

Maximizing Communication Success in Primary Progressive Aphasia

Until recently, there has been very little information available for clinicians, caregivers and family members with regard to treatment options and strategies for maximizing communication for people with primary progressive aphasia (PPA). The last 5-10 years, however, have seen an improvement in diagnosis as well as management of PPA. Speech-language pathologists (SLPs) now offer a variety of treatments, with emphasis on: rebuilding communication skills (e.g., word-finding and articulation of words); supplementing verbal communication with nonverbal modes of expression; and training for communication partners and caregivers.

The following case illustrates one individual's, Ben M.'s, progression through the stages of nonfluent/agrammatic PPA. We describe changes in his communication over time, and the role of his SLP and communication partners in facilitating the ability to communicate successfully, despite his decline in speech and language. In addition, we address some of the signs and symptoms that precipitated the need for Ben's transition to an assisted living facility.

THE CASE OF BEN M.

THE EMERGENCE OF SYMPTOMS OF MILD PPA, AGE 66

The first time Ben M. notices a change in his speech is when his "mouth doesn't cooperate" when he attempts to produce long words. In the earliest stages of PPA, pre-diagnosis, Ben has difficulty articulating more complex words (e.g. "presentation"). As these symptoms become more prominent, he seeks help from a neurologist, who diagnoses him with anxiety and prescribes anti-anxiety medication. Ben and his family notice an overall decline in his functioning and he decides to discontinue the medication. About a year later, his neurologist orders additional testing by an SLP, who suggests that Ben's symptoms are consistent with progressive aphasia. The neurologist orders an MRI scan that shows degeneration on the left side of Ben's brain, in areas that support speech and language. At this time, he receives a diagnosis of nonfluent/agrammatic variant primary progressive aphasia.

BEN'S COMMUNICATION

Although Ben knows exactly what he intends to say, he has difficulty producing longer words clearly and accurately. His wife and daughter are aware of this difficulty; however, they aren't terribly concerned with the subtle changes in his communication because they have no trouble understanding him. Ben's ability to read, write and understand are completely intact. However, he has noticed that he needs to spend a little extra time editing his emails, as some connecting words (e.g. "the," "and") are occasionally missing. He is still working as a business manager and has been able to meet the demands of his position by devoting increased time and effort to work-related communication.

Over the course of the next year, Ben begins to experience difficulty with "finding words," and pauses frequently in the middle of sentences to formulate what he wishes to say. At this time, his wife and daughter understand that there is a broader problem with his communication. Ben begins to make deliberate modifications to his speech and language during conversation. For example, he chooses to say words that occur frequently and are shorter in length (e.g., "car" instead of "convertible"). Ben occasionally corrects words that are mispronounced, and sometimes requires several attempts to produce a word correctly. He begins to feel increasingly frustrated and anxious about his speech. *(continued)*

PPA AND ITS SUBTYPES

Primary progressive aphasia (PPA) is a gradual decline in the ability to communicate, resulting from degeneration of speech and language networks in the brain.

PPA can be caused by different diseases, including FTD and Alzheimer's disease. The left side of the brain, which houses important speech and language regions, is affected first and foremost by these diseases in individuals with PPA.

There are currently three widely recognized clinical variants of PPA, each of which is associated with damage to different areas within the left hemisphere language network:

- Individuals diagnosed with the **semantic variant** have a profound disruption in the ability to name people and objects (replacing nouns with empty words such as "thing") as well as difficulty with comprehending spoken and written words.
- Individuals with the **nonfluent/agrammatic variant** have slow, labored speech and difficulty speaking in complete sentences. Their speech is often described as "telegraphic" (e.g., "man...and...woman...picnic" for "The man and woman went on a picnic.")
- Lastly, Individuals with the **logopenic variant** have trouble naming things and may make sound errors when doing so (e.g., "telecone" for telephone). They also have difficulty with "holding onto" and repeating information they have heard.

A clinical diagnosis of PPA and its subtypes is made via a comprehensive evaluation that includes a careful history of the onset of symptoms, a neurological exam, a neuropsychological exam, a speech-language evaluation and brain imaging.

