

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

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Symptoms**1. Are there known cases of a patient with PPA physically hurting their caregiver?**

Injury to caregivers is more common in the behavioral variant of FTD, but there have been uncommon incidents when those with PPA have injured their caregivers. These incidents may be related to behavioral or personality changes, or may be from agitation caused by difficulty with communication.

If you have concerns about aggression contact the neurologist or psychiatrist. If at any time the situation has escalated and you or the person you care for is at risk for harm- call 9-11 Emergency Services.

2. How can I deal with increased anger, depression, and some physical aggression (towards me) after a nurse assistant began coming weekdays for four hours for personal care and respite?

Obtaining additional care and respite are very important steps to take to assist you in the care of your family member. It is good that this has been put in place. However, many persons with dementia attempt to maintain their independence as long as possible. Although they are increasing becoming more dependent on others for their care and safety, due to their diminished ability to reason, the person may not understand why additional care is necessary.

It is important that you receive emotional support when anger and frustration are directed at you. This may be through a support group or individual counseling. But it is important that you find support in this situation.

A person with dementia can take longer to adjust to a new routine. As they are adjusting to the change, it will be important to identify what triggers may be causing the increased anger, depression and aggression. Please consider speaking to your physician, preferably a psychiatrist, to review these symptoms and discuss behavioral interventions or consider medications. If at any time the situation has escalated and you or the person you care for is at risk for harm- call 911 Emergency Services.

3. My husband has a diagnosis of PPA. Is it possible that his impotence (which has been unsuccessfully treated by a urologist) is related to brain changes due to PPA?

Not directly. However, there are many indirect effects of PPA and other dementias on sexual functioning.

4. Is lack of empathy a symptom of just FTD or PPA as well?

PPA begins with language impairment, but as it progresses, other FTD-like symptoms, including loss of empathy, can occur.

5. Is there a simple difference between the two other than “right brain – FTD, left – PPA”?

FTD and PPA are defined by the primary symptoms or signs that affect the patient. In FTD, attention, concentration, motivation, inhibition, and personality are primarily affected. In PPA, language is primarily affected. Most times, the left half of the brain is more heavily affected in PPA, whereas this trend is not seen in FTD.

6. What appears to be incontinence (e.g., soiled underwear)? It may be a loss of self-care (cleaning up). How do we know?

It can be difficult to know and in some cases, both may be occurring. Persons with dementia may be less able to communicate the need to toilet or adequately care for themselves. It is important that changes be reviewed by a physician. In many cases, changes in urine or bowel are treatable and unrelated to the dementia. Close monitoring may help provide a physician with more information to determine the cause. Due to a loss of interest in self-care and if there is no treatable cause for the incontinence, additional supervision will assist the person in maintaining better hygiene.

7. How do we deal with the physical and emotional challenges?

Every individual caring for a person living with dementia ultimately finds their own methods of coping or dealing with the various symptoms of the disease process. Some families find that being educated and informed on the disease process and symptoms can help identify strategies to address symptoms and cope with the changes. Many families look to professionals; doctors, nurses, social workers, or professional caregivers, to assist in addressing the physical and emotional challenges of this disease.

If the disease affects the patient emotionally and behaviorally, speak with your physician about non-medical interventions (social engagement, exercise, meaningful activity) and medications. The family’s emotional needs must also be addressed through individual counseling, respite, support groups, or possibly medications.

8. My husband, diagnosed with PPA, gets severe headaches in the temple area of his head. Is this related to PPA? Is this a cause for concern?

Headaches are not a part of PPA. Your husband’s physician should evaluate this.

9. My dad has PPA and his legs are always cold. Is that part of the disease?

This is not a commonly described feature in PPA and is likely unrelated. A physician should evaluate this.

10. What about spatial issues? My husband was diagnosed with FTD and has difficulty with the symptoms discussed but he also has many problems with opening drawers, getting dressed, locating things, folding, etc.

Visual and spatial issues can occur in some forms of dementia. Severe problems with attention, concentration, sequencing, and the like can cause problems with spatial tasks. Dementias like Lewy Body Dementia, and rare types of Alzheimer’s disease more commonly have symptoms that change a person’s

visuospatial and perceptual abilities. These symptoms can greatly affect a patient's quality of life and ability to perform daily activities. Often Occupational Therapists can visit the patient's home and can offer suggestions and recommendations to cope with these changes with a consideration for safety concerns due to increased risk for falls.

11. When the patient is always focused on pain or illness, how do you determine if it is real or exaggerated? The patient always wants to show new physical things such as chapped lips, pimples, etc.

Minor everyday physical complaints should be addressed by acknowledging them and then moving on. More serious symptoms warrant an evaluation because many times persons with FTD/PPA cannot communicate their distress very well. If evaluated and determined to be insignificant, they too can be acknowledged and then attempt to shift the attention to another topic.

12. Is trouble sleeping part of PPA? If a patient of PPA is having trouble sleeping, what are some suggestions for better rest? Our mother has taken numerous medications for this but it affects her handwriting, which is our only means of communicating.

Sleep changes may not necessarily be caused by PPA- but you need to consider how the diagnosis and symptoms are affecting the person's overall health, and well being. In some cases additional activity during the day can help individuals sleep better at night. In other cases a sleep study/evaluation is done to determine the cause of the sleep problems.

