



FTD/PPA Caregiver and Professional Education Conference August 10, 2009

Question and Answer Session

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The Basics/Symptoms/Caregiving

Many of the questions from the conference focused on the symptoms and outcomes of FTD/PPA and how caregivers cope. This section also deals with the important issue of the person's judgement.

What is the average age of onset for FTD/PPA?

The age of onset for FTD and PPA is variable. Onset can be as early as 20 (very rare) and as late as 80. Typically, the age of onset is in one's 50s or 60s.

Do you have a sense of whether the number of cases (FTD/PPA nationwide) is increasing?

Epidemiological studies are needed to answer this question accurately. Unfortunately, these studies have not been done. There are two reasons why it may seem that there are more PPA/FTD cases: 1) Awareness for PPA and FTD is increasing; and 2) Our ability to diagnose individuals is also improving.

Does PPA affect left-handed people differently than it does right-handed people?

There has been very little research to date investigating PPA in left-handed individuals. In right-handed individuals, language is predominantly lateralized to (controlled by) the left hemisphere of the brain. This is usually true for people who are left-handed as well. However, in a percentage of left-handers, language is lateralized to the right or both hemispheres of the brain. In those cases, the pattern of degeneration may be different; however, further research is needed in this area.

How quickly does PPA progress? 5 years, 10 years?

Each person's experience with disease is different. The progression has been as fast as 2 years for some and over 20 years for others. Researchers are actively investigating factors that may contribute to fast or slow progression rates.

What is the suicide rate of FTD/PPA?

This is unknown.

What are the symptoms that usually lead to correct diagnosis of FTD?

Symptoms by themselves are not sufficient to make a correct diagnosis. The history of how the illness started, how much the individual has changed from their former selves, and what other illnesses could possibly be causing the symptoms are important. The gradual onset of personality or character changes, poor judgment and difficulty keeping up with one's former level of responsibility raise suspicions about FTD.

Can unexplained temper tantrums be an early sign of PPA (or some form of FTD) which now seems to be manifest in word and speech disorders?

In some individuals, increased irritability and difficulty controlling agitation and anger as the only symptom can be a sign of FTD. The difference between FTD and PPA is best seen in the initial symptoms. FTD starts with behavioral changes; however, as the disease progresses individuals can develop problems with speech and language. In PPA, language is the area first affected. Some individuals with PPA can develop behavioral changes as their illness progresses. The first two years of symptoms helps to differentiate between FTD and PPA. The clinical differences are important in planning for management and education about how to cope with symptoms since both of these clinical profiles can be caused by similar neuropathology.

Does one's personality affect one's personality once they get FTD?

It differs from person to person. In some people, the former personality becomes exaggerated but in others, it may completely change.

My husband is hypersensitive to touch – he seems to perceive most touch as “pain.” It is difficult to gauge the degree of pain in, for example, a headache, i.e., should I continually give him something for the “headache?” He almost daily says he has a “migraine” but I suspect it’s not that great.

It is easy to attribute many symptoms to the “disease” when someone has FTD or related dementia. However, it is important to err on the side of caution. Patients with dementia often have difficulty expressing the exact nature and/or location of their pain. We would suggest that your husband should be specifically evaluated for these complaints because several different conditions could occur with these symptoms.

Any suggestions for monitoring increased desire for sweets and overeating? It is difficult to simply not purchase or replace the few items (ice cream sandwiches and small cookies) without prompting an altercation. “Why can’t I have (whatever),” “when can we go shopping since I can’t drive now?”

This is something that many families struggle with, especially in caring for someone in the early and middle stages of FTD. Some families have had success moving the item out of sight immediately after it is served, and then using redirection into another room/with another activity (that the person enjoys) to get their mind off the craving. Others have tried using an immediate stimulus (like a phone call) to get the person’s attention onto something else. If the person is craving sweets, look for items that take longer to eat and are more difficult to overeat (like popsicles) which gives you more time to redirect the person. If all else fails, speak to your neurologist or psychiatrist for a medication, such as an SSRI, to minimize the sweet cravings.