THE ROLES OF THE SLP AND THE CAREGIVER/ COMMUNICATION PARTNER IN TREATMENT

A primary role of Ben's SLP in the early stage of PPA is to thoroughly evaluate his speech and language abilities. This evaluation will serve as a baseline for the progression of his communication difficulties and will help to identify goals for treatment.

Ben's evaluation confirms that his most prominent deficit in

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communication is with the motor aspects of articulating words, with additional difficulties in grammar and word retrieval. The SLP works with Ben and his family to generate goals for treatment. The primary goal at this stage is to improve his intelligibility when producing long (multi-syllabic) words that are related to his job. He is instructed to slow his speech rate and to produce words in a syllable-by-syllable fashion.

Another goal involves training Ben to use word-finding strategies, such as describing objects he can't name or attempting to write part or all of a word he can't retrieve. Lastly, Ben begins to explore the use of additional (nonverbal) modalities for communication, including writing,

which he can use when his speech is misunderstood. Ben's SLP suggests that he carry a card identifying and explaining his condition (see **Online Resources**, page 4) but he declines, as he is still insistent upon using spoken communication.

Ben's wife begins to observe the speech-language treatment sessions that the SLP provides twice per week. The SLP and Mrs. M. create a home program to work on word-finding and articulation. In this way, Mrs. M. and the clinician work as a team to make the most of Ben's limited insurance coverage for treatment.

PROGRESSION TO MODERATE PPA, AGE 68

BEN'S COMMUNICATION

Two years into his diagnosis, Ben's speech production is more laborious and communication partners find him difficult to understand. Where previously, his difficulty in pronunciation was restricted to long words, now he has difficulty with initiating speech regardless of the word length. He uses only simple sentences and frequently omits grammatical words (such as "the") from his speech. As a result, his wife and daughter often have a hard time understanding his message, and simple communication exchanges require multiple attempts.

At work, Ben's superiors have noticed that his emails are very difficult to understand, due to missing and misspelled words. He is also unable to successfully give oral presentations, and he is experiencing increasing anxiety regarding his communication. Ben applies for and goes on disability leave, as he has become increasingly unable to complete the duties of his position. He begins to have some difficulty understanding what people are saying to him,

especially when the message is complex, and he may ask his wife or daughter to repeat themselves. In addition to his communication problems, Ben begins having trouble coordinating movements with his right arm and hand.

THE ROLES OF THE SLP AND THE CAREGIVER/ COMMUNICATION PARTNER IN TREATMENT

Ben's SLP implements a script training treatment, to facilitate fluent conversation about topics that he would like to discuss in his daily life. The speech pathologist works with Ben and his family to derive a set of scripts that will be functional for him, and he provides a majority of the content for the scripts. They are to include: a self-disclosure script regarding his PPA diagnosis, a script about his family and a script about football.

Ben practices his scripts with a video recording at home and works on using them in conversation during sessions with the clinician. He is gaining mastery of his scripts, and he and his wife report that he is using sentences and phrases from them in the community and with his family. He is encouraged to continue to use writing to supplement speech, however, this is becoming more challenging due to weakness in his right arm and hand. The SLP again suggests that Ben carry a card explaining his condition. After a routine traffic stop where Ben struggles to explain his speech difficulties, he agrees. The SLP suggests that a communication book may be useful when verbal communication is especially taxing. Ben declines, as he remains determined to focus on spoken communication.

Mrs. M. plays an integral role in developing topics and content for each script. She and the SLP also discuss ways that she may encourage Ben to use nonverbal communication strategies, such as gestures and pointing to pictures. They also discuss strategies to maximize conversational success, such as providing Ben with increased time to formulate and express his thoughts, and simplifying rather than repeating information when he has difficulty comprehending.

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MODERATELY-SEVERE PPA AND THE EMERGENCE OF NON-LANGUAGE SYMPTOMS, AGE 69

BEN'S COMMUNICATION

Ben is now communicating verbally through the use of single words, with occasional two-word utterances. These are often not understood by his wife and daughter, due to increasingly distorted speech. Phrases and words from his scripts do continue to be largely intelligible, and he relies on these practiced (*continued*)



words to communicate verbally. Ben is using many gestures to communicate his wants and needs. In addition, he uses the writing of single words or phrases to contextualize any verbal or nonverbal (e.g. gestures, drawing pictures) communication.

