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A continuum of communication supports for Primary Progressive Aphasia

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Oregon Speech-Language-Hearing Association

Learning Outcomes

1. Identify symptoms and assessment protocols for clinical diagnosis PPA
2. Describe 3 stages of SLP treatment for individuals with PPA
3. Explain the communication support approach for intervention:
    1. Restorative
    2. Compensatory
    3. Environmental/partner training

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SYMPTOMS OF PPA

What is PPA?

Definitions

- PPA is a clinical dementia syndrome caused by neurodegenerative disease
- Language function slowly declines due to neurodegenerative brain disease; eventually affecting additional cognitive, behavioral and functional domains

Characteristics

- Average age of symptom onset = mid-50's to early 60's (participation impact)
- Even representation of male & female
- Survival is ~ 7 years post diagnosis with highly variable prognosis

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Diagnosis of PPA: Clinical Options

- ✓ Neurological exam: Rate of onset, other illness, other symptoms, etiology: stroke vs. tumor vs. neurodegenerative vs. other
- ✓ Neuropsychological exam: Evidence of language domain impairment in absence of other cog/beh deficits
- ✓ Speech/Language Pathology exam: Assess language modalities and components

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Diagnosis of PPA: Neuroanatomy

- ✓Neuroimaging: (MRI, CT, PET)
  - to rule out other diseases
  - MRI may indicate regions of atrophy (evidence of L sided atrophy?)
  - PET may show physiological dysfunction (hypometabolic activity?)

Diagnosis of PPA: Neuropathology

- The disease as seen under the microscope
- Autopsy studies show PPA is associated with a particularly underlying pathology
- Advances in imaging and biofluid biomarkers in the coming years should facilitate the diagnosis of specific pathology in PPA
- Why is this important? Information leads to more effective medication intervention

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Clinical diagnostic criteria for PPA

Mesulam, M. 2003; Gorno-Tempini et al, 2011

Inclusion Criteria

1. Language deficits emerge slowly and progress
2. Language deficits **most prominent feature** of exam
3. Aphasia is the identifiable and principal cause of impairment in ADL, otherwise WNL
4. Aphasia is sole deficit (or most prominent) at onset and for initial stages of disease

Exclusion Criteria

1. Diseases other than neurodegenerative can account for the symptoms: stroke, tumor
2. Psychiatric diagnosis accounts for symptoms
3. Predominant initial episodic memory, visuospatial and or executive function deficits occur early in the course
4. Prominent initial behavioral disturbance

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The 3 variants of PPA

1. Nonfluent/agrammatic variant (PPA-G)
   - Resembles a degenerative expressive aphasia
2. Semantic variant (PPA-S)
   - Resembles a degenerative receptive aphasia
3. Logopenic variant (PPA-L)
   - Resembles a degenerative conduction aphasia or mixed expressive-receptive aphasia

PPA-G: Nonfluent/Agrammatic

Gorno-Tempini, Hillis, Wientraub, et al, Neurology , 2011

At least one of the following core features must be present:

- ✓ Agrammatism in language production
- ✓ Effortful halting speech with inconsistent speech sound errors and distortions (apraxia of speech)

At least 2 of 3 of the following other features must be present:

- ✓ Impaired comprehension of syntactically complex sentences
- ✓ Spared single-word comprehension
- ✓ Spared object knowledge

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VIDEOS of PPA-G:

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PPA-S: Semantic

Gorno-Tempini, Hillis, Wientraub, et al, Neurology , 2011

Both of the following core features must be present:

- ✓ Impaired confrontation naming
- ✓ Impaired single-word comprehension

At least 3 of the following other features must be present:

- ✓ Impaired object knowledge, particularly for low frequency or low familiarity items
- ✓ Surface dyslexia or dysgraphia
- ✓ Spared repetition
- ✓ Spared speech production

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Videos of PPA-S

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PPA-L: Logopenic

Gorno-Tempini, Hillis, Wientraub, et al, Neurology , 2011

Both of the following core features must be present:

- ✓ Impaired single-word retrieval in spontaneous speech and naming
- ✓ Impaired repetition of sentences and phrases

At least 3 of the following other features must be present:

- ✓ Speech errors in spontaneous speech and naming
- ✓ Spared single word comprehension and object knowledge
- ✓ Spared motor speech
- ✓ Absence of frank agrammatism

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First symptoms described by patients or observed by care providers

- *Anomia* or “trouble thinking of or remembering specific words when talking or writing” (PPA-G and PPA-S).
- Slow, hesitant speech frequently punctuated by long pauses and filler words (PPA-G).
- Marked increase in speech errors (substitutions or distortions; PPA-G).
- Struggle for speech sounds, apraxia (PPA-G)
- Difficulties understanding spoken words (PPA-S).

