

**FTD/PPA Caregiver Education Conference**  
**March 11, 2011****Question and Answer Session**

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**Caring for the person with FTD/PPA****1. If the FTD/PPA patient is living alone, how do you (as a caregiver) handle wanting them to be social and with other people without putting them in a nursing home too early?**

You might consider a day program for the person, schedule friends/family to visit, or engage in an activity together on a regular basis. However, due to changes in judgment, reasoning and other early stage symptoms of FTD, a person living alone is extremely vulnerable and should be carefully monitored. Contact your local department on aging (over 60) or department on rehabilitation (under age 60) at [www.eldercare.gov](http://www.eldercare.gov) for information about local day programs, transportation options, companionship and in home services.

**2. How do you get a patient to engage in some form of physical activity when they are capable but hesitant? My husband goes to daycare three days a week. When at home, he sits in front of the TV, not really understanding what he sees.**

It sounds like your husband is no longer able to initiate his own activities. Instead of expecting him to engage in something on his own, pick activities you know he will enjoy and help him engage. Making a regular schedule of activities can be helpful.

**3. How does a caregiver get a patient to be social when they are resistant but capable? Trying to avoid sitting in front of the TV alone or "early" nursing home placement.**

Sometimes, individuals respond better to one-on-one situations than group activities. If that is the case, consider finding a companion to assist in engaging them in or outside of the home. Regarding social situations outside of the home, you might avoid asking open-ended questions about what they would like to do. Limit choices. For example, "We are going for a walk now; do you want your red jacket or your blue jacket?" In this example, there is no choice about the walk, but they will still have some choice in the matter. Another example is "We are going out to dinner, shall we have Italian or Chinese?"

**4. When diagnosed officially as disabled with PPA, what rights legally does the patient have?**

When a physician makes a diagnosis, no legal rights are taken away from the patient. Only a judge can declare a patient incompetent, unable to make decisions and in need of a guardian or surrogate decision maker. There will come a time when the person is no longer able to make their own decisions about health care and finances. However, we do not know when this time will be, so at the time of diagnosis it is important to establish Power of Attorney for Health and Finances. A physician will be able to inform the family when he/she believes the disease to progress to a point where the Power of Attorney documents should be activated. This is usually at a point when a person with PPA cannot express themselves or communicate their own needs.

**5. Is adult day care something you can get help paying for? For someone who does not have a lot of money, how do we get the help we need? Insurance doesn't cover and too young for Medicaid – all out of pocket now.**

Adult Day programs are fee for service programs. Many are subsidized by state programs such as the Department on Aging (over 60) and Department of Rehabilitation (under 60) for those who financially qualify. Depending on the center, there also may be sliding scale fees. Visit: [www.eldercare.gov](http://www.eldercare.gov) for the state agency in your area.

**6. Do you know of a GPS that tracks a person's position at all times? My sister does not know where she is or where she is going. I heard of a GPS device in a medical bracelet. Do you know of any device?**

Before seeking out GPS technology to help keep track of a person with dementia like FTD, it is important to assess why such a device is needed. If a person is left unsupervised and is likely to go to unsafe locations, it will be important to consider increasing supervision for the person to maintain safety. Global Positioning System (GPS) tracking technology is only suggested as a supplement to supervision, not as a replacement to supervision. Most options include a device, such as a pager, cell phone, etc which will need to stay with the person to be accurate. Please read more about the GPS technology at <http://www.gps.gov/systems/gps/> Below is more information about two technologies developed for persons living with a dementia.

The Alzheimer's Association has a service using GPS tracking which has been developed for persons with early stage dementia. With Comfort Zone families designate a zone and if the person with dementia leaves the zone and has the GPS device on them, an alert is sent to their caregiver and then the GPS is used to help locate the person. To learn more visit [www.alz.org/comfortzone/](http://www.alz.org/comfortzone/).

In collaboration with the Alzheimer's Foundation of America Bread Crumbs developed a GPS tracking device Breadcrumbs is a GPS "bracelet" that is placed on the patient's ankle with a "hospital band" <http://breadcrumbgps.com/>.

**1. What are other ways of giving patients all of their pills if they won't take them at home? Is it OK to put in food or drink? What if they won't drink?**

Ask your pharmacist about mixing medications into food or drinks. Some drugs are safe and effective in this form, and others not.

**2. What are some ideas to give medications when the person with FTD refuses to take drugs?**

Some medications come in liquid or patch form, which can be more tolerable, others can be mixed into food or drinks. Consult the patient's physician regarding the specific medication.

**3. How can I get my 86-year old mother diagnosed when she will not let me take her to a doctor/neurologist? What are "successful" approaches to persons who you want to evaluate?**

It can be a challenge to take a person with a cognitive impairment to see a physician for evaluation and treatment. This is often because the person is not able to understand the importance of the evaluation or does not think it is necessary. If your mother goes to a primary physician for annual checkups, use that as an opportunity to discuss privately with the doctor the symptoms you are seeing. Also there are some physicians who do home visits, and it may be worth checking into this in your area.

Some families tell "Therapeutic Fibs" to help encourage an evaluation. For example, a family member may tell the patient that the health care insurance company is asking for a physician evaluation so that health insurance coverage can continue.

When at the doctor's office, make sure to spend some time alone with the physician to talk about the symptoms and problems that need to be addressed.

**4. Recently, we have taken a strong stance with my mom and insisted on home care. She only seemed to understand this fully when we get angry and lay down the law. Dr. Reed said that we should only approach my mom in an upbeat, directive manner; however, this has not been effective. Are there exceptions to the "no expressing anger" rule? We are hoping to avoid guilt.**

It is important when caring for someone with dementia to know that not all approaches will work for each family. Some approaches we know work more often than others. In this case it sounds like Dr. Reed is suggesting an approach that has worked for many families. But, if you find through trial and error that one approach works better than another, go with the approach that works for your mother and family.

But also keep in mind that your mother is less able to understand the reason for home care. She also may understand one moment and not the next. It is not important that she understand the details fully but it is important that she is safe and that her daily needs are met.

**5. My mother is the primary, full-time caregiver of my father who is in the late stages of FTD. She has made the decision to not put him in a nursing home, but has also become extremely stressed and miserable. When out in public, she pulls his hand like a child and repeats an instruction in a stressful tone. I would like to know, how do I approach her and educate on how to handle her situation in a less stressed manner?**

A person in the late stages of FTD requires a great deal of care. Caregivers might react with an abrupt tone or behave in the way you describe because the person's needs have become too overwhelming for them to manage alone. If taking your father out in public is becoming more difficult for your mother, it is important to consider a few things: (1) Is the activity causing him more anxiety and stress than your mother is able to manage? (1a) If he is able and enjoys going out, is it possible to engage the assistance of someone trained in dementia care? (2) Your mother may be experiencing tremendous caregiver stress which affects her mental and physical wellbeing, and may well be the reason she responds to him in this way.

Your mother needs respite and additional help caring for your father. Finding a regular respite opportunity for her will not only alleviate some of her stress, but also help her to realize that additional care is beneficial to them both. Time away from the care may rejuvenate her and she may be more open to ideas about how to respond to and best care for him. If she does not seem to be receptive to families' attempts at education or suggestions for respite, it would be helpful for someone other than family, or the patient's doctor to speak with her. Additional education about how to respond to a person with dementia in a compassionate and effective manner can be found by meeting with a social worker who specializes in dementia care, attending an FTD caregiver support group, or calling the AFTD's toll free helpline: 1-866-507-7222.