Partners in FTD Care

a quarterly newsletter for healthcare professionals

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FAMILY PARTICIPATION IN FTD RESEARCH

Frontotemporal degeneration (FTD) is caused by the atrophying of the brain's frontal and/or temporal lobes, gradually destroying one's ability to behave appropriately, empathize, learn, reason, make judgments, communicate and carry out daily activities. FTD is classified as a rare disease, and remains poorly understood relative to other neurodegenerative conditions. But opportunities to participate in FTD research are increasing. Persons with FTD and their families have shown eagerness to take part in clinical studies, but effective participation can require specially focused support. Healthcare professionals can provide guidance and coordination necessary to help them embark on this journey.

THE CASE OF ANNE L.

BACKGROUND AND EARLY ILLNESS

Anne L. was a dedicated nurse who received a master's degree in nursing with a specialty in cardiac care. She worked in direct care for 31 years in four different states and taught nursing in universities and community colleges. Anne married Paul in 1988 and loved being mother to their two children, Jane and Alan. Throughout her life she had a strong faith and was active in the Lutheran Church wherever she lived; she was devoted to serving others. She enjoyed many sports—jogging, tennis, hiking—and especially liked being outdoors in the sun.

Anne's clearest FTD symptoms started in 2003, when she was just 51. During a family visit, her mother complained of stabbing pains in her back. Despite being a trained nurse and caring daughter, Anne reacted with an uncharacteristic coldness. Later, her mother went to her oncologist and learned that her breast cancer had metastasized to her liver; she was given no more than two months to live. Paul asked his wife if she wanted to make a return visit to see her mom one final time. Her response was puzzling: "No, I just saw her." At the funeral, she acted in an inappropriately jovial manner, and was of little to no help cleaning out her mother's home.

Over the next few years Anne's personality and judgment continued to change. She no longer showed affection with her children and quarreled more frequently with her husband. Once a skilled card player, Anne now made frequent mistakes and became confused about the rules of certain games. She seemed to lose interest in her family and friends; meanwhile, she started compulsively donating money to any charity that mailed a solicitation. She craved carbohydrates, especially sweets—Paul stopped buying ice cream after she ate a carton in one day. In time she became obsessive about water, often drinking 10 or more glasses in one sitting. In 2005, she lost her nursing job because of her deteriorating judgment. Eventually she had to stop driving. Yet through it all, Anne could not see how her changes were affecting her and her family.

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THE IMPORTANCE OF FTD RESEARCH

FTD is classified as a rare disease, with an estimated prevalence in the U.S. of 60,000. But successful FTD research could have ripple effects that extend far beyond itself. Many scientists now believe that a deeper understanding of FTD could have an outsized impact on our understanding of other dementia-causing diseases, such as Alzheimer's, as well as other neurodegenerative diseases, including ALS and Parkinson's.

Fully understanding FTD could give researchers the clearest picture of how such illnesses "work" – and, therefore, how they can be treated and perhaps cured. This is due to several reasons. For example, because FTD symptoms begin at a younger age, researchers seeking to understand it are not faced with confounding, age-related changes in the brain. Additionally, up to 40 percent of FTD is hereditary, a much higher percentage than Alzheimer's and most other forms of dementia. The genes responsible provide key insight into disease mechanism, as well as tractable tools for research.

Finally, because FTD is categorized as a "rare disease," it qualifies under the Orphan Drug Act of 1983 for special considerations at the FDA when approval is sought for new drugs. These considerations, which include smaller, shorter—and thus less expensive—clinical trials, serve as an incentive for industry investment.

At her mother's funeral, Anne acted in an inappropriately jovial manner.

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FTD RESEARCH: URGENTLY NEEDED, UNIQUELY CHALLENGING

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 study participants.

Families who choose to take part in FTD research often do so in the hope that the results will help others, even if they themselves don't directly benefit. Participating in research can present certain challenges, however, and families should be prepared to encounter them. Travel to an academic research center, for example, can be time-consuming and expensive, and may not be reimbursed. Cognitive and behavioral symptoms can make unfamiliar settings like airports and hospitals stressful for both the person with FTD and the care partner accompanying them. And the study protocol itself, which may include procedures people with FTD find confusing or difficult, such as remaining still during MRI scans, can be an additional source of stress. As symptoms increase in later stages of the illness, these challenges mount, eventually reaching a point where the affected individual is no longer physically capable of continuing in the study.