Progression of disease varies

- Yes/No confusion for responses
- Apraxia of Speech (PPA-G)
  - Articulatory groping with difficulty self correcting
  - Vowel distortions and inconsistent errors
  - Increased frequency of articulatory errors as word or phrase length increases
- Written language often mimics spoken language
- Mutism

ASSESSMENT PROTOCOLS

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Speech/language pathology exam for PPA

1. Assess language *competence*: articulation, fluency, syntax, grammar, word retrieval, repetition, comprehension, reading & writing
2. Assess language *performance:* demands of environment to & functional communication skills needed for different settings and situations

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Speech/language pathology exam in PPA

Sapolsky, D., Domoto-Reilly, K., Negreira, A., Brickhouse, M.,McGinnis, S., Dickerson, B 2011

Domain	Test instruments
Articulation	Apraxia Battery for Adults, motor speech exam
Fluency	BDAE seven point scale for phrase length, WAB fluency, Grammatical Competence & Paraphasias scale, clinician impression of fluency from spontaneous speech/picture descriptions
Syntax/grammar	BDAE seven point scale for phrase length, WAB fluency, Grammatical Competence and Paraphasias scale, Northwestern Anagram Test, analysis of language samples
Word retrieval	BNT, phonemic/category fluency tasks
Repetition	WAB and BDAE repetition tasks (words, phrases, sentences)

Speech/language pathology exam for PPA Sapolsky, D., Domoto-Reilly, K., Negreira, A., Brickhouse, M.,McGinnis, S., Dickerson, B 2011

Domain	Psycholinguistic test instruments
Auditory comprehension	WAB and BDAE following commands tasks, BDAE Complex Ideational Material, PAL Sentence Comprehension, CYCLE Sentence-Picture Matching
Single word comprehension	BDAE Word Comprehension, WAB Auditory Word Recognition, CSB Category Comprehension, PALPA Spoken Word-Picture Matching, Peabody Picture Vocabulary Test
Reading & writing	WAB and BDAE written language tasks
	BDAE: *Boston Diagnostic Aphasia Examination;* ***BNT****: Boston Naming Test;* ***CSB****: Cambridge Semantic Battery;* ***CYCLE****: Curtiss-Yamada Comprehensive Language Evaluation –Receptive;* ***PAL****: Psycholinguistic Assessment of Language;* ***PALPA:*** *Psycholinguistic Assessments of Language Processing in Aphasia;* ***WAB****: Western Aphasia Battery*

Functional assessment tools

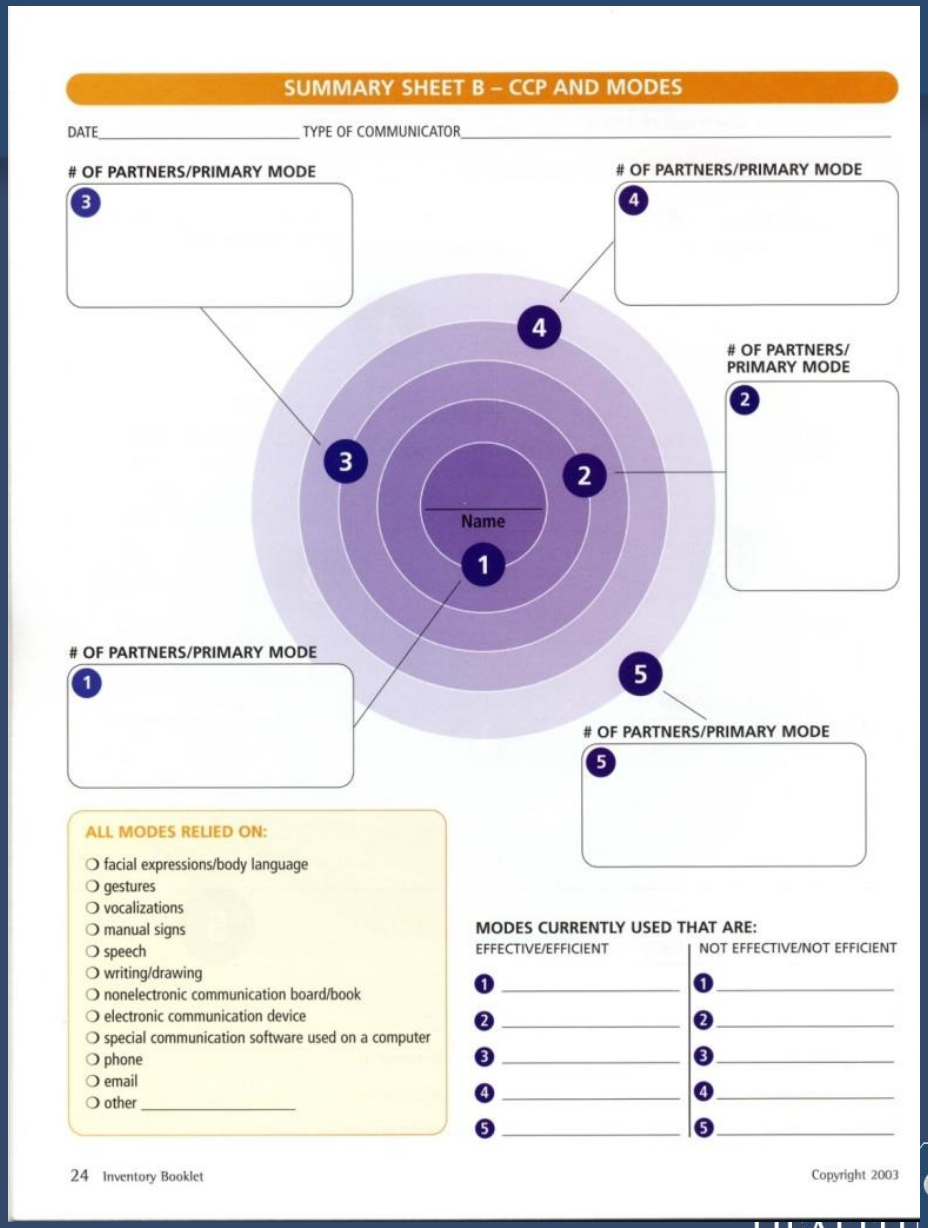
- Social Networks Inventory (Attainment Company)
- Aphasia Needs Assessment (Garrett & Beukelman, 2006) http://aac.unl.edu
- CETI: Communicative Effectiveness Index (Lomas et al., 1989)

