

FACILITATING PARTICIPATION IN FTD RESEARCH

Scientists have made substantial progress in understanding how FTD affects the brain. However, there are still many gaps in our knowledge and no effective treatments, creating an urgent need for more research—and for willing volunteers. Family members, friends and health professionals can support study participants in many ways.

UNDERSTANDING AND FINDING FTD RESEARCH STUDIES

- Learn how to evaluate research participation options. Ask questions about the research site(s), funder(s) and qualifications of the researchers.
- Encourage people with FTD and their family members to join the FTD Disorders Registry: www.FTDregistry.org.
- Visit www.ClinicalTrials.org and search for FTD-related key words (“frontotemporal dementia,” “primary progressive aphasia,” etc.) for information and eligibility criteria for studies.
- Sign up for AFTD’s newsletter and visit the AFTD website—www.theaftd.org—for updates about FTD research and emerging studies.
- Consider brain donation early and pre-register with at least one brain bank.

**HELP THE CAREGIVER IDENTIFY WHAT
RESOURCES ARE AVAILABLE TO FACILITATE
PARTICIPATION, SUCH AS FINANCIAL HELP.**

SUPPORTING PARTICIPATION

- Encourage the person diagnosed and their caregiver/research partner to share their motivation to participate in research with family, care managers, day program and facility staff who may not understand why research participation is so important to the family and all those affected.
- Help the caregiver identify what resources are available to facilitate participation, such as financial help; some may be consumed by caregiving and not be able to investigate fully.
- Assist the primary caregiver to gather necessary medical history, clinical evaluations and test results.
- Use creativity to help the caregiver get the person with FTD to go to the study. People with FTD may not think they have an illness or understand the purpose of the study. Some may see the clinical/research team only once per year; it can be challenging to get them to go back again. Many important studies require multiple visits over time. Long-term commitments to basic research may prove difficult for families, notwithstanding the “carrot” of medication testing.
- View online videos of research procedures in the study with the participant to help them prepare. Some videos are available at <https://www.alzheimers.org.uk/researchvideos>.
- Review facility policies regarding patients involved in pharmaceutical clinical trials. Meet with the clinical staff to discuss the study and their specific roles in it (for example, do they document specific behaviors?).

- Provide emotional support to individuals who wish to participate but are ineligible, or who are distraught when they must discontinue due to progression of the disease.
- Ensure current contact information. Ensure that family and clinical staff have access at all times to the steps necessary for brain donation. Donation for research must be done within a maximum of 24 hours of time of death.
- Keep brain-donation information in a section of a facility chart labeled “Do Not Remove/Thin.” As a person’s chart gets thicker over time, or if they are moved to hospice care, this information may be removed or hard to find.

TRAVEL TO RESEARCH CENTER

- Plan travel carefully to anticipate the patient’s needs and reduce possible behavior triggers; consider stress management needs of the caregiver/study partner.
- Schedule tests when the person is at their best. Be mindful of the patient’s needs.
- Do not introduce any unnecessary stress the day before travel. On travel day, plan for enough time and assistance to ensure timeliness.
- While traveling, adequately supervise the person diagnosed to reduce their chances of getting confused or lost.
- Arrange for a friend, family member or favorite facility staff person to accompany the patient and caregiver as needed.

**WHILE TRAVELING, ADEQUATELY SUPERVISE
THE PERSON DIAGNOSED TO REDUCE THEIR
CHANCES OF GETTING CONFUSED OR LOST.**

DEVELOP STRATEGIES FOR SPECIFIC SYMPTOMS OR ANTICIPATED BEHAVIORS

- Use an individualized approach to encourage participation if the person no longer understands. Arrange travel to the research site with a favorite relative, or include a preferred stop or treat after completion of the study testing.
- Have the person wear a bright color or something easily visible in a crowd to avoid getting lost.
- Take a recent photo of the person with you and ensure they are carrying identification information in case they walk off.
- Public family restrooms can be rare, so carry a sign saying “One moment please: This restroom is being used by a member of the opposite sex to assist a family member with dementia.”
- Move furniture in front of the hotel door or disguise the door knob to discourage compulsive nighttime searching for food or drink.