Research on FTD, particularly clinical trials of new drugs, also poses unique challenges to investigators. Simply recruiting enough participants for a study can be difficult; although FTD is the most common dementia in people under the age of 60, it's still uncommon compared to other neurodegenerative disorders. The difficulty of diagnosing FTD accurately raises questions about a prospective volunteer's eligibility to participate, while mistakes in differentiating FTD subtypes or determining underlying pathology in the absence of a known genetic mutation may lead to mismatches. For example, a person may be enrolled in a study evaluating a drug to treat FTD-tau when they have FTD-TDP-43. Finally, delays in diagnosis—on average, FTD is diagnosed three and a half years after symptom onset—make it hard to determine if a new drug is ineffective or simply being tested too late in the course of the disease.

Families need to be aware of the demands of participation before committing to take part in FTD research; with preparation, many of the burdens of those demands can be reduced. And both persons diagnosed and their caregivers should know how deeply their efforts to participate are appreciated. Because the number of people affected by FTD is small, every person who contributes to FTD research can make a big difference.

In April 2006, Paul began to investigate why Anne was acting so differently. Six months of doctor's appointments followed, including visits to two primary care physicians, two psychologists, a psychiatrist and a neurologist. Finally, after undergoing neuropsychological testing, she was diagnosed with behavioral variant FTD (bvFTD).

DECISION TO PARTICIPATE IN RESEARCH

After Anne's diagnosis, Paul began to search for additional information about FTD. Although his family lived in North Carolina, he reached out to an academic medical center in the Midwest to schedule an appointment for a second opinion in late 2006. The medical center's director spoke about the research value of receiving postmortem brain tissue donations from people with FTD. This sparked Paul's interest in doing anything possible to help others affected by this devastating disease.

The following year he attended an FTD education conference in Philadelphia and found that Anne met the criteria for a longitudinal FTD study at a nearby academic research center. The study would include the opportunity to donate her brain, both to confirm her diagnosis and to contribute to research. Paul felt confident that, given his wife's nursing background, she would want others to learn from her experience. With Paul as her Power of Attorney, they enrolled in late 2007.

During Paul and Anne's first visit, the center's research team met with them to discuss the protocol and to obtain informed consent. Several days of tests followed, including a neuropsychological evaluation, simulated driving test, lumbar puncture, genetics testing and a functional MRI, plus an exam by the center director. The study protocol required them to return every six months for additional evaluation. Paul and Anne participated for four years, absorbing the cost of travel and lodging themselves. In the beginning the greatest obstacle to participation was arranging care for their middle-school-aged children.

As her disease progressed, Anne remained content and cooperative but developed additional symptoms. Her judgment continued to decline, as did her awareness of safety. She needed more assistance with activities of daily living and required constant monitoring, which started making travel stressful for Paul.

A SECOND STUDY

In October 2008, Paul took Anne to participate in an additional FTD research study, conducted by the National Institute of Neurological Disorders and Stroke (NINDS), part of the National Institutes of Health (NIH) in Maryland. To be accepted for the study, he had to provide her diagnosis history—which he had already compiled for her Social Security Disability Insurance application—as well as detailed information about his wife's symptoms, diet, family history, exposures, etc. (Anne's sister helped to gather family history information.)

Paul's parents flew from California to North Carolina to stay with Jane and Alan, while Paul and Anne travelled to NIH. They arrived the day before the start of the study, appreciative that NIH covered all travel and lodging. Travel had become complicated due to Anne's symptoms, particularly her compulsive eating and drinking. Ignoring the "fasten seatbelt" sign, she searched the airplane for food and something to drink (water, coffee, soda). She took Trazodone to help calm her nonstop need to drink, but it interfered with her ability to sleep.

Getting through hospital security on the first morning was unnerving. Anne was confused. She did not want to give up her bags or go through the metal detector. Checking in and finding the clinic took a long time.

Paul and Anne met for several hours with the lead researcher, who confirmed that the testing was purely to better understand the how the brain's frontal lobes function. This was a broad research study only; NIH did not see anyone on an ongoing basis. The researcher reviewed informed-consent documents with them and explained they were free to leave at any time. Testing was to occur in daily 90-minute sessions over the course of four days.

One of the sessions involved a PET scan, which would use glucose to watch Anne's brain functioning and activity. To ensure the procedure's effectiveness, she could not have caffeine after noon the day before, and no food or drink after midnight. Since she typically snacks and drinks all night, Paul had to hide her food stashes and monitor her constantly. It was a stressful night.

