The Management and Implementation of Online Dementia Caregiver Support Groups: A Proposed Framework for Guidelines

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AAIC 25 Alzheimer's Association International Conference

106009

Background

Caregivers of individuals living with dementia are at increased risk for social isolation, stress-related illnesses, and other adverse outcomes. Participation in a caregiver support group can provide connections to others in similar situations and to resources and strategies, all of which likely reduce adverse outcomes. Prior to the COVID-19 pandemic, caregiver support groups were primarily conducted in-person. With the proliferation of online support groups post-pandemic, we believe a framework for optimal online support group management and implementation is needed to prioritize caregiver safety and well-being.

Methods

Due to the COVID-19 pandemic, the long-running AFTD-affiliated Boston-area frontotemporal dementia (FTD) caregiver peer support group shifted from meeting in-person twice a month for two hours each session to meeting weekly for one hour via Zoom in March 2020; weekly groups alternate between morning and evening.

Association for Frontotemporal Degeneration (AFTD)-trained support group facilitators (SGFs) attend every meeting to manage online meeting technology, promote adherence to group structure and guidelines and record meeting notes.

Potential new members are screened to confirm FTD caregiver status and then approved for registration. Once registered, they are added to the group mailing list and receive thrice weekly emails: a meeting reminder, a meeting Zoom link and a follow-up email. The follow-up email contains information about upcoming events and resources discussed in the session that week.

SGFs have created support group guidelines that officially recognize the philosophy and norms of the group. These guidelines are reviewed at the beginning of the session on a quarterly basis. In recognition of safety and wellbeing, members are required to provide emergency contact information in the registration process.

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Results

Between March 2020 and June 2025, 311 unique caregivers have registered for support group and 249 have attended at least one session. Attendance each year has increased, from 780 cumulative attendees in 2021 to 914 in 2024. From January to June 2025, cumulative attendance has been 461. Weekly average attendance has grown from 11 members per meeting in 2020 to 18 in 2025. Support group members attended 10 meetings on average in 2024.

Importantly, the barrier to attending support group has diminished since caregivers no longer have to find someone to sit with their person living with FTD and travel to attend a monthly support group. Offering support group in alternating morning and evening sessions means that working caregivers can attend the evening session, while caregivers making use of adult day health programs or in-home paid care, can attend the morning session. Support group members have attended from eleven states in 2025 (so far), including individuals from more rural areas that do not have local, in-person support groups.

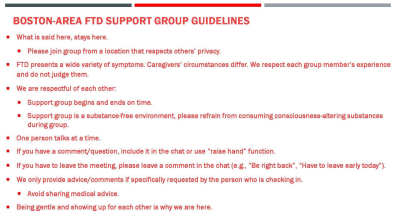

Figure 1: Support Group Guidelines
Support Group Facilitators created guidelines reflecting the philosophy, norms and etiquette desired in group meetings.

These guidelines are reviewed with support group members on a quarterly basis.

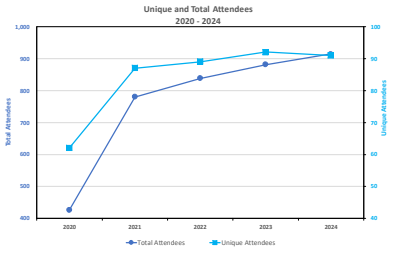

Figure 2: Unique and Total Support Group Attendees
The Boston-area FTD caregiver support group has grown in attendance each year since launching in March 2020. Since 2022, about 90 unique members have attended at least one support group each year. Most members attend more than one session each year, with over 900 cumulative attendees at the 51 support group sessions in 2024.

Note: Groups began meeting on March 24, 2020; there were only 38 meetings in 2020, compared to 50 or 51 in 2021-2024.

"I know I haven't attended group in a long time, but for some reason, I don't want to sever the cord." - Past Caregiver of Spouse Living with BvFTD, Current Caregiver of Parent Living with Alzheimer's Disease

Results (cont.)

Support group members have provided open-ended responses to customer satisfaction surveys about areas of support group that were most valuable to them. Highlights of responses included benefits of receiving weekly follow-up emails, problem solving, and sense of community with other members.

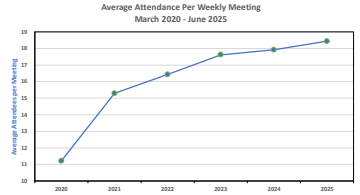

Figure 3: Average Attendance per Weekly Meeting
As support group members became acclimated to online meeting technology (Zoom) and became acquainted/ comfortable with each other, average weekly attendance increased from 11 members each week in 2020 to over 18 members each week in 2025.

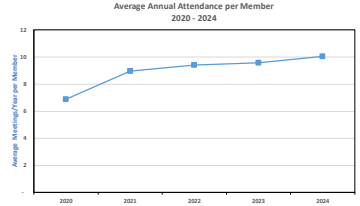

Figure 4*: Annual Attendance per Member
The Boston-area FTD caregiver support group encourages flexibility with regard to attendance, once a member has registered for the year. Most members attend multiple sessions each year, with an average of 10 sessions per member. Approximately 80% of registered group members attend at least one session.

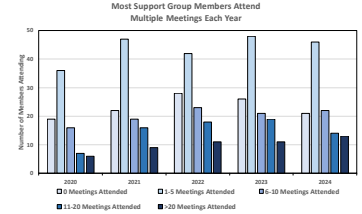

Figure 5*: Number of Support Groups Attended
The Boston-area FTD caregiver support group encourages flexibility with regard to attendance, once a member has registered. Most members attend multiple sessions, with approximately 40% of registered members attending 6 or more meetings per year; 25% of registered members attend 11 or more meetings per year.

** Groups began meeting on March 24, 2020; there were only 38 meetings in 2020, compared to 50 or 51 in 2021-2024.*

"Participating this year in the sessions has been so helpful. Such a valuable resource and wonderful groups of caregivers."
- *Caregiver of Spouse Living with PPA*

"Thank you for running the Support Groups and providing info through the newsletters. I find them very helpful."
- *Caregiver of Parent Living with BvFTD*

"I want to learn more about this disease and how to work as a family to care for my son."
- *Caregiver of Child Living with FTD*

"I am grateful for the support and having a place to share difficult feelings."
- *Caregiver of Spouse Living with PPA*

Conclusion

The framework and guidelines developed by the SGFs for this support group create a safe and welcoming environment for caregivers to share all aspects of their caregiving journey. Providing caregivers of people living with FTD with a regular online support group with established guidelines for behavior can diminish the isolation that dementia caregivers often experience, promoting opportunity for high quality care for care recipients.

Discussion

- Understand the elements of a high-quality support group.
- Discuss the benefits of support group attendance for caregivers of individuals living with dementia, including reduced social isolation and increased access to educational resources.
- Illustrate how clinicians may encourage and effectively refer caregivers to engage with an appropriate caregiver support group.

Acknowledgements

We would like to thank the hundreds of FTD caregivers who have shared their wisdom, love and struggles with us.
We would like to thank everyone at the Association for Frontotemporal Degeneration who enable the nationwide FTD Caregiver Support program.