

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

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Disease Progression**1. After diagnosis of PPA and FTD, what is the life expectancy? What is the length of progression for PPA/FTD from diagnosis to end stage?**

As you may have read, each person is different. The length of progression varies, from 3 to as long as 17 years with a mean course of 8 years from the time of diagnosis. In some cases, related neurologic dysfunction will eventually lead to problems with swallowing, balance, or regulation of body functions. In those cases, the time course is not always predictable.

2. PPA seems to always be considered as separate from FTD. What is this based on?

PPA begins with language impairment but is in the same family of disorders as FTD.

3. Will all PPA patients get FTD? Are there other physical disorders that PPA patients will have?

As PPA progresses more FTD-like symptoms can arise. PPA is not associated with other physical symptoms/disorders.

4. The patient is 77-years old with PPA/FTD. What happens towards the end? Is staying at home better for the patient?

Towards the later stages of the disease, a person becomes unable to walk, eat, and swallow. The decision to care for someone at home or have them cared for in a facility is different for each family and the decision must be based upon the person's needs but also the family's needs and their ability to provide additional care. In some cases, people are able to be cared for in the home. In other cases, additional facility care is necessary. Wherever it is provided, towards the end of life, care must emphasize comfort and dignity.

5. Are there defined stages in FTD (specifically criteria for hospice as in Alzheimer's disease)? What are the main characteristics of late stage FTD? How do people with PPA die?

While some have defined stages in FTD, they are not as generally used as in Alzheimer Disease.

Late stage FTD and PPA patients can have impairments in all cognitive and functional domains. They become unable to walk, speak, eat, swallow and need assistance in self-care. In the advanced stage patients are vulnerable to serious complications such as pneumonia, infection, or injury from a fall. The most common cause of death is pneumonia.

Palliative care and hospice can be a helpful resource in the later stages. This approach to care promotes comfort and dignity at the end of life. Hospice and palliative care services can be implemented if disability or health is sufficiently affected, regardless of staging. Contact a local hospice agency for an evaluation or speak with your doctor. To find a local hospice, visit: <http://www.hospicenet.org/>.

6. If a person is diagnosed with PPA, how often should they see a follow-up?

After the diagnosis is established, routine follow up with a neurologist is often spaced out to every 6-12 months.

7. Are the end stages of FTD similar to Alzheimer's?

End stage FTD patients can have impairments in all cognitive and functional domains, so it can resemble end stage Alzheimer's.

8. What is the youngest age of a person you've seen diagnosed with FTD or PPA?

Unlike Dementia of the Alzheimer Type, which generally begins after the age of 65 years, onset of FTD and PPA can begin in the late 40s or 50s. There have been patients with behavioral changes in their late 20s who have been diagnosed with FTD, but this is exceedingly rare.

9. How do patients do in nursing home placement vs. staying home (mortality rate)?

Research specifically in FTD and PPA has not been done on this subject. However, there is evidence that people with dementia admitted to nursing homes and care facilities die comparatively quickly. It is known that mortality rates are high, initially, when people move from their own homes. Mortality rates are especially high in nursing homes. In many ways this seems logical. You would expect that people admitted to a nursing home need more care and attention and in all probability will be sicker. However, research varies as to whether the severity of dementia or certain behaviors experienced by people affects survival rates in nursing homes; therefore it is difficult to make any conclusive statements. More research is required.

10. Are FTD patients typically prohibited from driving (by doctor's advice) early in their diagnosis? How do you take the car away?

Doctors suggest a patient should limit or stop driving when behaviors or cognitive changes affecting a person's ability to drive and impair judgment are identified. It can be very difficult on the person with FTD and family when the person must stop driving, however, there are resources available to help. Each person responds differently to this loss. Speaking with a counselor experienced in FTD through your doctor's office or at AFTD (866-507-7222) or the Alzheimer's Association (800-272-3900) can help your family identify strategies or approaches that are best for you and your loved one. For more information, visit the AFTD page on driving:

<http://www.theaftd.org/support-resources/driving-privileges>.

11. In later stages of FTD and PPA, what is the impact on physical ability and ability to take simple direction?

Some forms of FTD are accompanied by slowing of movements, tremors, poor balance, and other physical limitations. These sometimes also occur in the late stages of PPA. Additionally, following directions can be affected for numerous reasons, including not being able to understand directions, not being able to remember or focus on directions, or not wanting to follow them.

12. To what degree is the immune system going into overdrive and attacking itself in neurodegenerative diseases so anti-inflammatory compounds may be useful in slowing progression of FTD/PPA (and Alzheimer's, too)? For example, residents of India have lower rates of Alzheimer's, maybe due to turmeric, which has anti-inflammatory properties.

There is no clear evidence that immune system overdrive is related to neurodegenerative disease. Additionally, most anti-inflammatory drugs have serious side effects, including risk of bleeding and even possibly increased risk of blood clotting that can lead to strokes or heart attacks. As for the incidence rates of diseases in other countries, it is very difficult to compare statistics between different countries, as there are differences in how these statistics are collected, how the diagnoses are made, and how many people come to see their doctors for these conditions. Other factors, such as average age and other overall health issues can affect these statistics. As such, the rate of Alzheimer Disease in India is not particularly low.