

# The VOICE of FTD

SUMMER 2019

## The Value of Your Voice

### *AFTD study results show survey participation benefits science*

People make assumptions based on their knowledge and individual life experiences. Yet when science steps in to determine whether those assumptions are facts, the findings can be surprising.

Such was the case with an [Association of Frontotemporal Degeneration \(AFTD\)](#) study that aimed to quantify the socioeconomic burden of frontotemporal degeneration (FTD) compared to previously published data for Alzheimer's disease and other dementias.

"The survey was to find out the cost of an FTD diagnosis in the United States as well as understand the social burden faced by families," said Nadine Tatton, Ph.D., AFTD's Scientific Director. "One of our goals was to make more people – including legislators, employers, medical personnel, and insurance companies – aware of the challenges facing those affected by this rare disease."

The study involved a 250-question survey that was completed by current and former primary caregivers of persons diagnosed with various types of FTD, including behavioral-variant FTD (bvFTD), primary progressive aphasia, FTD with motor neuron disease, corticobasal syndrome, or progressive supranuclear palsy.

"This survey was completed by caregivers as we sought to discover the costs associated with FTD by having them complete certain health utilities questionnaires," noted Dr. Tatton. "We also wanted to understand their specific burden as a caregiver."

The survey was created by [Dr. James Galvin](#), Pro-

fessor of Integrated Medical Science at the [Charles E. Schmidt College of Medicine, Florida Atlantic University](#) in Boca Raton, as part of a research study funded by a grant from AFTD. "We worked with Dr. Galvin to develop questions that were FTD appropriate based on our experience with our community of FTD families," Dr. Tatton explained.

To invite potential participants, the AFTD's Communications Team developed a well-orchestrated campaign, which included sending emails to its database and using social media. In addition, Dr. Tatton Susan L-J Dickinson, AFTD's Chief Executive Officer, and Sharon S. Denny, AFTD's Senior Director of Programs, assisted in designing survey questions.

While 956 caregivers began the survey, 674 spent an average of two hours to complete all 250 questions, for a response rate of just over 70% which was remarkable, Dr. Tatton said. The survey included validated scales for disease staging, behavior, activities of daily living, caregiver burden, and health economics, as well as questions about patient and caregiver experiences with FTD.

"It was not an easy, simple survey to fill out. There were lots of questions, and the responses were not something you would remember off the top of your head. We queried things like number of doctor visits, trips to the hospital, medications prescribed, and household income 12 months prior to and 12 months after diagnosis," explained Dickinson.

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“The people who live with this disease every day are the real experts. No one else can provide what these people can. It is a fate they have to shoulder,” she said. “Sharing their experience and what they have learned is, hopefully, one positive that can come from their journey with FTD.”

Surveys offer great benefits, noted Jary Larsen, Ph.D., a neuropsychologist at the [University of California, San Francisco](#) (UCSF) / [Zuckerberg San Francisco General](#) (ZSFG). Dr. Larsen is a research neuropsychologist and Institutional Review Board (IRB) Chair at the [VA Northern California Health Care System](#); a former Board Chair of AFTD, and president of the FTD Disorders Registry LLC. The results provide statistical insights to the research community, to the FTD community, and to the government, he said.

“The window of study participation was not that long,” less than three months, Dr. Larsen noted. “The fact that there was a high level of participation speaks volumes. People wanted to participate. They wanted the broader public to know how different this disease is from other illnesses and dementias.”

Dr. Larsen noted that the more complicated someone’s life was dealing with this disease, it seemed the greater their incentive was to participate and complete the survey. “This was important to them. They wanted to be heard. They wanted to share their story in the hope that it would help others.”

## Survey Participant Recruitment

Because the FTD Disorders Registry (FTDDR) did not exist at the time of this survey, recruiting participants was addressed through a multi-faceted approach. As sponsor, AFTD promoted the study via emailing contacts in its database as well as through online avenues including its website and social media. They also promoted it in newsletters, including one specifically for caregivers.

However, AFTD also used its network of researchers,



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clinicians, universities, and medical advisory members to reach caregivers of persons diagnosed with FTD. “Basically, everybody we could think of working in FTD,” explained Dr. Tatton.

Today, such a survey would be run through the FTDDR. “The Registry would be extremely helpful in providing a platform to administer surveys to the more than 2,000 participants enrolled in its database, as well as draw attention to this type of patient/caregiver focused research,” Dr. Tatton said. “The Registry would be the mechanism, and AFTD would also promote such research studies via our website, social media, newsletters, etc.”

The FTD Disorders Registry LLC is an online database that collects information from those affected by all clinical subtypes of frontotemporal degeneration. Persons diagnosed, current and former caregivers, family members, and friends can join the Registry, participate in surveys, and be eligible for additional research studies, explained Registry Director Dianna Wheaton, Ph.D.