What are examples of judgment problems?

Examples of judgment problems include making large extravagant unnecessary purchases, or giving away large sums of money to sweepstakes or telemarketers. A person whose judgment is impaired may leave a baby alone in the house, allow strangers into the home, cook with rotten foods, or not know what to do in the event of an emergency. Also, driving a car requires good judgment and this ability becomes impaired as the disease progresses as well. Clearly when a person’s judgment is impaired they and their families can become very vulnerable so it is important to be mindful of changes in judgment.

How do you get the person to realize what some of their behaviors are and how they may not be acceptable? Should the person with FTD know all the specifics of the disease?

Because the disease affects the part of the brain responsible for insight, logic, reasoning and judgment, the person with the illness is unable to understand that a certain behavior is inappropriate. However, you can do your best to limit the ways in which the behaviors offend others. If a person with FTD wants to know about the diagnosis, it is appropriate to tell them as much as is helpful to them. However, limited insight may result in a denial of any problems even with a cogent explanation.

What are the typical driving problems that occur in FTD/PPA?

Some signs of a driving problem include: incorrect signaling, trouble with turns, confusion at exits, inappropriate speed, delayed responses, increased “road rage” and scrapes and dents on the car. These are not necessarily limited to those with FTD and PPA but may trouble individuals with a variety of different cognitive disorders. The Pick’s Disease Support group has great information in this area:

http://pdsg.org.uk/general_information/driving_and_dementia/

How do you know when someone with FTD/PPA should stop driving?

Giving up driving is a difficult transition for most individuals. If the person lacks insight into their disease, they may not agree that anything is wrong and resist attempts to stop their driving.

As a caregiver or a loved one, you do not need to be the one who determines when the person should no longer drive. The person’s doctor or neurologist can make this recommendation and make a referral to a driving evaluation center. The individual would be given an exam and road test to determine if they are safe to drive. (This is different and more involved than the test given at the Department of Motor Vehicles). If you are uncertain about a person’s abilities, The Hartford Financial Services Group offers a list of warning signs that indicate if a person should be evaluated:

<http://www.thehartford.com/alzheimers/warning.html>

At what point with PPA is the individual not cognitively aware of what is going on?

Each person’s experience with disease is different; therefore, there is no set time at which the individual will stop comprehending their surroundings. There is no test to determine if the person is aware or is not. Therefore, it is important to always take steps to maintain the individual’s integrity, for example, never talk about the person in front of them as if they are not there. This question is also often asked by caregivers who are trying to make a decision about nursing home placement. This is a difficult decision and would benefit from consultation with professionals who can assess the family’s and patient’s needs.

When my wife was diagnosed with PPA in 2005, her neurologist told us that typically PPA progressed to the point where she would need full-time professional care. Can you provide any generalizations about progression? What are the ranges of outcomes?

Unfortunately, it is difficult to generalize about progression because the range varies for each person. We have seen individuals live for many years with neurodegenerative conditions like PPA. Depending on when a person was diagnosed, the range could be from 3- 20 years, with an average being at about 8 years. PPA is a progressive and neurodegenerative disease, which means that over time, the disease spreads and affects other areas of the brain and, as a result, the person begins to develop other cognitive symptoms. This illness, like other neurodegenerative dementias, is terminal. Over time, some individuals develop significant memory, behavior and personality changes, and in the end stages need care and assistance for all of their daily living activities. Because progression is unpredictable and uncertain, it is important to be knowledgeable about local resources and care options that can assist when more help is needed. You can find information from Northwestern’s FTD and PPA Resource List:

<http://www.brain.northwestern.edu/ppa/resources.html>

Will my wife’s ability to function and do normal everyday tasks in the house diminish? How about personal care?

