

### Communication Strategies in Frontotemporal Degeneration

Communication relies on our ability to speak and understand what others are saying. Speaking, reading, writing and naming common objects are parts of language that can be lost due to the atrophy of the frontal and temporal lobes of the brain that occurs in FTD. As language declines, care becomes challenging due to the person's lack of ability to understand and respond which can result in frustration for the resident and the caregiver.

While FTD is a degenerative disease, there is a place for the speech-language pathologist on the team. This service should not only be used for restorative therapy; it can be of great value to maintain language functioning and optimize communication and successful exchanges of information. Training direct caregivers to use suggested interventions is essential for continuity of care.

#### Meet Karl

Karl, a 59-year-old male, was diagnosed with FTD at the age of 54. He has a four-year college degree and was always able to articulate well. Karl has been in a care facility for two years. Initially when Karl entered the care facility, he was able to communicate his needs and understand plans for the day. As the disease progressed, the areas of the brain that control language declined; he became non-verbal except for an occasional word or two. As his ability to express and respond to communication changed, issues his care became a challenge. When asked a question, he responded with a blank stare. When staff called his name, he did not act like he heard them and kept walking. Simple requests were not followed, e.g., "It is time for supper" and "let's get your teeth brushed." Family became distressed over his lack of ability to express needs such as hunger, thirst or pain.

The team suggested that Karl be evaluated by a speech therapist. The therapist assessed all modalities of language (reading, writing, listening and speech). By using cards that matched function to objects, she determined that his comprehension was better than his expression. She noted that he did much better in a setting where other distractions were minimized. They invited family to observe and showed them that Karl could answer yes/no or limited-choice questions when they were written on paper. Staff learned to take Karl's hand, get his attention and lead him to the dining area. They realized he needed time to follow a request to sit down due to the delay in processing. He responded to visual and verbal cues when the staff showed him a toothbrush and made a brushing motion. They used an erasable board or paper and pencil to get a response to limited-choice questions. It was stressed that approach, facial expression and tone of voice are all important to communication.

These interventions empowered the staff, which was reflected in respect for Karl, improved care and quality of life.

#### Discussion Questions:

1. How does FTD change the person's ability to express and understand?
2. How did speech therapy help to evaluate the current language ability and assist the staff with ideas for care?
3. What are some of the communication techniques that were used? Can you suggest others?
4. What resources are available for further information?

*Partners in FTD Care is an education initiative of the Association for Frontotemporal Degeneration that brings together health professionals, experts and families to promote understanding of FTD and to develop best practices in community care.*

### SERVE PEOPLE WITH FTD WITH CONFIDENCE

People with FTD need access to quality facility care. Partners in FTD Care training materials are available to train and support your staff. Packet includes: AFTD's film *It Is What It Is*, print material and case studies. Order online: [www.theaftd.org](http://www.theaftd.org).

### COMING SOON: ONLINE ANSWERS FOR HEALTH PROFESSIONALS

Ask questions and get assistance and ideas to serve people with FTD in an adult day or residential care setting. Watch for AFTD's on-line forum for health professionals coming in early 2012. Email [ftdcare@theaftd.org](mailto:ftdcare@theaftd.org) to sign up for Partners in FTD Care announcements.



## Discussion Questions:

- 1. How does FTD change the person's ability to express and understand?**
    - People may experience a variety of symptoms related to reception and/or expression of language.
    - Problems in the ability to name objects, speak, and write affects expression.
    - The capacity to "decode" what others are saying; read and understand written words affects reception.
    - Due progressive atrophy in areas of the brain responsible for language, the ability of the resident to communicate will decline. The plan of care has to be adjusted.
  - 2. How did speech therapy help to evaluate the current language ability and assist the staff with ideas for care?**
    - Provided a systematic assessment of all modalities of language for comprehensive picture.
    - Used techniques to identify hidden strengths as well as weaknesses.
    - Approached communication as shared activity between Karl and staff/family with emphasis on how caregivers can facilitate it, e.g.: reducing competing stimulation and distractions, patiently allowing time to process information.
    - Suggested forms of communication other than speech and modeled them for staff/family: demonstrating with hand motions; using props, picture and diagrams.
  - 3. What are some of the communication techniques that were used? Can you suggest others?**
    - Insuring Karl's full attention by limiting distractions in the environment.
    - Personal care was assisted by visual and verbal cuing – leading Karl to the sink, giving him the toothbrush, making a brushing motion.
    - Using touch – taking him gently by the hand and leading him to the dining area.
    - Using writing tools to elicit answers to short sentences or questions with limited choices (yes/no responses).
- Other suggestions:**
- Deliberately approach the person in a calm way, patiently, and with a pleasant tone of voice. Responding to a resident's blank stare and lack of response to verbal requests with impatience or annoyance could contribute to an anxious or agitated response.
  - Use of routine or rituals for easing daily care
  - Use the same terms consistently for care issues, for example in toileting
  - Singing – changing the words to familiar tunes or adding music may be helpful in gaining cooperation.
  - Technology – iPads and software programs like Proloquo2Go ([www.proloquo2go.com/](http://www.proloquo2go.com/)) are getting increased attention to aid communication. They may be helpful for some people with early primary progressive aphasia (PPA), but require other skills and set-up support to use effectively. A speech therapist could assess for potential benefit.
- 4. What resources are available for further information?**
    - The Association for Frontotemporal Degeneration (<http://www.theaftd.org/>)
    - The National Aphasia Association (<http://www.aphasia.org/>)
    - Aphasia Research Project at University of Arizona (<http://slhs.arizona.edu/research>)
    - Northwestern University: Cognitive and Alzheimer's Disease Center (<http://www.brain.northwestern.edu/>)
    - University of California at San Francisco Memory and Aging Center (<http://memory.ucsf.edu/>)

## TROUBLES & TIPS

### *What's in that look?*

**Q:** *"We have a resident who doesn't respond when you ask him a question; he just stares at you with a blank, angry-looking scowl that makes people nervous. What does that blank stare mean?"*

**A:** *Most importantly is what the blank stare does NOT mean--this is not intended to be threatening.*

Several things may contribute to the frequency of this stare in FTD. Many people with FTD develop "flat affect" with reduced expression of emotion and apathy. They may also lose the ability to read social cues and forget that it's not polite to stare. At times the person with FTD may perseverate or "get stuck" on a word, issue or thought; some may get stuck in a staring mode.

And, their ability to understand language and respond with appropriate speech may be a contributing factor. Think of when you are asked to solve a difficult problem or you cannot understand what someone is asking you – no output is produced.

Don't scowl back! Stay positive, and maintain a friendly, calm approach. Use familiar terms and visual cues. Give the person time to respond. If staring bothers other residents, redirect the person to another activity to get them "unstuck!"

## TELL US WHAT YOU THINK!

Partners in FTD Care seeks to build a community of professionals working together for high quality services. Send us your questions, suggestions for care scenarios and/or needs by email to [ftdcare@theaftd.org](mailto:ftdcare@theaftd.org) or call 267.514.7221.