Social Networks

Blackstone & Berg, 2003

Client's Circles:

1. Intimate partners (family)
2. Good friends
3. Acquaintances
4. Employees
5. Strangers



SUMMARY SHEET B – CCP AND MODES

DATE _____ TYPE OF COMMUNICATOR _____

OF PARTNERS/PRIMARY MODE
3

OF PARTNERS/PRIMARY MODE
4

OF PARTNERS/ PRIMARY MODE
2

Name

OF PARTNERS/PRIMARY MODE
1

OF PARTNERS/PRIMARY MODE
5

ALL MODES RELIED ON:

- ❍ facial expressions/body language
- ❍ gestures
- ❍ vocalizations
- ❍ manual signs
- ❍ speech
- ❍ writing/drawing
- ❍ nonelectronic communication board/book
- ❍ electronic communication device
- ❍ special communication software used on a computer
- ❍ phone
- ❍ email
- ❍ other _____

MODES CURRENTLY USED THAT ARE:

EFFECTIVE/EFFICIENT	NOT EFFECTIVE/NOT EFFICIENT
1 _____	1 _____
2 _____	2 _____
3 _____	3 _____
4 _____	4 _____
5 _____	5 _____

24 Inventory Booklet

Copyright 2003

PRINCIPLES OF TREATMENT

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Treatment themes in PPA

- Unlike chronic stroke, speech-language abilities gradually decline in PPA
- Start early & be proactive so person with PPA can learn to use communication strategies and tools as soon as possible
- Consider all modalities (stimulation and compensation)
- Environmental/partner training from the beginning and throughout
- Adjust treatment as concomitant cognitive and motor difficulties develop

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Consider the goal: Functional communication

- Maximize communication at each stage of disease
- Consider the individuals in the context of their environment and their multiple conversation partners
- Tailor treatment approach to current status; plan for likely progression and educate

Ideal model: Staged treatment approach

- Assess ⟶ Treat ⟶ Assess ⟶ Treat
- Goals evolve with symptom progression
- 3 stages
  I. Restorative
  II. Shift toward aided approaches
  III. Environmental support and partner training

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Other contributing factors may affect treatment outcomes

- Changes in cognition
  - Memory (working memory and new learning)
  - Executive functions
  - Visuospatial processing
- Changes in behavior
  - Social and emotional changes
  - Disinhibition, apathy
- Motor changes
  - Weakness, incoordination
  - Limb apraxia
  - Fine motor dyscoordination

STAGES OF TREATMENT

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Staging PPA treatment

Fried-Oken, Rowland & Gibbons, 2010

Stage	Treatment	Partner Involvement
I: RESTORATIVE Detectable language lapses with hesitations, dysfluencies and word-finding difficulties	Education; behavioral strategies to support conversation. Introduction of low tech AAC.	Behavioral training: -how to ask questions -provide choices -alter verbal and physical environment to support communication
II: COMPENSATORY Reduction in language use (circumlocutions, paraphasias, simplification, agrammatism)	*Stage I* + additionallow tech AAC. Transition to additional tools and techniques for multi-modal communication system, (mobile devices and SGD)	Device training: Partners learn message selection techniques and operations of each AAC tool.
III: ENVIRONMENTAL No functional language	Environmental Support	Co-construction training: Partners lead successful interaction; support participation with multi-modal techniques.