Yes, there will be a time where a person can no longer independently perform everyday tasks in the home, and as the disease progresses, they will also need assistance with personal care (bathing, toileting) While a person is needing more assistance overtime, with the help of an Occupational Therapist, you can identify ways that the person can remain involved in their care for as long as possible. Even though a person may no longer be able to care for him or herself, it is important that he/she be included in and involved in his/her own care. Neurodegenerative diseases are terminal illnesses but the rate of progression can vary considerably.

How do self-employed people cope with FTD?

There comes a time when a person with FTD or PPA can no longer work. When that time comes, they may be eligible for Social Security Disability and Medicare (after 2 year wait). We encourage you to ask the neurologist for a letter to accompany the application that explains the diagnosis and why the person can no longer work. The application guidelines are at the web site below: <http://www.ssa.gov/disability/>

Are there any “checklists” that I can follow?

In the 2009 FTD and PPA conference book there is a Newly Diagnosed Check List on page 23. There are other checklists available including when interviewing for a personal caregiver or what to look for when visiting a nursing facility. The Family Caregiver Alliance provides helpful information for family caregivers. The web address is: <http://www.caregiver.org/caregiver/jsp/home.jsp>

A number of checklists are available to help in evaluating what types of help are needed:

Home Safety: <http://www.nia.nih.gov/Alzheimers/Publications/homesafety.htm>

Driving: <http://www.thehartford.com/alzheimers/warning.html>

Respite Care: http://www.alz.org/national/documents/brochure_respitecareguide.pdf

Since all dementias end the same, are the different diagnostic categories more important to the medical community than patient/caregivers?

Not at all. Patients and their caregivers must live with the symptoms and illness for many years before the end stages. Differences in the diagnoses reflect differences in the symptoms. Short-term memory loss, prominent in Alzheimer’s disease, is not the main issue limiting the life of individuals with PPA and FTD. Recommendations for care need to be tailored to the symptoms associated with the different diagnoses. In addition, the diagnoses reflect different forms of brain pathology so that drugs that target Alzheimer pathology are not going to be helpful in someone with FTLD pathology.

My wife has PPA. I feel guilty about the deep relief I feel when I can be alone during the day and irritated and fighting not to show my frustration when I am with her. I’m in therapy and have many supportive friends. What are some of the less obvious strategies I should try?

It is normal to sometimes get frustrated and irritated when caring for a loved one, and many caregivers often feel guilty about spending time away. Caregiving is both emotionally and physically demanding, so it is essential that caregivers get rest and sufficient time to themselves in order to provide adequate care to their loved ones.

When caregivers are busy trying to cope with each day, they do not always see the tremendous amount of work they are doing. It is important to acknowledge that you are doing the best you can, but that you also have limits. If you find yourself getting frustrated more often than not, and it affects your ability to enjoy your time together, this is a sign you need more respite. There are a number of agencies that can provide this in the form of a companion, in-home care, long-term respite (for a weekend or a week) or a day program. As the disease progresses and your wife needs more care, you will need more respite in order to best support her. If you have additional help that allows you these needed breaks, you can put your energy into truly enjoying your time together.

Where can a caregiver get help? Will he or she be able to live with him or herself if they just leave?

As a person’s cognitive abilities progressively worsen due to FTD/PPA, they will eventually no longer be able to care for themselves alone. Because of the progressive nature of the illness, the person with the illness will become increasingly dependent on others for more care. Family members cannot provide this care alone. Other care arrangements will be needed and there are social service agencies that can provide this support and assistance. Providing care is very demanding work and it is normal for caregiver to feel overwhelmed, but there are programs and services that can help. If a caregiver is feeling they not able to

care for the person, they should contact the doctor's office to request information about local care resources. You can also contact the AFTD: 866 507-7222 and the Alzheimer's Association for additional support and help: 800.272.3900.

How successful is secure assisted living vs. skilled nursing for long-term care?