The day of Anne's PET scan, the radiologist inserted a thin tube into her wrist, drawing blood at very specific intervals to measure her glucose levels. The researchers were concerned that Anne's frequent need to use the bathroom would interfere with the testing, but the PET scan went well. However, after lunch, when the researchers tried to conduct an MRI, she was too active, so part of it had to be re-done.

On their last day in Maryland, Paul met with the clinic director to review the results of Anne's PET scan and MRI. They showed that her frontal lobe was atrophying, which was the cause of her issues with judgment, organization and executive functions; meanwhile, her temporal lobe, which is more associated with language, had relatively fewer issues. These results would be shared with Anne's neurologist back home.

The doctor told Paul to provide Anne with daily mental stimulation and physical exercise, and recommended continued professional and informal support for himself and their children. The doctor invited Paul to follow up with him and explained the importance of advocacy and seeking funding for FTD, since little was happening with the drug companies. While there were a few difficult moments during the trip, Anne was content and generally cooperative the whole time.

RESEARCH IN MIDDLE-STAGE DISEASE

As Anne's FTD progressed, she needed more assistance with her activities of daily living. Paul needed to work, but could not leave her home alone. So, in early 2010, she started attending an adult day program, where she could be supervised and safely interact with other people. The staff was very patient and understanding of Anne's condition, although over time her actions made some attendees quite unhappy. For example, she developed a fondness for coats, so she would walk around taking people's coats for herself.

Eating became Anne's most dangerous activity, requiring close supervision. She ate very quickly, and, since she refused to wear dentures, had perilously few bottom teeth with which to chew her food. She did not understand that hard foods like raw carrots presented a choking hazard. Anne also became incontinent. Wet clothes, bedding and furniture were an ongoing problem at home and at her day program, even though she wore Depends.

Nevertheless, Anne developed a comfortable daily routine. Always an avid reader, she now kept busy reading magazines, although she often spent the whole day on a single page. She also would compulsively work through word-search magazines. It was no longer possible to carry on a conversation with Anne; she would endlessly perseverate a single phrase—e.g. "I'll be meeting you in the car" or "I'll be putting on my seatbelt." Risperidone, an antipsychotic, was helpful with agitation during the day; and though Klonopin helped her sleep soundly at night, bedtime was often a struggle.

Traveling to the research site had become complicated due to Anne's symptoms, particularly her compulsive eating and drinking.

Travel to the study site in Philadelphia became increasingly difficult. Paul could not let Anne out of his sight for a moment, which made using the bathroom in public a stressful task—family bathrooms were hard to find. She moved quickly; if left alone, she would become distracted and get lost. On one trip Paul was so afraid she would wander out of their hotel room, he blocked the door with a heavy coffee table. He had no idea how the research team helped her to sit still for the tests, but appreciated that they gave him the chance to take a break. All other times, he had to be "on."

In October 2011, they flew to Philadelphia one last time. The center's director did an evaluation and confirmed that Anne's disease had progressed to the point that it could now be considered "middle stage." Given this fact—and since Anne could no longer effectively take the required tests—Paul and the director decided that it was no longer necessary to make the exhausting journey to Philadelphia to participate in research. The director thanked them for their participation.

Because Anne and Paul registered for brain donation with the center in Philadelphia, researchers there would conduct a brain autopsy upon Anne's death, identifying the disease pathology and, together with the longitudinal clinical data, helping researchers to understand FTD. The researchers were clear that participants would not gain personally from the research, but still Paul quietly hoped he would. He learned from his meetings with the director at each visit, but never got feedback from the testing data.

ADVANCED DEMENTIA AND BRAIN DONATION

Over the next year, Anne's decline quickened. She was no longer as sharp; even singing church songs with her family was getting harder. In the spring, Paul started to look at assisted living facilities. He knew that, with Jane and Alan leaving for college in the fall, caring for his wife by himself would become too difficult. At the suggestion of a geriatric care manager and with the help of a friend, he found a group home that focused on caring for people with various kinds of dementia. Encouraged by his children, Paul placed Anne in the group home in early June. Since Jane and Alan hadn't yet left for college, they helped their father adjust to his wife's absence.

Anne quickly adapted to her new environment. Paul and the kids visited twice a week, singing songs, reading to her. Paul began to recover from the strain of caregiving, and felt he had found new ways to "reach" Anne.

In early October the staff reported that Anne was getting more agitated and difficult to contain. Then, in November, she choked while eating breakfast and lost consciousness.

