Living with Primary Progressive Aphasia:
Meaningful Strategies to Increase Functional Communication

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Disclosure

Owner of a for profit company, MemoryCare Corporation, which provides services to patients with dementia. (2010 - present)

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Overview: Treatment of PPA

- Overview of PPA
- Pharmacological interventions/TMS
- Evaluation
- Treatment strategies
- Panel of experts
- Q & A Session
Overview of Primary Progressive Aphasia

- PPA is a clinical dementia syndrome caused by neurodegenerative brain disease

- Progressive difficulties with language processing that initially emerge in the absence of other cognitive or behavioral changes

- Most often caused by forms of FTLD neuropathology (e.g., tauopathies, such as Pick’s disease; others; TDP-43 proteinopathies and other forms of FTLD)
Overview of PPA: Diagnosis

- Clinical Assessment:
  - Neuropsychological Evaluation

- Neuroimaging

- Laboratory Bloodtests
Inclusion & Exclusion Criteria for PPA

- **Inclusion Criteria:**
  - Language impairment is the most salient symptom in the clinical evaluation
  - Language impairments account for any difficulties in ADL
  - Aphasia is the predominant symptom initially and remains the most impaired relative to other domains throughout the course of illness

- **Exclusion Criteria**
  - Pattern of deficits is accounted for by another neurodegenerative disease or illness
  - Symptoms due psychiatric illness
  - Additional cognitive or behavioral deficits are present
  - Earliest symptom was behavioral disturbance rather than aphasia
Overview of PPA: Subtypes

- **Logopenic Variant (PPA-L)**
  - Absence of grammatical difficulties
  - Preserved single word comprehension
  - Hesitant speech with pauses for word finding

- **Agrammatic/nonfluent variant (PPA-G)**
  - Agrammatism in speech, writing and/or comprehension
  - Preserved single word comprehension

- **Semantic variant (PPA-S)**
  - Impaired single word comprehension and naming
  - Preserved grammar
Pharmacological Intervention

- No pharmacological treatment to date has been found to help slow or stop language decline in PPA.
- Have all been trialed with no results:
  - Dextroamphetamine (McNeil et al. 1995)
  - Bromocriptine (Reed et al. 2004)
  - Galantamine (Kertesz et al. 2008)
  - Oral steroids (Decker & Heilman, 2008)
  - Memantine (Johnson et al. 2010)

- Future pharmacological interventions will need to target specific forms of disease based on the suspected neuropathology.
Repetitive Transcranial Magnetic Stimulation

- Noninvasive
- Focuses on the inhibition or excitation of neuronal function
- Results have shown promise, but further research is needed

- Finocchiaro et al., 2006
- Tsapkini et al., 2014
Behavioral Interventions

- Impairment Directed
  - Focuses the intervention on targeting areas of impairment

- Activity/Participation Directed
  - Focuses the intervention on the individual needs of the individual and catering goals to meet these needs
  - Involves use of AAC, education and counseling, caregiver training, and group treatment (Croot et al., 2009)
Circumvents both geographic limitations and poor access to care by delivering speech-language therapy through a user-friendly, personalized, Internet-based portal

Participants: mild-to-moderate aphasia symptoms due to dementia

Initial evaluation, eight web-based SLT sessions, and three evaluations at 2-, 6-, and 12-months post-treatment
THE COMMUNICATION BRIDGE RESEARCH PROGRAM USING INTERNET-BASED SPEECH THERAPY TO IMPROVE QUALITY OF LIFE AND ACCESS TO CARE

- Areas of investigation:
  - To evaluate the effect of speech-language treatment (SLT) for individuals with PPA in three areas:
    - Functional communication ability
    - Quality of life measurements
    - Interpersonal communication
  - To assess what types of strategies used in SLT sessions are most effective for individuals with PPA.
  - To explore the feasibility of internet-based video-practice SLT and PPA.
Holistic Approach to PPA

- Combining impairment-directed interventions with activity/participation-directed interventions
- Taking into account:
  - Variant of PPA/Communication Strengths & Weaknesses
  - Stage of PPA
  - Individual’s hobbies and interests
  - Motivation
  - Insight into deficits
  - Caregiver involvement/support
- Frequently adjusting strategies to meet individual’s changing communication needs
- Taking advantage of skills that remain intact
The Communication Bridge Portal: Main Page