STAGE I:
RESTORATIVE
COMPENSATORY
ENVIRONMENTAL

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Naming treatment in Stage I PPA:

- Semantic feature cuing (category, function, location, associations, etc)
- Phonetic cuing
- Substitution (synonym or antonym)
- Circumlocution; description
- Picture sorting
- Encourage self-cuing (Henry, ML, Rising, K., DeMarco, AT, Miller, BL, Gorno-Tempini, & Beeson, PM. 2013)

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STAGE II:
RESTORATIVE
COMPENSATORY
ENVIRONMENTAL

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Stage II: A shift toward aided approaches

Fried-Oken, Beukelman & Hux (2012)

- Expressive language is less efficient
- Verbal participation in all activities decreases
- Telephone use decreases or is avoided
- Conversations become imbalanced

Communication Supports

Unaided Approaches (Natural modes)

- Speech
- Vocalization
- Gestures
- Eye gaze
- Body language
- Sign language
- Partner co-construction

Aided Approaches (Low tech and high tech tools)

- Paper and pencil
- Communication books
- Communication boards and cards
- Speaking computers
- Talking typewriters
- Speech generating devices
- Mobile technologies

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Consider communication demands

- Different settings
  - Employment
  - Homes
  - Groups
  - Community events
- Different partners
- Topics
  - Familiar vs. unfamiliar
- Modes of communication
  - Telephone
  - Face to face, spontaneous
  - Written
  - Electronic

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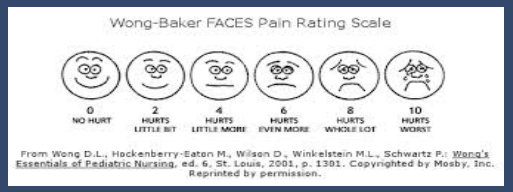
Low tech options

- Communication books
- Communication passports
- Photo albums
- Pictures
- Newspapers
- Communication boards
- Cards
- Remnants
- Written choice and continuum lines
- Paper and pencil



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High tech options

- Dedicated speech generating devices
- Mobile technology devices

User features to consider

- Previous experience with technology
- Support for training
- Partner's experience with technology
- Working memory abilities
- Vision and hearing abilities; fine motor
- Cognitive strategies and skills
- Motivation
  - "I bought this for mom to use."
  - "She can't seem to find the correct page."

The research challenge

There is little empirical evidence that AAC helps people with PPA-G with their daily expression. We only have case studies and clinical descriptions.

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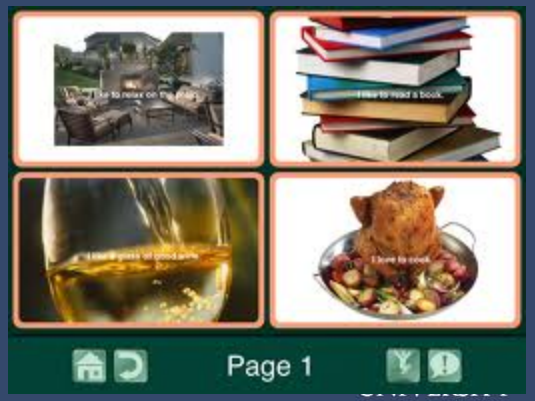
Our research purpose

To provide evidence that low tech AAC (communication boards) and high tech AAC (mobile technology and apps) support adults with PPA during conversations.

To demonstrate that AAC supports lexical access so that individuals can participate in daily activities as language skills decline.



Four studies

- Study 1: Do personalized low tech AAC boards in *controlled conversations with research assistants* improve expressive communication?
- Study 2: Do personalized, daily activities AAC boards used in *conversations with frequent partner (spouse, child, caregiver)* improve daily communication?
- Study 3: Is there generalization and maintenance of AAC over 6 months?
- Study 4: Does use of mobile technology for language support improve conversation in people with PPA?

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Low tech AAC study (Fried-Oken & Rowland, submitted)

Method

- 20 individuals with PPA
- 10 neurotypical adults and 20 individuals with AD
- Personalized communication boards
- Trained in board use with RA and with spouse
- Scripted and natural conversations; 6 *with* and 6 *without* AAC

PPA Results

- Targeted words produced at initial prompt significantly greater with AAC
- Number of questions posed by RA or spouses to elicit target words significantly reduced with AAC

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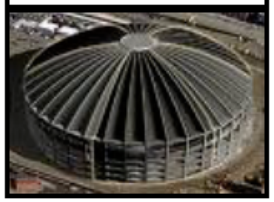
Conversational board: My sports teams

King Dome



Clyde Drexler

Greg Oden

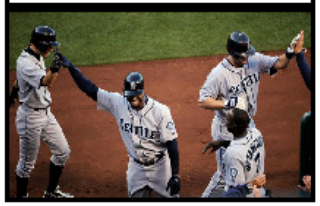
Rose Garden

Ichiro Suzuki

Edgar Martinez

Brandon Roy

Home Run



OSU Beavers

Ken Griffey Jr.