FTDDR is both a Contact Registry and a Research Registry. As a Contact Registry persons can join and receive emails about FTD including its newsletter, important updates and study opportunities. (Note: Contact Registry enrollment is open to the United States and the international community.)

As a Research Registry, persons diagnosed, their caregivers, family members, and friends can provide their unique perspective and describe their experiences. (Note: Research Registry enrollment requires an individual to be at least 18 years of age and a resident of the United States or Canada. [See additional eligibility requirements.](#))

“Every participant’s data is confidential,” Dr. Wheaton emphasized. (See [Privacy and Data Security Poli-](#)

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[cies.](#)) “Data used for research purposes is de-identified so that no personally identifiable information will ever be shared.”

## The Burden of an FTD Diagnosis

“The (economic burden) study actually put a dollar amount to the cost of FTD,” said Dr. Larsen. “Thus, it enables individuals who are on the outside to better understand the unique aspects of this devastating disease. It communicates the unique burden people face.”

While some people were surprised by the AFTD survey results, Dr. Larsen was not. “I was familiar with how devastating the economic impact can be,” he said, referring to his brother, Peter, who was diagnosed with FTD in 2006 at age 55 and died in 2013. “He was fortunate that he could take early retirement. For some families, the diagnosed person has to quit working and the caregiver also has to quit their job.”

FTD is among the most common causes of young onset dementia with a typical onset range between 45 and 65 years of age. While previous research had determined the economic effects of Alzheimer’s disease and dementia in the elderly, Dr. Larsen noted that the AFTD survey delved into the details of these younger individuals with a diagnosis of FTD when they should be making the most money in their career and often have school-age children.

“It was important to quantify how an FTD diagnosis impacts our families. Until you see the numbers in front of you, it is easy to gloss over them and just make assumptions about disease burden,” he said. “An FTD diagnosis is doubly devastating for a family because there are the personality changes as well as the effects to the quality of life; and not just immediately. Sometimes those effects are 10, 15, or even 20 years down the line.”

Due to the onset of FTD at a younger age, the disease has a significant impact on young families. It can affect such things as savings planned for children’s college

education and retirement plans as families face long-term care facility costs, adult day care, or hospice care, Dr. Larson said. In addition, economic effects can be felt 10-15 years after the father or mother dies.

“People think of the economic cost during an illness, but not down the road,” he noted.

## Study Findings

The early age onset of FTD places a unique burden on patients, families, and society as many patients are in their prime earning years, have young children, and require access to services that often are only available to older adults, noted study authors Dr. Galvin, a board-certified neurologist, and [David D. Howard](#), Ph.D., a professor in the [Department of Health Policy and Management](#) at [Emory University](#) in Atlanta, Georgia. The AFTD’s Dickinson, Denny, and Dr. Tatton also co-authored the first paper written based on survey responses.

“Although differing in presenting and emergent symptoms, all forms of FTD lead to significant social and economic challenges,” stated Dr. Galvin. “To better understand the socio-economic burden of FTD on patients, families, and society, we conducted the web-based survey to characterize the patient and caregiver experience with diagnosis, symptom management, interactions with healthcare providers, resource utilization and costs.”

The study concluded that the economic burden of FTD is substantial. Counting productivity-related costs, per-patient costs for FTD appear to be higher than per-patient costs reported for Alzheimer’s. “There is a need for biomarkers for accurate and timely diagnosis, effective treatments, and services to reduce this socioeconomic burden,” Dr. Galvin noted.

Results determined that direct costs (2016 U.S. dollars) equaled \$47,916 and indirect costs were \$71,737, for a total annual per-patient cost of \$119,654, nearly two times higher than reported costs for Alzheimer’s disease. These numbers were compared to one of the largest studies in

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the United States ([“Monetary Costs of Dementia in the United States](#), The New England Journal of Medicine, April 2013 <https://www.nejm.org/doi/full/10.1056/nejmsa1204629>) examining dementia costs which reported annual direct costs of \$33,329 and annual indirect costs of \$30,839 for a total annual cost of \$64,168 for Alzheimer’s disease.

FTD Patients older than 65 years of age with later stages of disease and those with bvFTD correlated with higher direct costs, while patients younger than 65 years of age and men were associated with higher indirect costs, Dr. Galvin noted.

“An FTD diagnosis produced a mean decrease in household income from a range of \$75,000 to \$99,000 12 months before diagnosis to between \$50,000 and \$59,999 12 months after diagnosis, resulting from lost days of work and early departure from the work-force,” he stated.