Hi, Madelyn
You have 6 items on your to-do list

To-do list
This week's tasks

- Practice PPA Script
- Picture Cards
- Oral Reading Task
- Multisyllabic Words
- Picture Description Task

Welcome to Communication Bridge
Click on the To-do List items to get started!
<table>
<thead>
<tr>
<th>Practicing Personally Relevant Words</th>
<th>How to Practice a Script</th>
<th>Taking Pictures to Facilitate Communication</th>
</tr>
</thead>
<tbody>
<tr>
<td>Practicing Personally Relevant Words</td>
<td>How to Practice a Script</td>
<td>Taking Pictures to Facilitate Communication</td>
</tr>
<tr>
<td>A program to help you practice meaningful words in your daily life.</td>
<td>How to practice a conversation script before use.</td>
<td>A strategy you can use to help convey a message during conversation.</td>
</tr>
</tbody>
</table>
Speech-Language Pathology Evaluation

- **Standardized Testing**
  - Helpful for diagnosing or in a research context
  - Usually not helpful for the development of patient-centered goals

- **Progressive Aphasia Severity Scale (PASS)** (Sapolsky et al., 2010)
  - Assessment tool for profile of communication strengths and weaknesses
Informal Evaluation

- Identify top barriers to communication
- Obtain a language sample while asking the patient questions regarding their family, occupation, and interests
- Dynamic assessment of all language skills
- Consider presence of non-language cognitive deficits
- Consider the variant of PPA
- Determine what skills remain intact
- Determine new strategies that will be needed in the next phase of the disease
- Complete patient and caregiver education and training throughout the evaluation
Goal Writing

- Always include the individual’s and family’s input
- Goals should be individualized and should focus on functional outcomes
- Goals should be realistic; may need adjust the level of cueing as the disease progresses so that goals can be met
Treatment: Accepting PPA

- Goal is communication, not perfection
- Adapting to new forms of communication
- Learning to use new communication strategies and tools
Self-cueing strategies

Help the individual use strategies to either retrieve the missing word or to communicate the message

- Semantic circumlocution
- Phonemic self-cueing
- Trying to write the word
- Visualizing the word
- Using gestures
Mild Stages

Should family members fill in the word?

- It is up to the individual with PPA!

- Discuss the issue and determine a signal that indicates they would like help

- Filling in the word may allow the conversation to move forward more quickly

- Filling in the word will NOT result in language deteriorating more quickly
Mild Stages

Rehearsal of Personally Relevant Words

**Theory:**
Constant practice of frequently used words will result in easier retrieval or pronunciation during conversation. These words may be easier to retrieve even as the disease progresses.
Mild Stages

Rehearsal of Personally Relevant Words

- Individual should make a list of words or phrases that are important and used on a daily basis, especially those that are difficult to retrieve or pronounce.

- Words are rehearsed daily through the use of flashcards, a notebook, or with a flashcard app.
Apps to practice word rehearsal:

- Quizlet (free)
  - Good audio cues
  - No visual cues

- FlipCards Pro ($3.99)
  - More difficult to initiate audio cues
  - Allows you to insert photographs
The Communication Bridge Portal: Picture Naming

[Image of a website interface with an apple image and a text box to enter a name.]
The Communication Bridge Portal: Picture Naming

Hi, Madelyn

Home
Return to homepage

Contact/Help
Call or email

Calendar
Dates and times

Watch
Instructional videos

Connect
to therapy sessions

It is a type of fruit.

Enter the name here

Get a hint
Answer
The Communication Bridge Portal: Picture Description

**To-do list**

- Practice PPA Script
- Picture Cards
- Oral Reading Task
- Multisyllabic Words
- Picture Description Task

**Picture Description Task**

Read the instructions for the following exercise.

- Look at each picture and talk about it.
- Try to say around 3-5 sentences for each picture.
- Practice 5 days a week for 10 minutes each.

