

The VOICE of FTD

FALL 2021

Voice of the Patient (VOP) Report

Summary of the EL-PFDD meeting and the FTD Insights Survey

Frontotemporal Degeneration: A Voice of the Patient (VOP) Report, which analyzes and summarizes data and perspectives from people living with FTD, caregivers, and family members, was released on October 27, 2021.

Produced by [The Association for Frontotemporal Degeneration](#) (AFTD), the VOP Report contains information from the Externally Led Patient-Focused Drug Development (EL-PFDD) meeting held in March with the U.S. Food and Drug Administration (FDA) as well as results from the FTD Insights Survey conducted jointly by AFTD and the FTD Disorders Registry prior to the meeting.

The 75-page report includes statistics from the survey and results from polls administered during the meeting, as well as quotes given by meeting participants.

“People living with a rare disease are uniquely positioned to provide information to increase our understanding as well as for the development and evaluations of treatments,” said Registry Director Dianna Wheaton, MS, Ph.D., CHES “We are grateful for those who participated.”

[Read the full Voice of the Patient Report](#)

The report outlines five key themes that emerged from the meeting and survey:

- 1. Devastating impact of FTD symptoms:**
People across FTD diagnoses and even within a specific subtype experience a variety of symptoms that are devastating in all areas of their lives.
- 2. Difficulty obtaining reliable FTD diagnoses:**
Many challenges exist in getting an FTD diagnosis, including receiving misdiagnoses.
- 3. Impact of familial FTD:**
Multiple generations are affected by these diseases; and for those who carry a known gene, their at-risk family members must decide if they want to be tested.
- 4. Lack of effective treatment for FTD:**
Therapies are often experimental and not effective, and they come with side effects.
- 5. Research participation:**
People are willing to participate in research, even to risk side effects, but some trial designs are challenging.

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FTD Disorders Registry LLC

2700 Horizon Dr., Suite 120
King of Prussia, PA 19406
888-840-9980
manager@FTDregistry.org



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FTD INSIGHTS SURVEY

In preparation for the meeting, the FTD Disorders Registry together with AFTD developed a survey that asked persons diagnosed with FTD, their family members, current and former caregivers, and friends to share their experiences of living with FTD.

The survey covered several broad areas related to the diagnostic journey, disease symptoms and impacts on daily life, experiences with treatments, and hopes for future treatments, as well as perceptions of research and willingness to participate in future studies.

“Existing surveys for Demographics, Disease Impact, and Research Readiness, that serve as core Registry data collection tools, were used as a backbone for the development of the FTD Insights Survey,” Dr. Wheaton said. “We blended elements of the Registry’s surveys together with surveys distributed at previous FDA-led PFDD meetings, guided by input from FTD experts including researchers and clinicians.”

The FTD Insights Survey was hosted on the Registry’s infrastructure. Invitations to complete the survey were sent via emails and social media posts through Registry and AFTD channels. Additionally, a special invitation was sent to persons who were enrolled in the United Kingdom arm of the [Genetic Frontotemporal dementia Initiative](#) (GENFI).

Some 1,241 people diagnosed with FTD, their care partners, caregivers, and family members completed the FTD Insights Survey.

Responses received in the fall of 2020 were used when considering the EL-PFDD meeting focus. Results from all responses, which were collected through March 31, 2021, were analyzed and have been included in the VOP Report.



Some of the survey findings are highlighted below:

- First symptoms vary within each FTD disorder. For example, among those with PSP and CBD whose characteristic symptoms involve movement, 58% reported motor dysfunction as the first sign something was wrong, meaning almost half had different initial symptoms.
- While 82% of respondents reported the presence of language symptoms (99% of those with PPA), 27% of people diagnosed reported being most distressed by language symptoms.
- Of those who reported language issues, challenges included finding the right word (86%), speaking (70%), writing (65%), understanding long sentences (63%), reading (60%), and identifying familiar objects (42%).
- 14% of respondents diagnosed with FTD reported cognitive impairments as being the most distressing symptom.
- Of those who report symptoms related to thinking, they specifically noted problems with decision making and judgment (91%), problem solving (88%), planning (83%), organizing (80%), and paying attention (79%).

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More survey findings:

- Of those who reported symptoms related to memory, they cited problems remembering recent events (83%), remembering names of new people (68%), remembering names of friends and family (57%), and remembering the way around familiar streets (50%).
- 10% of respondents with an FTD diagnosis reported motor/movement symptoms being the most distressing; however, 69% of respondents noted some presence of physical symptoms (90% of those with PSP or CBS/CBD).
- Those who reported motor/movement symptoms noted challenges related to worsening balance (81%), difficulty writing (68%), weakness (60%), difficulty walking (60%), tremors (58%), and difficulty swallowing (40%).
- 68% of respondents reported some presence of mood changes. They noted challenges caused by anxiety (70%), irritability (61%), depression (59%), anger (47%), and emotional outbursts (46%).
- While only 3% of care partners and 1% of people diagnosed said delusions and hallucinations were the most distressing symptom, 20% of respondents noted the presence of delusions or hallucinations, especially those with bvFTD (29.3%) and FTD-ALS (27%).
- While 2% of respondents with an FTD diagnosis reported sleep and eating/drinking symptoms to be the most distressing symptoms, nearly half of respondents reported some changes in eating/drinking and sleep.
- 2% of people diagnosed indicated personality and relationship impairments were the most distressing, while more than 15% of caregivers noted these domains were most distressing for them. Examples included lack of motivation (78%), not realizing their effect on others (78%), not caring about others' feelings (73%), and acting inappropriately (58%).
- Caregivers reported 22% of persons with bvFTD are mostly or fully aware of their symptoms, compared to 52% of persons with other FTD disorders.
- More than 50% of all respondents reported that the person diagnosed saw three or more doctors before receiving an accurate diagnosis, and 44% reported having initially received a different diagnosis, including Alzheimer's or Parkinson's disease, anxiety, depression, or bipolar disorder, menopause, or mid-life crisis.
- Respondents were open to procedures including blood samples (93%), genetic testing (86%), MRI scans and EEG recordings (82%), PET scans (77%), skin biopsies (76%), answering detailed questions (70%), and lumbar punctures (42%).

EL-PFDD MEETING

More than 550 people participated in the EL-PFDD meeting on March 5, 2021, including people living with FTD, care partners, family members, and former caregivers. They were joined by healthcare, research, and regulatory professionals.

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Those who participated in the meeting, which was hosted by AFTD, shared details of dealing with disease symptoms and the impact they have on daily life that are most important to them. They also provided their perspectives on treatments.

"The findings of this report demonstrate not only that FTD profoundly impacts families in countless ways – they also show that this community is ready and willing to participate in clinical trials to hasten the development of urgently needed treatments," said AFTD CEO Susan L-J Dickinson, MSGC.

The Voice of the Patient report will be a resource to FDA regulators as they evaluate future FTD therapies.

"Our community has given the FDA a resource to understand the perspectives, needs, and priorities of people and families with first-hand experience with FTD," said Penny Dacks, Ph.D., AFTD Senior Director of Scientific Initiatives. "It's an invaluable tool to regulators as they make key decisions on the benefits and risks of any potential therapy."

More information, including the full report and recording of the meeting, can be found on the [AFTD website](#).

[Read the full Voice of the Patient Report](#)

[Watch a recording of the EL-PFDD Meeting](#)


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