Mariners

Terry Porter

Blazers

Safeco Field

Miguel Batista

Oregon Ducks

Functional activities board

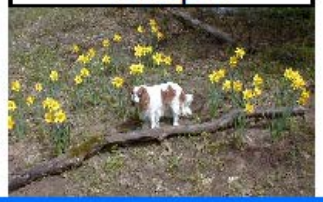
Weeding

Firewood

Beach House

Ocean View

Casper



Stair Repair

Clamming

Fireplace

Stern Wheeler

Boulder City

Walmart

Costco

Laughlin

London Bridge

Fred Meyer

Thriftway

Thriftway

Proud of Being Locally Owned & Operated

Interpretation of results

- Low tech AAC provides meaningful lexical support during structured conversations for people with PPA.
- Low tech AAC significantly reduces lexical scaffolding provided by the conversation partner.
- This approach should be part of a PPA treatment protocol.

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Current mobile technology for PPA study: Sharing new information with/without AAC

Method

- *Justification: "I can understand what he is saying when I start the conversation. But when Jim comes up to me and wants to tell me something, and I don't know the topic, I have no idea what he is talking about!"*
- 4 adults with PPA (2 mild; 2 severe)
- Completed 3 activities with RA
- RAs populated 5 different layouts in *GoTalk Now* app with photos & speech
- Barrier task: Tell your spouse what you did this afternoon
- 3 conversations *with no* AAC support; 3 conversations *with* AAC

Results

- Significantly greater report of gist with AAC than with no support
- For subjects with severe PPA: Total words spoken with AAC increased significantly compared to speech only condition;
- Specific app layout did not affect language performance

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Visual Scene in GoTalk Now app

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3 videos: (1) speech + gestures
(2) speech + gestures + writing
(3) speech + gestures + writing + GoTalk Now app

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STAGE III:
RESTORATIVE
COMPENSATORY
ENVIRONMENTAL

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Stage III: Emphasis on environmental modifications

- Engineering the environment
- Communication partner training

Natural environmental supports

- Pointing to weather pictures in newspaper to indicate time of day
- Pointing to framed boards on the family picture wall *at eye level*
- Using mail received from the bank to indicate questions about finances
- Flipping through pictures in photo book during a family visit
- Placing cue cards throughout environment
- Remnant boxes

Partner training

- “Should I finish his sentences? Give him the words?”
- Support all forms of communication
- Count to 10 in your head before expecting a response
- Speak in a quiet environment, establish eye contact and reduce distractions
- Set up a way to “come back to that later.”

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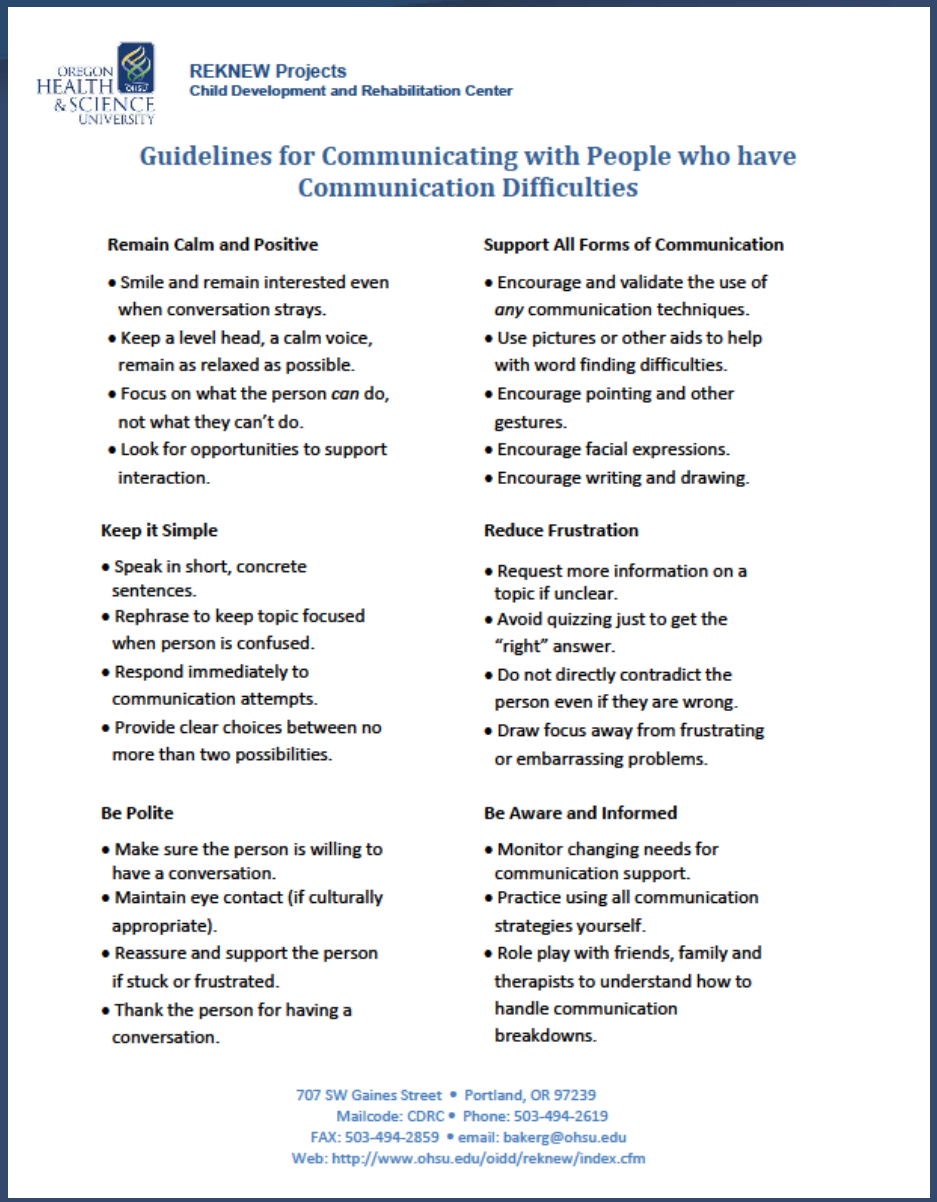
www.reknewprojects.org -> Primary Progressive Aphasia -> Communication supports