Anne was put on life support. At the hospital, her family made care decisions according to her wishes. She donated a kidney to someone who badly needed it, which they knew would thrill her.

Anne passed away with family at her side. The local hospital coordinated the donation of her brain with the center in Philadelphia for FTD research, as Paul had previously arranged. An autopsy confirmed FTLD-tau pathology.

A brain autopsy would identify the disease pathology and help researchers better understand FTD.

Questions for Discussion

What did Paul expect to gain from participation in several different FTD studies? Was there benefit to Anne or his family?

Paul learned how important brain donation is to FTD research when Anne obtained a second opinion at an academic research center. While Paul knew she would not directly benefit from the research, he became interested in doing whatever they could to help others affected by the disease. He felt confident that, given his wife's nursing background, she would agree. The first longitudinal study offered participants access to clinicians who were experts in FTD, as well as the opportunity for brain donation. A brain autopsy would provide a definite diagnosis and contribute to research, both of which were important to Paul. He gained insight from meetings with the director at each visit, but never any feedback from the testing data. The NIH study was purely for research purposes so the investigators could better understand the functioning of the frontal lobes of the brain.

Partners in FTD Care Advisors

The Partners in FTD Care initiative is the result of collaboration among AFTD, content experts and family caregivers.
Advisors include: Sandi Grow, RN, caregiver • Lisa Gwyther, LCSW, Duke Family Support Program • Barbara Harty, GNP, UNTHSC • Susan Hirsch, MA, HCR ManorCare • Jill Shapira, PhD, RN • Rebekah Wilson, MSW

AFTD extends special thanks to this issue's special guest contributor, Paul Lester, a former FTD caregiver and current member of the AFTD Board.

Researchers shared the results of brain imaging and other clinical information with Anne's doctors at home to guide her care.

What challenges had to be overcome to continue to participate?
Paul was grateful that his wife remained pleasant and cooperative throughout, and that they could absorb the cost of airfare, train fare and lodging, which were not funded in this study. Their greatest challenges involved Anne's ability to travel as her cognitive and behavioral symptoms increased. Paul could not leave her for a moment or she would become distracted and get lost. Airport security confused her; she did not want to give up her bags or go through the metal detector. Her compulsive eating and drinking routines caused challenges. Public family bathrooms were hard to find, and Paul could not let her use the bathroom alone. She ignored the airplane's "fasten seatbelt" sign as she sought food and drink. Paul had to limit caffeine after noon the day before the PET scan and restrict food and drink after midnight, which required him to hide all her food stashes and monitor her constantly. The PET scan required drawing blood from her wrist at very specific intervals to measure the glucose levels. Researchers were concerned about Anne's frequent need to go to the bathroom, especially during a 90-minute test. At one point she was too active during an MRI scan and it had to be done again. After four years, travel to the study site became too difficult, and she was no longer able to complete necessary tests in the protocol.

How did family, friends and healthcare providers support Anne and Paul's participation in research?
Paul and Anne did not have family that lived close by but were active in their local faith community. When it was clear that his wife had no insight and would not be hurt or worried about what he shared, Paul decided to be open with their friends about her diagnosis and the challenges their family would face. He shared whatever he thought others needed to know in order to be supportive. While it was his decision to enroll in research, their extended family recognized that Anne would be pleased that her experience would benefit others, and they supported Paul's decision. Her sister gathered family history information needed for the NIH study. Paul's parents flew from California to North Carolina to stay with Jane and Alan while Paul and Anne were in Maryland. When his wife moved to a group home, Paul informed staff of her plan to participate in brain donation. He ensured that her chart contained all the information needed to carry out that plan, should she die unexpectedly. In Anne's case, the local hospital ended up coordinating donation of her brain with the academic research center.

CURRENT RESEARCH OPPORTUNITIES FOR PEOPLE WITH FTD

Several types of studies are open to families who want to participate in FTD research:

FTD Disorders Registry: This is the most inclusive research opportunity. Participation is open to individuals diagnosed with an FTD disorder, as well as family members, caregivers and friends of a person diagnosed. For more information visit www.ftdregistry.org.