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He has less anxiety regarding his communication, as he becomes more proficient with and accepting of using modalities other than speech. Ben has difficulty understanding some messages, and his wife and daughter speak to him in simple sentences. They also check for comprehension often, and summarize the main points of their communication exchanges.

Ben continues to have increasing weakness and rigidity in his right hand and arm, and has difficulty coordinating his movements. It is recommended that the

family consult with a doctor to discuss ways to minimize Ben's risk of falling due to limb weakness and incoordination ([see the *Partners in FTD Care Summer 2015 issue*](#), which includes information on falls prevention.)

THE ROLES OF THE SLP AND THE CAREGIVER/ COMMUNICATION PARTNER IN TREATMENT

As spoken communication becomes increasingly challenging, the SLP focuses on creating an augmentative and alternative communication (AAC) system. A low-tech communication book is chosen by Ben and his family. This book contains short phrases and questions paired with symbols (e.g., "May I have a drink?" with pictured choices of beverages). In addition, the book contains pictures of familiar people and places with written labels. Once the book

has been completed, the clinician works with Ben on using it to ask and answer questions and to initiate communication exchanges. Ben then practices using the book with his family and friends.

The SLP also focuses on providing training for multi-modality communication for Ben and his family. This involves using gestures, writing and drawing pictures to convey his message dynamically to conversation partners. The goal of therapy at this stage is to foster communication through any modality, rather than to focus solely on verbal communication. Mrs. M. is trained to model multi-modality communication by using a variety of verbal and nonverbal communication strategies with Ben. Family and friends are encouraged to take an active role in communication exchanges in an attempt to increasingly shift the burden away from Ben. They work to simplify their messages and to give him plenty of time to communicate.

ADDITIONAL SYMPTOMS AND A TRANSITION IN LIVING, AGE 70

Ben begins to have greater difficulty coordinating his limbs, especially when walking. His short-term memory and cognition have shown some decline, and his motivation to communicate has diminished. Although his wife has modified the home environment to reduce his fall risk, Ben has fallen on several occasions.

In addition, Ben begins to cough when drinking liquids. He develops pneumonia and is taken to the hospital for treatment. He is diagnosed with dysphagia, a swallowing disorder ([see the *Partners in FTD Care Summer 2015 issue*](#)), subsequent to an evaluation with an SLP. Upon discharge, Ben returns home, where Mrs. M. prepares modified meals for him daily (e.g., thickened liquids and pureed solids).

When left alone, Ben frequently does not follow the modified diet. He develops pneumonia a second time and is again hospitalized. The level of care that he requires upon discharge is more than Mrs. M. and her daughter can manage. (*continued on page 5*)

As PPA Progresses...

In later stages of PPA, individuals may become functionally mute or speak in an unintelligible "jargon." Their comprehension of language may be very limited. In addition, as the disease spreads in the brain, non-language symptoms typically emerge. Individuals often develop cognitive difficulties, including deficits in memory, attention, planning, problem-solving and visuospatial processing. Some individuals, particularly those with nonfluent PPA, may develop motor challenges, including: limb weakness, rigidity, balance and gait issues, slowed movements, apraxia and dysphagia. Some will develop behavioral issues, with inappropriate behaviors akin to those seen in the behavioral variant of FTD (e.g., apathy, disinhibition, agitation, impulsivity and mood changes).

In PPA, as in other FTD disorders, a clinical diagnosis is made based on the earliest symptoms, and the most prominent ones at the time of evaluation. As the disease progresses, features of other FTD disorders often emerge. While emergent symptoms may be consistent with the clinical characteristics of behavioral variant FTD (bvFTD) or a movement disorder such as corticobasal degeneration (CBD), the prior clinical diagnosis typically does not change.

People diagnosed with bvFTD frequently become mute as this disorder progresses. However, this decline in verbal communication is not aphasia. In bvFTD, loss of verbal language is most often due to a decline in desire for social interaction and the ability to initiate conversation.