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REKNEW Projects
Child Development and Rehabilitation Center

Guidelines for Communicating with People who have Communication Difficulties

Remain Calm and Positive

- Smile and remain interested even when conversation strays.
- Keep a level head, a calm voice, remain as relaxed as possible.
- Focus on what the person *can* do, not what they can't do.
- Look for opportunities to support interaction.

Keep it Simple

- Speak in short, concrete sentences.
- Rephrase to keep topic focused when person is confused.
- Respond immediately to communication attempts.
- Provide clear choices between no more than two possibilities.

Be Polite

- Make sure the person is willing to have a conversation.
- Maintain eye contact (if culturally appropriate).
- Reassure and support the person if stuck or frustrated.
- Thank the person for having a conversation.

Support All Forms of Communication

- Encourage and validate the use of *any* communication techniques.
- Use pictures or other aids to help with word finding difficulties.
- Encourage pointing and other gestures.
- Encourage facial expressions.
- Encourage writing and drawing.

Reduce Frustration

- Request more information on a topic if unclear.
- Avoid quizzing just to get the "right" answer.
- Do not directly contradict the person even if they are wrong.
- Draw focus away from frustrating or embarrassing problems.

Be Aware and Informed

- Monitor changing needs for communication support.
- Practice using all communication strategies yourself.
- Role play with friends, family and therapists to understand how to handle communication breakdowns.

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Web: http://www.ohsu.edu/oidd/reknew/index.cfm

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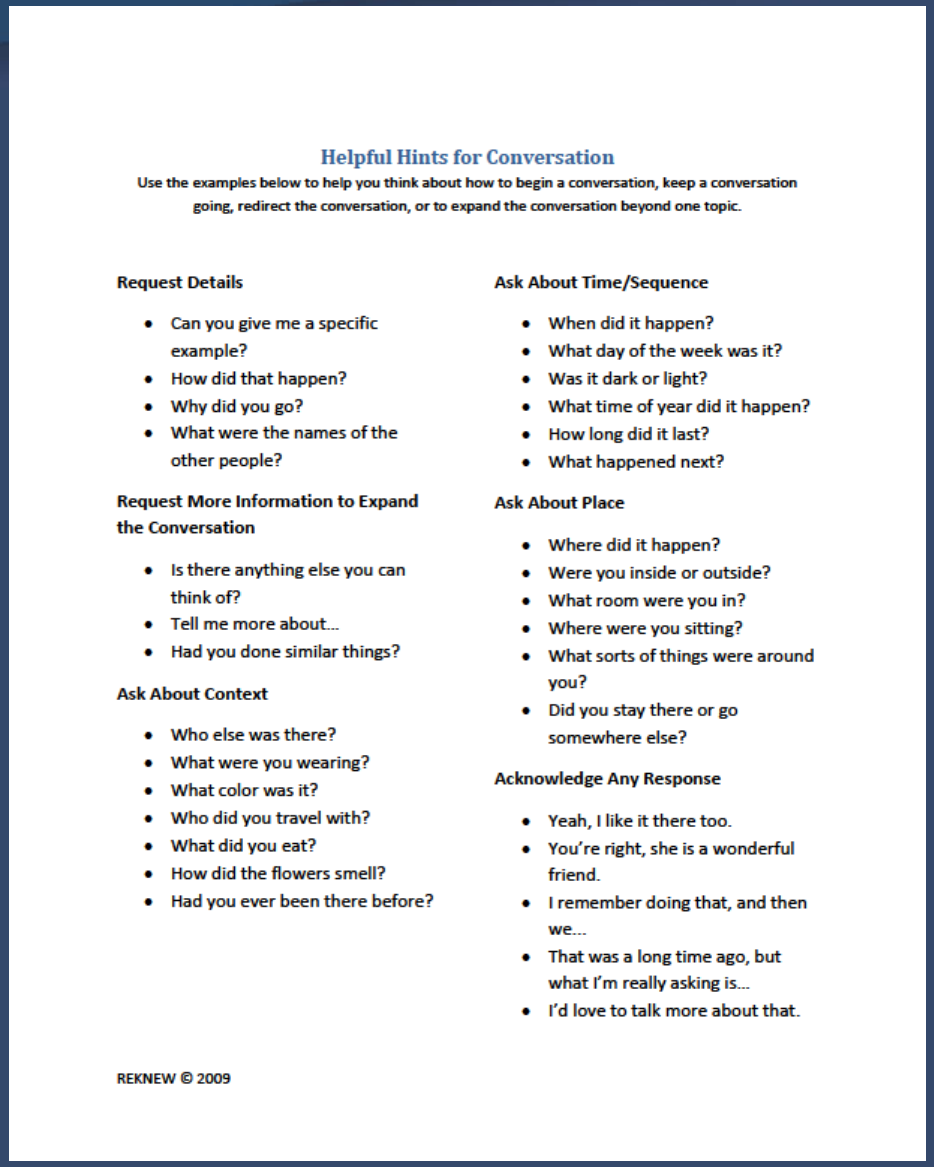

