivers who were still working reported a median loss of seven full days of work over the previous four weeks because of FTD-related issues.

Caregivers report notable declines in their own health – and increased costs for their own healthcare.

The burden on FTD caregivers is not just economic. Two out of three reported notable declines in their health, and more than half said that they had incurred increased health care costs due to their own health decline.

Miscellaneous costs linked to FTD also added up.

Other FTD-related costs noted in the survey included poor financial decisions by person with FTD (reported by 58% of respondents), crises requiring emergency department services (19%), emergency medical services (11%), urgent psychiatric care (8%) and police intervention (6%).