Online Resources

CLINICAL AND RESEARCH CENTERS WITH PARTICULAR INTEREST IN PPA

- Aphasia Lab, The University of Texas at Austin
<http://moody.utexas.edu/aphasiab/projects>
- Northwestern University Feinberg School of Medicine, Cognitive Neurology and Alzheimer's Disease Center
<http://www.brain.northwestern.edu/dementia/ppa/index.html>
- University of California, San Francisco Memory and Aging Center
<http://memory.ucsf.edu/education/diseases/ppa>

SUPPORT FOR PEOPLE WITH PPA AND THEIR CARE PARTNERS

- **AFTD**
<http://www.theaftd.org/life-with-ftd/i-have-ftd/support>
- Information and awareness cards:
 1. <http://www.theaftd.org/life-with-ftd/resources/awareness-cards>
 2. <http://www.theaphasiacenter.com/pocket-card/>
- National Aphasia Association
<http://www.aphasia.org/aphasia-resources/primary-progressive-aphasia/>

Note: The Internet has many examples of communication wallets and books. Use the Internet/YouTube search term: *aphasia communication book*.

INFORMATION ON PPA AND ALTERNATIVE COMMUNICATION STRATEGIES

- **The Dr. Lawrence Albert Memorial Webinar Series for Speech Language Pathologists Treating PPA**
Presented by experts in the field, this free webinar series seeks to improve understanding and treatment approaches for SLPs working with persons with PPA.
<http://www.brain.northwestern.edu/about/events/webinar.html>
- **Augmentative and Alternative Communication (AAC) for Persons with PPA**
In this recorded webinar, Dr. Melanie Fried Oken describes her research on AAC intervention for people with primary progressive aphasia and provides examples throughout.
<http://www.allreadable.com/1bbe2cPb>
- **AAC Strategies and Tools...**
This article, published in the American Speech-Language-Hearing Association publication, *The ASHA Leader*, discusses communication strategies and tools for people with dementia.
<http://leader.pubs.asha.org/article.aspx?articleid=2291890>
- **Fresh Look at ACC and Dementia with Melanie Fried Oken**
This blog post offers examples of practical, low-tech communication techniques and approaches for professional and family caregivers.
<http://practicalaac.org/practical/fresh-look-at-aac-and-dementia/>

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Partners in FTD Care Advisors The *Partners in FTD Care* initiative is the result of collaboration among AFTD, content experts and family caregivers. Advisors include: Sandi Grow, RN, caregiver • Geri Hall, PhD, ARNP, Banner Alzheimer Institute • Lisa Gwyther, LCSW, Bryan Alzheimer's Disease Research Center at Duke • Barbara Harty, GNP, UNTHSC • Susan Hirsch, MA, HCR ManorCare • Jill Shapira, PhD, RN • Rebekah Wilson, MSW, Choices in Senior Care

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Frontotemporal Degeneration
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Partners in FTD Care
4 • Winter 2016

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(continued from page 3) Together, they decide to move Ben into an assisted living facility, where nursing staff can help to manage Ben's increasingly complex medical needs.

TRANSITIONAL SUPPORT PROVIDED BY SLP AND CAREGIVER/PRIMARY COMMUNICATION PARTNER

Ben's SLP and Mrs. M. introduce the staff at the assisted living facility to the various communication tools that he is still able to utilize. For example, facility staff are oriented to Ben's communication book and a new communication "wallet," which he wears on a lanyard. The wallet contains functional pictures and words that he is likely to need during daily routines (e.g., pictures of foods, self-care items and daily activities), as well as words that will be useful as fall prevention and dysphagia management practices are introduced.

The SLP also creates a communication board, which contains symbols for common objects in his room so that he is able to non-verbally communicate his wants and needs to the staff. The staff is familiarized with words and phrases that Ben is likely to use, including his practiced scripts, in order to provide them with a context for his communicative attempts. When possible, the staff uses words

and ideas from his scripts when communicating with him, given that he appears to have somewhat preserved comprehension for this content.

Recordings of Ben's scripts in his own voice (from his early days in speech therapy) have also been programmed into his iPad. He uses this vocal "bank" of scripts to communicate with the staff and other residents. He seems to enjoy being able to "speak" using his own voice to introduce these familiar topics. Occasionally, Ben feels frustrated by his limited communication and increasing physical needs and becomes aggressive toward staff or other residents. In these instances, staff are instructed to shift the interaction toward the use of nonverbal communication, when possible, and to emphasize feelings rather than words during interactions. Ben's SLP provides an in-service to the staff, focusing on strategies for communicating with individuals with aphasia. These include: using a welcoming but adult tone of voice; simplifying the message (to single words and short phrases); allowing additional time; and using multi-modality communication. With these simple guidelines, caregivers in the facility are better equipped to communicate not only with Ben, but with other individuals in their care who have difficulty with communication as well.

