

## **CARING FOR PRIMARY PROGRESSIVE NON-FLUENT APHASIA**

### **Family & Community Services, Banner Alzheimer Institute, Phoenix, AZ**

#### **Introduction**

About four to six million Americans suffer from dementing illness. While the majority will be diagnosed with Alzheimer's disease and/or vascular dementia, a significant minority – perhaps as many as 2 million people -- who have other diseases that are just as troubling and disabling as Alzheimer's disease. The care of the people suffering from non-Alzheimer type dementias is often different than the care needed for people with Alzheimer's disease, however there is not much written to help these families. The purpose of this article is to describe primary progressive non-fluent aphasia and suggest strategies for care.

Aphasia is a loss of the ability to understand and produce language, whether written or spoken. There are five types of progressive aphasia: non-fluent; fluent; anomic; mixed; and aphasia associated with motor neuron disease (Caselli, 1995; Caselli, Windebank, Petersen, et al, 1993). Each type differs in the following areas: patient understanding; type of language deficit; ability to comprehend written materials; write; and name things. Careful assessments by a dementia specialist and regular speech therapy consultations can assist caregivers with defining exact changes in language and identifying appropriate strategies to enhance communication and care.

#### **Non-Fluent Aphasia**

Non-Fluent aphasia occurs when there is deterioration to the frontal lobe of the brain on the dominant side; thus is a part of frontotemporal dementias (FTD). If a person has non-dominant FTD we tend to see several types of symptoms including apathy, non-fluent aphasia (loss of language abilities), emotional instability (lability), and a high degree of awareness.

Non-fluent aphasia is characterized by halting, effortful, labored speech production, whether expressing original ideas or repeating. The person knows what they want to say but is unable to program the tongue, teeth, palate, and lips to get the message out. And, the more they try to get the words out, the worse the problem gets.

- In the early stages of the disease people can occasionally increase language when distracted or if encouraged to sing what they want to say. This can be very frustrating for the person and result in anger or depression. Try to help them find words and communicate by “filling in the blanks” or asking simple yes/no questions about what they are trying to say.

- The person with non-fluent aphasia may be able to read and understand until the late stages of the illness and they often remember what they see. People with non-fluent aphasia may be safe to live alone for a year or so. The person may even be able to drive for quite a while after the diagnosis however this should be evaluated regularly by the family for safety.
- The main problem with living alone and driving is when the person is tries to communicate in an emergency. If pulled over, the driver with non-fluent aphasia may be judged by law enforcement to be “driving under the influence.” It is extremely important that this patient wear an identification bracelet such as a Medic-Alert (available at most pharmacies). They should also carry a card or letter explaining their condition that can be given to police if stopped.
- In the home, use of a Lifeline can assure that emergency personnel can be summoned without needing an explanation from the patient.
- Speech therapists can help to find ways of helping the person to communicate. People with non-fluent aphasia may be able to use language boards, lists, and written materials. They can generally respond to pictures and signs. If diagnosed early the patient may be trained in use of alternative communication devices, such as a light writer. While these may not be helpful forever, adaptive equipment can add to the person’s quality of life and social activity for several years.
- Most people with progressive non-fluent aphasia lose the ability to speak in two to three years. As this happens they will also begin to have problems with understanding what is being said to them. For a while they may be able to answer yes/no questions by shaking their heads, however eventually that too is lost. It is critically important that advanced directives are developed and signed as early in the disease process as possible because the person will lose their ability to express their desires. Moreover many people develop problems with coordinating swallowing, necessitating the early discussion of whether the person would want a feeding tube.
- Once a person with non-fluent aphasia has significant difficulty with forming words, the ability to coordinate swallowing and management of secretions (saliva and phlegm) must be closely monitored with the increasing danger of aspiration (breathing in food, liquid, and secretions). If choking, drooling, or mishandling food once in the mouth are noticed, a swallowing study is indicated to suggest the best ways to feed and most appropriate food consistency. The patient and family need to be counseled regarding advanced directives for alternatives to oral feeding.

- Swallowing also affects taking medications. The family will need to work with all physicians to reduce medications to only those that are critical and to decrease the number of doses each day to the bare minimum. Once the person is unable to take medications by mouth, they may wish to locate a “compounding pharmacist” in their area. These are pharmacists who can formulate medications into syrups, suppositories, creams, and other forms the person can use. A local hospital should either have or be able to direct you to the nearest compounding pharmacist.

## **Apathy**

In FTD apathy is called “abulia.” It means that the person appears “flat” or depressed to family members and that they are unable to start activities until they are instructed. For example, a caregiver might set out a sandwich for the person but the person with abulia will not eat until told to do so. This means caregivers may have to provide almost constant direction as the disease progresses. This is not something the person can control, even though it may appear they are lazy or disinterested.

## **Disease Progression**

As with most dementing illnesses progressive non-fluent aphasia worsens with time. The person will have less and less understanding and use of language until they become essentially mute. At the same time, the disease spreads through ever-widening areas of the brain, especially the front of the brain. This can lead to some of the following behavioral issues. It is important to keep in touch with your physician or provider in order to help you manage and cope.

- Decreased inhibitions – the person may do things that are unsafe or make poor judgments at a moment’s notice. Families have to be prepared to deal with this and alter social participation appropriately. This might include the following:
  - Taking food from other diners’ plates in a restaurant
  - Having spontaneous bowel movements in large or crowded places
  - Undressing spontaneously
  - Hugging strangers
  - Becoming sexually assertive – even with strangers
  - Shoplifting
  - Swatting at grandchildren
  - Smearing excrement

- Hyperorality – This is where the person begins to put anything, food or non-food items in their mouth for the purpose of chewing and eating it. This means the family must take extreme care as some people will eat pet food, fabric, glass items, cleaning fluids, candles, and almost anything one might think of. The number of the poison control center should be posted near the phone. If the person eats something that might be hazardous, like certain plants, glass holiday balls, and so forth, call 911 and have them take the person to the nearest emergency room (ER) as soon as possible. Always accompany the person to the ER as the person will not be able to give a history or cooperate with care.

### **Getting help-contact us**

The Banner Alzheimer Institute is committed to helping our patients receive the best possible care. If you have questions about what you are seeing, what to do, or how to manage day to day care, please do not hesitate to call us at (602) 239-6900. Or write us at

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For other contact information see their website:

<http://www.bannerhealth.com/Alzheimers/About+Us/Contact+Us.htm>

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