Natural History Studies: In natural history studies, researchers observe participants over time and document the changes in their health. The National Institutes of Health funded two natural history studies of FTD in 2014: Advancing Research and Treatment of Frontotemporal Lobar Degeneration (ARTFL) and Longitudinal Evaluation of Familial Frontotemporal Dementia Subjects (LEFFTDS). These studies are currently recruiting participants through a network of 15 clinical centers in the U.S. and Canada. ARTFL includes both sporadic FTD (meaning an occurrence of FTD without any family history) and familial FTD, while LEFFTDS is open only to individuals with one of the three most common gene mutations in FTD (*MAPT*, *GRN*, or *C9ORF72*). There may be additional restrictions on participation.

- **ARTFL**: To find an ARTFL site near you and learn about opportunities to participate, email JoinARTFL@ucsf.edu or call (415) 476-7777 today. Find more information about the ARTFL study at ClinicalTrials.gov.
- **LEFFTDS**: More information about the LEFFTDS study and contact information for the clinical coordinators at specific trial sites is also available at ClinicalTrials.gov.

Clinical Trials: This is a special type of clinical research study used to test a new treatment, diagnostic tool or prevention strategy. (A chart explaining how researchers use clinical trials to evaluate new treatments can be found at the National Institutes of Health's website.) To minimize the possibility that irrelevant factors will confuse the study results, researchers develop strict eligibility guidelines, so not everyone who would like to participate will be able to do so.

The most common clinical trials are those that evaluate new medications, also known as drug trials. Clinical trials of FTD medications are currently recruiting participants; information can be found on the AFTD website and at ClinicalTrials.gov.

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TROUBLES & TIPS

Q: A woman in our hospice program wanted to enroll her husband for brain donation. One of our staff found information online and helped her to pre-register with a brain bank interested in neurodegenerative disorders. When he died, there were complications and the autopsy coordinator said that brain donation would be impossible. Only the wife's dogged round-the- clock advocacy made it happen. What can we tell families to make this process better?

A: Advanced planning and clear communication are key! Brain tissue intended for research must be obtained within 24 hours of death. Meeting this deadline requires coordination between the research center or brain bank, the family, the pathologist or autopsy technician, the funeral home, and hospice or residential care providers – a process that can easily lead to unexpected complications.

The decision to donate a loved one's brain for research is a sensitive personal matter, yet doing so requires considerable paperwork, logistical planning and potentially some cost to the family. Providers and other family members can help ensure that the primary caregiver has a full understanding of the process by referring them to reputable sources of information as early as possible (AFTD and the resources below can help). Encourage the caregiver to take time to explore options and understand how they may differ. When the potential donor and family pre-register with a research center or brain bank the staff there will provide information about the donation process, costs to the family (if any) and contact information for the autopsy coordinator. Because the needs of researchers and storage capacity of the facility can change over time, some people choose to pre-register with more than one brain bank.

The autopsy coordinator will provide paperwork to complete and instruct the family about gathering clinical and neurological records. The value of pathology studies on the donated brain is greatly increased when considered in light of clinical information from the course of progression during life. Requesting documentation from physicians can take time.

The primary caregiver should communicate their wish to participate in brain donation with family, friends and providers. This education can help others to understand and respect the caregiver's choice and support the process. The brain bank autopsy coordinator will provide contact information and steps to follow at the time of death that can be shared with others involved with the diagnosed persons care as needed.

When notified of a brain donation designation, the administrator of a care facility will educate staff and include relevant contact information (for example, for the patient's funeral home) and other instructions in the resident's chart. The administrator should also confirm that staff know how to obtain consent from the family at the time of death. To prevent this information from getting lost over time as the chart grows thicker, a good practice is to put it in a separate section marked Do Not Remove. Families should carry the autopsy coordinator's contact information with them at all times, and ask that the outside of the chart or notice by the bed indicate the donor status. Timely execution of the plan upon death is critical.

Two resources that may be helpful to families considering brain donation are:

- Brain Support Network: Offers assistance to people interested in brain donation, including an informative article on the requirements and process.
- Brain Donor Project: Assists families in making a brain donation to one of six brain banks in the NeuroBioBank network. These brain banks are located in New York, Boston, Baltimore, Miami, Pittsburgh and Los Angeles.

(**Research Opportunities**, *continued from previous page)*

Brain Donation: Another way people with FTD and their families can participate in research is to donate the brain of the affected individual to an FTD research center or a brain bank, a facility that collects and stores donated brain tissue for future research. Brain donation requires planning. Each center or brain bank has criteria for enrollment and study protocols they must follow. Upon enrollment, families should confirm whether they will receive a pathology report. If a patient qualifies for the research program, there may be little cost to the family, but the details of what is and is not reimbursed should also be confirmed with the brain bank.

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.