Questions for Discussion

(Use for staff in-service training or in resident-specific situations.)

1. What communication strategies did the speech-language pathologist target with Ben as his aphasia progressed?

Mild PPA:

- The SLP worked with Ben to decrease his speech errors, focusing on a set of functional words that he used frequently when at work. He was instructed to speak slowly and produce these words syllable by syllable.
- The SLP also worked with him on strategies for finding words during instances of naming difficulty. Strategies included describing the thing he couldn't name, and attempting to write part or all of the word.
- Ben was encouraged to use nonverbal modalities for communication when his speech was difficult for others to understand.

Moderate PPA:

- The SLP implemented a script training treatment for topics that Ben reported he would like to discuss in his daily life.
- Ben was encouraged to continue to utilize writing and nonverbal modalities to supplement his verbal communication.

More Advanced PPA:

- The strategies used in this stage focused on multimodality communication (gestures, writing and drawing). Ben's family was instructed in these techniques as well, in order to "normalize" their use during conversation.
- The SLP worked with Ben and his family to develop a communication book containing words paired with pictures, in order to promote successful nonverbal communication.

2. What signs and symptoms indicated that a change in living situation was necessary?

Ben began to fall frequently and had increasing difficulty walking. In addition, he was hospitalized due to his trouble with swallowing, and his diet was subsequently modified. He did not consistently adhere to his dietary modifications and, as a result, he was again hospitalized. Ben's wife and daughter decided that he would be safer and more comfortable in an assisted living facility.

3. How can communication partners (e.g., family members) and facility staff be trained to promote successful communication for individuals with primary progressive aphasia?

Communication strategies that can be implemented by communication partners and facility staff include:

- Using simple, short phrases with gestures or drawings to provide redundancy for the message.
- Providing increased time for the individual with PPA to convey their message.
- Modeling and promoting the use of multi-modality communication (e.g. drawing, gesturing, writing).
- Using a communication book or communication board to provide a context for comprehension and expression.

In Ben's case, incorporating words and phrases from script training and encouraging him to use recorded videos of scripts to communicate about important topics were both productive.



Question: A 57-year-old woman with PPA moved into our assisted living community. Her verbal communication is unintelligible, except for occasional one- or two-word phrases. What communication strategies and tools might the staff use to engage her?

People with PPA continue to know what they want to say, even as verbal skills decline. Finding alternative ways to communicate can promote the staff-resident relationship, improve understanding of needs and reduce behaviors that might result from misunderstanding or frustration. Something as simple as a resident using a dry erase board to communicate can be an effective tool. There are many low-cost, low-tech approaches that can help an individual with impaired verbal language skills to communicate their needs and interests. Remember, because the abilities of someone with PPA continue to change, each strategy will need to be evaluated often and adapted over time.

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Alternative communication systems have the greatest impact when developed as part of speech-language therapy in the early or moderate stages of PPA. If the new resident has worked with an SLP, family members can introduce effective communication strategies to ease the resident's transition and help staff establish rapport. If scripts were developed and practiced to promote fluency, the resident and family should review the content, update as needed and provide written statements as a way for a person to introduce themselves to others. A self-disclosure script may say "Hi. My name is Sue. I have PPA, which makes it hard to speak. I moved here from New York. Nice to meet you." Other scripts might address a description of the individual's family, hobbies or career experience.

Use of a communication book can be introduced in the residential setting. A communication book is a notebook or binder that contains short phrases and questions paired with symbols (e.g., "May I have a drink?" with pictured choices of beverages). In addition, the book contains pictures of familiar people and places with written labels. Once the book has been completed, the care staff and family can help the resident use it to answer and ask questions and to initiate communication exchanges.

Similarly, a communication "wallet" is carried in a pocket or worn on a lanyard. The wallet contains functional pictures and words that a person is likely to need during daily routines (e.g., pictures of foods, self-care items and daily activities).