It will be most helpful to work with the physician who prescribed the sleep medication to see if there is not a better option that does not affect the patient's handwriting/communication. Also ask your physician about a Sleep Consult/Evaluation to determine the cause of the sleep problem and identify appropriate interventions.

13. How do I know the difference between depression and progression of FTD? Does the depression mask symptoms?

Depression can often be associated with FTD and can impair activity and worsen functional status. Evaluation and treatment for depression by a psychiatrist can help.

14. What are "stereotypical movements" mentioned in outline?

Repetitive, habitual, or compulsive movements are sometimes referred to as "stereotyped."

15. The FTD patient is very adamant about specific words and doesn't seem to be able to relate other words as the same. Is this the beginning of PPA?

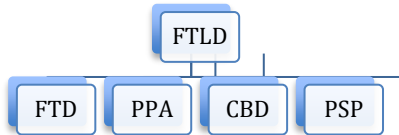
Behavioral variant FTD (bvFTD) begins by affecting a person's ability to plan, organize, along with personality and emotional/behavioral changes. As the disease progresses it affects other regions of the brain, like the language region. As a result, it is common for patients with bvFTD to have trouble with their language abilities.

Keep in mind that PPA and bvFTD are two different diagnoses. PPA starts with language problems, with no behavioral, organizational, emotional, memory or personality changes. As bvFTD progresses there can be a variety of language impairments which may look similar to PPA, but this would not change the diagnosis.

16. How do you distinguish symptoms of mental illness and FTD, PPA, etc.?

While this can be difficult at times, especially since people can have both, we recommend a consultation with an expert in Neuropsychiatry or Behavioral Neurology.

17. Why are FTD and PPA always grouped together? Can you have PPA without FTD?



Both PPA and behavioral variant FTD (bvFTD) are in a class of neurodegenerative diseases called Frontotemporal Lobar degeneration (FTLD). As the title indicates, these diseases affect neurons in the Frontal and Temporal lobes of the brain. The frontal lobe is responsible for our ability to organize, reason, and regulate emotion and personality. The Temporal Lobe is the area of the brain where our language functioning is regulated.

Also, from a clinical symptom point of view, PPA can often progress to include behavioral symptoms that are more FTD-like, but some individuals may have only language impairment for many years. PPA and bvFTD are related based on the pathological findings in the brain. This means that what is found at brain autopsy is often similar in those who have PPA and bvFTD.

18. Is reading out loud common? Speaking louder? Why is that?

In some people with PPA or FTD, doing these things may help them keep track of what they are reading or saying.

19. Are behavioral symptoms common with PPA?

PPA begins with language impairment, but as it progresses, other behavioral, FTD-like symptoms can emerge.

20. Will PPA become full-blown FTD?

PPA can often progress to include behavioral symptoms that are more FTD-like, but some patients can have only language impairment for many years.

21. Do you find FTD patients have sleep disorders? My husband stays up sometimes two days straight. He gets 3-5 hours of sleep when he does sleep. Other times, he'll sleep 12-14 hours straight. He is on trazodone, prazosin, and mirtazapine, which help sometimes.

People with bvFTD often have sleep disturbances; some sleep excessively and in some cases the person may sleep less. This could be related to the way the person's behaviors are changing. Also, medication reactions may be a cause of sleep changes and should be evaluated by a physician.

22. My husband has PPA and just recently is having muscle spasms. Could this be related to PPA?

This is not a common symptom of PPA, but should be evaluated by your husband's physician.

23. What causes this obsession with sweets exactly? Is this specifically a way that FTD/PPA physically affects the brain, or is it a behavioral indication of the disease?

Generally, the behavioral indications of the disease are caused by physical effects on the brain, so there is no distinction between the two. In FTD, areas of the brain responsible for inhibiting inappropriate behavior or cravings is affected, which can cause "junk food" cravings to emerge.

24. Can a PPA agrammatic patient have a mix of the other two PPA language symptoms?

Yes, the subtypes are generalizations and many patients will have some degree of overlap.

25. My husband chokes often. Is this connected to his PPA?

This symptom could be related to progression of the disease and it should be evaluated by your husband's physician. As any dementia progresses, (Primary Progressive Aphasia (PPA), Progressive Supranuclear Palsy (PSP), Cortical Basal Degeneration (CBD), FTD behavioral variant (FTDbv)), persons may have trouble with swallowing at various stages of the disease. This is related to the motor changes caused by the disease and how the impairment affects brain functioning. If the patient is choking on solids or liquids speak with a physician about ordering a swallowing test to better understand this problem and also investigate interventions, for example a thickening solution if the person chokes on liquids.

26. Would learning sign language be beneficial for individuals with PPA (as a good form of communication)?

Unfortunately, no. As PPA is a disorder of language, not just a disorder of speaking, all forms of word-based communication including writing or sign language, will typically be impaired. However, speaking with a speech therapist can help you identify other alternative and augmentative forms of communication.

27. Early stages of FTD are similar to several other clinical diagnoses. If FTD is being considered as explanative of symptoms, is an MRI/CT/PET useful in identifying one over the other?

These tests can sometimes be very telling if a clear pattern of brain abnormalities can be seen, or if there are indications of another diagnosis, such as strokes or tumors. When these tests are normal, they are not as helpful.