Because of the willingness of caregivers to participate in this survey, results showed in the first 12 months following an FTD diagnosis:

- 3% of the patients were still working
- 45% of the caregivers still worked
- 74% of the caregivers worked full-time
- 25% of the caregivers reported lost days of work due to patient health issues
- 21% of the caregiver reported lost days of work due to their own health issues
- Caregivers and patients who were still working full-time reported a median loss of seven days over the previous four weeks due to FTD-related matter
- 31% employed some form of paid caregiver several times per week
- 37% of the caregivers were no longer employed after the patient’s FTD diagnosis
- 67% of FTD caregivers reported significant decline in their health, and 53% reported significant personal health care costs
- Additional patient-related health costs included

an average of 6 overnight respite stays, 16 daytime respite stays, 35 clinician visits, and 2 hospitalizations or emergency room visits in the previous year

- Additional caregiver-related health costs included an average of 7 clinician visits and just under 1 hospitalization in the past year
- 55% of caregivers faced some type of crises over the previous year. Examples include: 19% ED, 11% EMS, 6% police, 6% lawyer, 5% inpatient psych, 3% outpatient psych

Dickinson noted two significant surprises for her from the survey: First, that the hit the household income took from 12 months before diagnosis to 12 months after was as much as 50 percent; and second, that caregivers were out of work seven of the previous 21 days. “This would prevent a caregiver from advancing their career, earning more, being able to support their family, not to mention the emotional costs,” she said.

The economic burden aspect of the survey’s results was initially published online in the [Neurology](#) journal in October 2017. The AFTD also has produced materials about these results, including a [Talking Points](#) handout and an [Infographic](#).

Meanwhile, last fall Dr. Galvin along with Lilah M. Besser, Ph.D., assistant professor in the [School of Urban and Regional Planning](#) at [Florida Atlantic University](#) in Boca Raton, Florida, published additional survey results in a second paper, [“Perceived burden among caregivers of patients with frontotemporal degeneration in the United States”](#) (PubMed: [National Center for Biotechnology Information](#), [U.S. National Library of Medicine](#), [National Institutes of Health](#), November 2018).

A third paper, which is currently under review, features survey information about the disease experience, including anxiety, depression, social inhibition, and lack of empathy.

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## The Birth of the FTD Disorders Registry

The socioeconomic burden survey was conducted in 2016, prior to the launch of the FTDDR in March 2017. While the Registry handles similar surveys, people must first sign up to participate in research to be eligible.

“This (economic burden) survey was the premise upon which the Registry was built,” stated Dickinson. “If we were to do another economic survey today, we’d use the Registry and promote it through AFTD.”

“The Registry now captures the information,” she said. “It’s a wonderful tool where we can pool data.”

FTDDR is a shared vision between AFTD and [The Bluefield Project to Cure Frontotemporal Dementia](#). A diagnosis of FTD can be isolating, so the Registry is meant to be a resource for patients and families to appreciate their place within the broader FTD disorders community and also apply their unique experience to advance research efforts toward therapies and a cure.

“You may think these are just stories and not important. But when you share your stories and experiences, it translates into science,” noted Dr. Tatton. “We are having opportunities come our way (to advance the science) because of this and other studies. And that helps everyone.”

“By participating in the Registry, you become a citizen scientist working with other scientists to drive new research. Your story holds the promise of healing for you and others,” said Dr. Wheaton.

“We can work together to translate each person’s journey with FTD into a powerful tool to change the way clinical trials are run, and to help answer key questions about each disorder. Together, we can change the course of this disease,” she added.

“The Registry is a great gift for these kinds of surveys. It is a central place where people can be recruited for clinical trials,” Dr. Tatton stated. “It is a challenge to find enough people to fill all of the trials, and some are more difficult than others. The future can’t be down the

road. We have to be doing it now, and the Registry is key in recruiting potential candidates.”

The socioeconomic study of 2016 demonstrated the importance of soliciting information directly from persons diagnosed, caregivers, family members, and friends; the importance of creating the FTD Registry; and the importance of participating in the Registry and surveys.

“The Registry is the perfect place for these kinds of surveys,” Dr. Larsen said. “Now that the Registry is set up, we have a great platform for doing these kinds of surveys, especially since it is a secure platform.”

“We know there is tremendous passion in the FTD community by the dedicated caregivers, by family members, by medical professionals including researchers and clinicians,” Dickinson said. “Science is an iterative and incremental process. You have to roll up sleeves, collect data, and unfortunately this takes time. You have to step up if you want change.”

The more people who participate in the Registry and complete its surveys, the more information is collected and learned about this devastating disease. “The more we learn, the greater the opportunity to advance the science and develop treatments and a cure,” Dr. Wheaton said.

“Everyone’s perspective is important, whether diagnosed person, caregiver, family member, or friend,” she said, “because in some surveys you represent yourself and other times you represent the voice of your FTD affected loved one who may not be able to speak for themselves.”

**Join the Registry.  
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Advance the Science.**

***“Together, we can make a difference!”***

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