Helpful Hints for Conversation

Use the examples below to help you think about how to begin a conversation, keep a conversation going, redirect the conversation, or to expand the conversation beyond one topic.

Request Details

- Can you give me a specific example?
- How did that happen?
- Why did you go?
- What were the names of the other people?

Request More Information to Expand the Conversation

- Is there anything else you can think of?
- Tell me more about…
- Had you done similar things?

Ask About Context

- Who else was there?
- What were you wearing?
- What color was it?
- Who did you travel with?
- What did you eat?
- How did the flowers smell?
- Had you ever been there before?

Ask About Time/Sequence

- When did it happen?
- What day of the week was it?
- Was it dark or light?
- What time of year did it happen?
- How long did it last?
- What happened next?

Ask About Place

- Where did it happen?
- Were you inside or outside?
- What room were you in?
- Where were you sitting?
- What sorts of things were around you?
- Did you stay there or go somewhere else?

Acknowledge Any Response

- Yeah, I like it there too.
- You're right, she is a wonderful friend.
- I remember doing that, and then we…
- That was a long time ago, but what I'm really asking is…
- I'd love to talk more about that.

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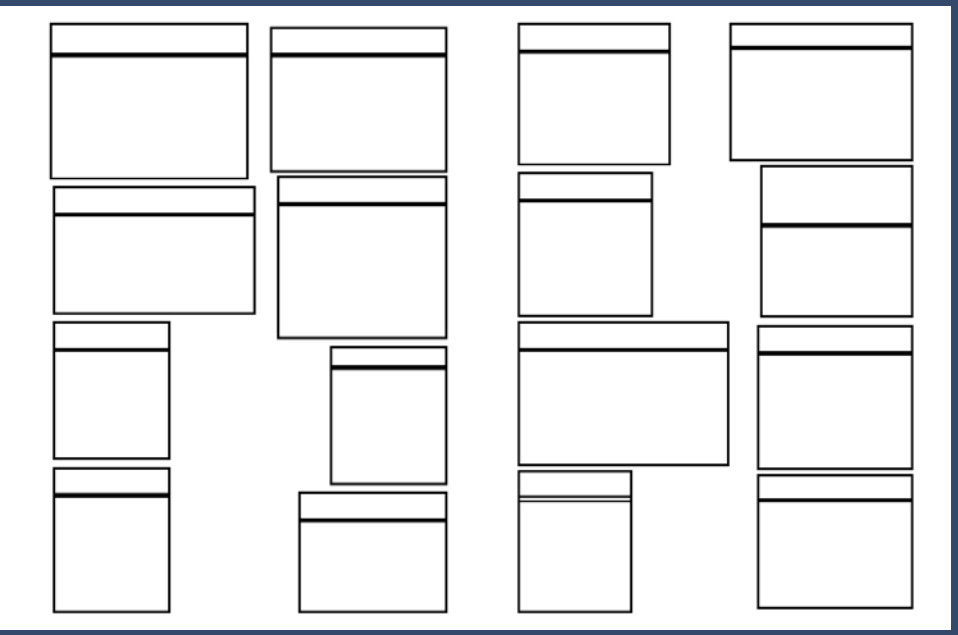
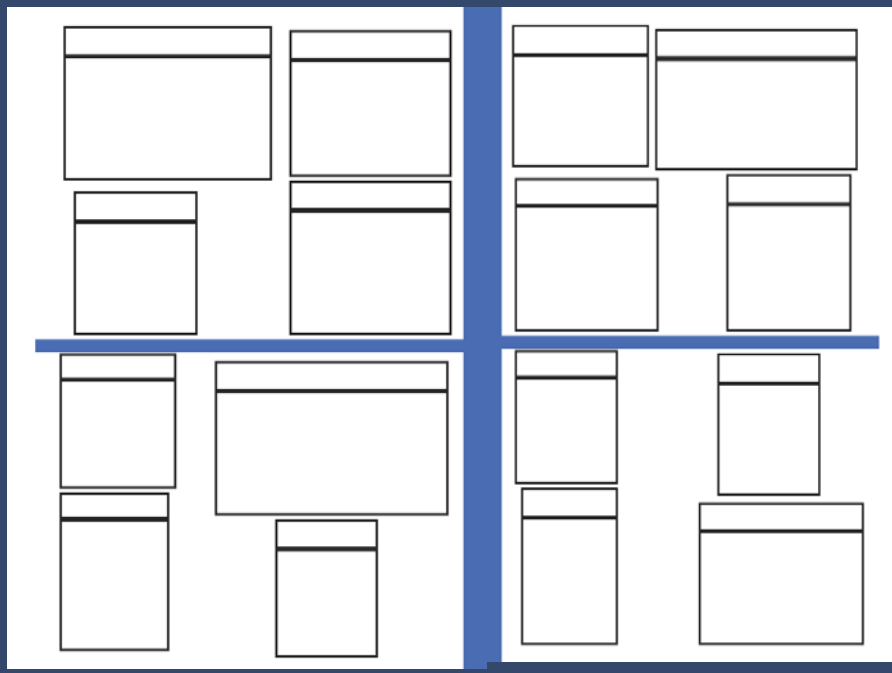
Templates: 1 and 4-topic boards (Microsoft Publisher)