An SLP will also create a communication board, which contains symbols for common objects in the resident's room, so that they are able to nonverbally communicate wants and needs to the staff.

An SLP evaluation is not necessary to create a low-tech ACC system. Family and residential care staff can develop a communication book, wallet or board to pair words with pictures. However, developing a tool that the individual and team can use effectively requires thoughtful planning and follow-through. If available, an SLP is a valuable resource to evaluate the resident's language skills, and recommend the best tools and strategies to encourage their use by the individual and the care team.

The use of smart-phones and technology has driven the creation of a rapidly-increasing number of applications and devices for augmentative and alternative communication. SLPs urge caution in introducing new technology at any stage of PPA. Commercial systems such as Proloquo2Go, Lingraphica or Dynavox are expensive and not always appropriate for individuals with PPA. The complexity of new technology often leads to frustration and reduces the use of the communication system. However, some individuals who have experience with applications may prefer an application-based communication system. In these instances, it's important that training take place with the application, and that particular pictures and words are decided on by the individual with PPA. Matching the device or book to the person's ability and motivation to use it is critical for success.

Primary Progressive Aphasia (PPA)

Primarily progressive aphasia (PPA) is a gradual decline in the ability to communicate, resulting from degeneration of speech and language networks in the brain. Speech-language pathologists (SLPs) now offer a variety of treatments, with emphasis on rebuilding lost function, supplementing verbal communication with nonverbal modes of expression, and training for communication partners.

Early Stage

- Obtain an evaluation with a speech-language pathologist to evaluate communication abilities thoroughly and establish a baseline for treatment.
- Reduce background noise and distractions to ensure the person with PPA is able to understand the message.
- Face the person, speak slowly and allow time for a response.
- Use compensatory techniques (cueing, clarifying meaning, describing the word) to facilitate successful, rather than perfect communication.
- Include spouse/partner or primary caregiver in speech-language therapy session to supplement training at home.
- Practicing and rehearsing personally relevant words or phrases are used to maintain retrieval and pronunciation.
- Encourage nonverbal communication strategies to supplement when speech is not understood (e.g., "Can you show me?" and offer paper/pencil for concurrent writing/drawing).
- Ask for clarification if a response is incomplete or unclear; do not pretend to understand.
- Suggest that the person carry a card identifying and explaining their diagnosis of primary progressive aphasia.
- Monitor for depression. People with PPA experience frustration and loss over diminishing communication and are at an increased risk of depression.
- Participation in a communication support group can encourage practice and use of language.
- Caregivers may also participate in support groups to learn strategies from other caregivers.
- Evaluate augmentative and alternative communication device or book with SLP, although the individual with PPA may not be interested in these at this stage. *(continued)*

In the early stage of PPA, it's important to obtain an evaluation with an SLP to evaluate communication abilities thoroughly and establish a treatment plan.

Primary Progressive Aphasia (PPA) *continued*

Middle Stage

- Use script training developed in speech-language therapy for topics the person would like to discuss in daily life (e.g., information about their diagnosis, family, favorite activities, etc.).
- Use shorter sentences with a more simple structure for improved comprehension.
- Give one direction or ask one question at a time.
- Use questions that offer a choice, rather than open-ended questions (“Do you want coffee or juice?” rather than “What do you want to drink?”).
- Develop a personalized communication notebook or communication wallet (pocket sized cards on keyring). These offer a visual lexicon with pictures of key words, people and activities for access by the person with PPA and communication partners.
- Use all modalities to support communication (gestures, pictures, props, visuals).
- Use affirming statements (e.g., “Take your time, I’ll wait.”)
- With an SLP, evaluate an augmentative and alternative communication device or book.

Late Stage

- Use multiple modalities (gestures, writing single words, drawing) as verbal communication becomes increasingly challenging.
- Check for comprehension often.
- Encourage regular use of a communication book, wallet and/or other augmentative and alternative communication device.
- Train home health, adult day and residential care staff to use identified communication strategies and tools.
- Adapt key words, personally meaningful phrases and scripts for changes in setting as an adult day program or residential care is introduced.
- Engage speech-language pathologist for evaluation of swallowing and dysphagia as needed.
- Observe triggers for behavior changes and a generalized increase in symptoms; frustration over an inability to communicate wants or needs is often expressed in challenging behaviors.