Assisted living and skilled nursing offer very different levels of care. Assisted living is designed for more independent people who are mostly able to care for themselves, but need some assistance. Assisted Living facilities generally provide recreational activities, meals, housekeeping, laundry and transportation. Definitions of assisted living and the specific regulations differ from state to state. While some are secure and provide 24-hour staff, most allow residents to come and go as they like.

A nursing home offers more skilled nursing care, assistance with daily care needs, 24-hour supervision and in some facilities, dementia specific care. While a person with FTD can live in some assisted living facilities in the earlier stages of the disease, it cannot provide the type of care they will need as the disease progresses. However, in some individuals with FTD, behavioral symptoms are so extreme that they cannot be managed in most facilities and may require a secure (locked) unit.

What features should a facility have to be ideal for an FTD patient?

Good care requires an understanding of FTD and the goals of care. Ideally, a facility caring for someone with FTD should have knowledge of FTD and staff trained in dementia care. The staff should offer a person-centered approach to care, which means designing care based upon the person's strengths, likes, and abilities. Because people with FTD are often younger and more physically fit, it is important that the facility offer active programming (art, music therapy, exercise) that would allow the person opportunities to express themselves and get physical exercise.

It is unlikely that all staff will be familiar with FTD so it is also essential that the staff be willing to learn from you and rely on your involvement in the care plan. They should also be willing to work with you to problem solve should any concerns about care arise. Overall, make sure that you feel comfortable at the facility, and if plan to visit frequently, make sure that it is a manageable distance from your home. At times, however, the FTD symptoms may be so extreme as to warrant special restraints, such as a secure (locked) unit. In this event, it would be very important to educate staff about the difference between FTD and other disorders leading to extreme behaviors.

What are some wandering registries?

MedicAlert® + Alzheimer's Association Safe Return® is a 24-hour nationwide emergency response service for individuals with Alzheimer's or a related dementia that wander or who have a medical emergency. The web address for the Safe Return Program is: www.alz.org/SafeReturn
GPS systems designed for families with dementia have been emerging for a number of years and we should see these available soon.

I run a caregiver support group that focuses on various causes of dementia. Is there some place in the Chicago area where I can check out or rent videos to show the group?

There are not many resources yet for patients and families living with FTD. However, for resources more generally appropriate, the Alzheimer's Association National Office in Chicago maintains the largest library specifically on dementia materials. You can visit the Greenfield Library in person or call/email to request articles, books and videos.

Web: http://www.alz.org/we_can_help_library_services.asp

Visit: 225 N. Michigan Ave, 17th Floor Chicago, IL

Call: 1.800.272.3900

E-mail: greenfield@alz.org.

Also, Northwestern's Health Learning Center, a health library located in the Galter Building at the downtown hospital, is another resource for these kinds of materials. The health educator can help you find articles, books or videos on dementia.

Visit: 251 E. Huron St., Suite 3-304 Chicago, IL

Call: 312-926-LINK (5465)

e-mail: hlc@nmh.org

If I want to start a support group in my area, how do I identify others in my area?

You may begin by contacting both Association for Frontotemporal Dementias (AFTD) (866 507-7222) and the Alzheimer's Association local chapter (800.272.3900) to let them know you are interested in forming a group. You may also contact your local diagnostic center to inquire if they can help connect you with others interested in a group. Another option is join an on-line group, post that you are interested in starting a group in your area.

Are there any support groups for PPA? The FTD support groups focus on behavior.

The early stages of FTD and PPA are very different. Persons with PPA have a decline in language ability for the first two years while those with FTD have pronounced behavior changes. FTD support groups do tend to focus on behaviors. The reason the two are often grouped together is because as the disease progress the symptoms overlap causing people with FTD to experience language problems and people with PPA to eventually experience behavior changes. We know that there are specific online support groups for PPA. Connecting with others on these websites can lead to starting a local in-person PPA group.

PPA Support Group Online: <http://groups.yahoo.com/group/PPA-support>

Pick's Disease Support Group Online: <http://www.pdsg.org.uk>

Frontotemporal Dementia Support Forum: <http://www.ftdsupportforum.com>