1-topic board
Placed on file folder
Box sizes can be manipulated



4-topic board
Placed on file folder
Box sizes can be manipulated



Documenting successful outcomes for people with PPA

- Stability = progress
- Comprehension and production in any modality is acceptable

Poll everywhere

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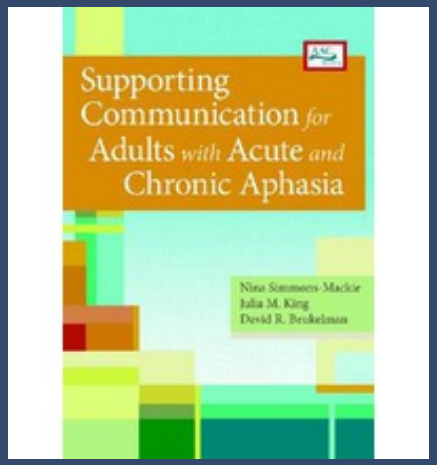
Book and website references for AAC

- www.aac-rerc.com: Research to practice AAC for PPA webinar (AAC Rehabilitation Engineering Research Center)
- http://memory.ucsf.edu
- www.brain.northwestern.edu (Cognitive Neurology and Alzheimer's Disease Center)
- Simmons-Mackie, King & Beukelman (2013) Brookes Publishing



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Webinar Series for PPA: http://www.brain.northwestern.edu/about/events/webinar.html

Dr. Lawrence Albert Memorial Webinar Series for SLPs treating Primary Progressive Aphasia

The Northwestern CNADC partnered with the National Aphasia Association and the Association for Frontotemporal Degeneration to develop a series of webinars for Speech and Language Pathologists (SLPs) who treat people with primary progressive aphasia (PPA). This collaboration was formed to improve understanding and treatment approaches for SLPs who have had limited experience with PPA in their training or career. The live events were held in the 2013 Spring/Summer.

The archived webinars are available on demand and are complimentary to SLPs, other professionals and families who wish to learn more about primary progressive aphasia and speech therapy.

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Archived Webinars

"The ABCs of PPA for SLPs: Clinical Attributes, Biology and Care of Primary Progressive Aphasia". Presented by Sandra Weintraub, PhD, of the Northwestern CNADC. To view an archived recording of this presentation, please click here. For a PDF version of the slides, please click here.

"Treatment for Persons with PPA: An Adaptable Communication Support Approach". Presented by Melanie Fried-Oken, PhD, CCC-SLP of Oregon Health and Science University and Maya Henry, PhD, CCC-SLP of University of California San Francisco. To view an archived recording of this presentation, please click here. For a PDF version of the slides, please click here.

"Living with Primary Progressive Aphasia: Challenges Experienced by PPA Patients and Families and How SLPs Can Help!" Presented by Darby Morhardt, MSW, LCSW of the Northwestern CNADC and Jamie Reilly, PhD, CCC-SLP of University of Florida. To view an archived recording of this presentation, please click here. For a PDF version of the slides, please click here.

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Fried-Oken, M., Beukelman, D., & Hux, K. (2012). Current and future AAC research considerations for adults with acquired cognitive and communication impairments. *Assistive Technology, 24*, 56-66.

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- We have no financial or nonfinancial interest in any organization whose products or services are described, reviewed, evaluated or compared in the presentation.

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