Watch this instructional video:

*Taking Pictures to Facilitate Communication*

Go To Exercise
Hi, Madelyn

This is The macarons I baked last weekend.
Mild Stages

Communication Wallet

- Materials: Cut index cards down to wallet size or type up, print, and laminate wallet-sized cards
- Punch hole in corner of each card
- Place on keyring
- Keep in pocket or purse
Mild Stages

Communication Wallet

Programs:

- Microsoft PowerPoint
- iPad app: “Avery Design & Print” (free)

- Consider Size, Font, & Spacing

- Level of cueing needed to generalize use of wallet at conversation level
Communication Wallet

How to use

- Use for reference during conversation
- Studying particular names or vocab before going to a social or work event
- Facilitating auditory comprehension
Simple 8x11 Communication Aid

- Non-portable version of communication wallet
- Copy and paste information from wallet onto both sides of 8x11 sheet of paper

Smart Phone Aid

- Input personally relevant words and phrases into categories on smart phone, for easy reference (e.g., using “Notes” app)
Mild Stages

Writing Strategies

- Use word prediction feature
- Use spell-check feature
- Use pocket dictionary
- Use speech-recognition software (e.g., “ABC Speller” by Transcreative Software)
- Use templates
- Use visual aids
Auditory Comprehension Strategies

- Face the individual when speaking and making sure you have his/her full attention before starting to speak
- Speak slowly, and allow enough time for the individual to respond to questions
- Use gestures to help communicate your message
- Increase use of nonverbal cues: facial expressions, tone of voice, touch (for those who have difficulty interpreting facial expressions, focus on tone of voice and touch)
- If a response is incomplete or not clear, ask for clarification; repeat back what you heard. Do not pretend to understand if you do not
- Manage the environment (background noise, number of people present)
**Auditory Comprehension Strategies**

- Give one direction at a time
- Use simple grammatical structure
- Replace complex words with more common vocabulary words
- Try asking questions that require a choice between two items or possibilities
- Try asking questions that can be answered with YES/NO
- Try using pictures to supplement your speech (should be personal pictures for PPA-S)
Conversation Scripts

What is a script?

*Written or typed statements that are practiced frequently until patient can say them more fluently and with greater confidence*
Moderate Stages

Conversation Scripts

Can be used to:

- Talk to a family member or friend over the telephone and in other environments (e.g. with grandchildren)
- Order food at a favorite restaurant, schedule an appointment, or ask for directions over the telephone
- State personal information or biographical facts
- Explain the condition of aphasia/PPA and ask listeners to be patient
- Tell jokes or stories
- Give a lecture or speech
- Say prayers
Conversation Scripts

How to Practice:

- The key to success is repeated practice
- Read through script
- Highlight difficult words/phrases
- Repeat each of these 5 times
- Read through entire script again
- Practice scripts for ~20 minutes daily
- Practice telephone scripts directly before making a call

(Youmans et al., 2005)
Communication Book/Boards

- Should be catered towards the individual’s personal needs and interests
- Assess the appropriate format, font size, and word/phrase length for the book
- Train the patient and family members to continue adding pages.
- Use of the patient’s own digital pictures for the book is recommended, particularly for patients with PPA-S
Communication Book

- Remind individual and family:
  - Does NOT replace spoken language at first; supplements it when needed

- Communication partner may need to prompt use of book during conversation
Communication Books

- Can buy pre-made book
- Can buy computer program to help make book
- Individual and family can make themselves using Microsoft PowerPoint or iPad app PicCollage (free)
Moderate Stages

- Coffee
- Creamer
- Banana
- Cereal
- Bagel
- Pancakes
- Take a walk
- Read
- Volunteer
- Gardening
- Listen to music
- Nap
Moderate Stages

SENDING AN EMAIL

1. TAP EMAIL BUTTON

2. "COMPOSE" BUTTON

3. TYPE EMAIL ADDRESS HERE

4. TYPE IN YOUR SUBJECT

5. TYPE MESSAGE

TAP "SEND" BUTTON
Using smart phone pictures to facilitate communication:

- Encourage individual with PPA to frequently take pictures with smart phone throughout the day
- Individual can use pictures to supplement daily conversation
  - E.g., To help answer question, “What did you do today?”
Severe Stages

Augmentative & Alternative Communication Devices

PPA & Speech Generating Devices (SGD)

SIMPLE IS BEST.

A combination of low and high tech aids for different contexts may be the most helpful.
Severe Stages

Considerations for buying SGD:

- Does the individual have experience with computers or high tech devices?
- Does the individual want to communicate with a device?
- Does the individual have significant difficulty with comprehension?
- Does the individual have low vision?
- Does the individual have fine motor deficits?
- Does the individual have visuospatial deficits?
- Does the individual have sequencing deficits?
- Is the device portable?
- Is this a device that the individual will most likely be able to use as his/her cognitive skills get worse?
Severe Stages

Will insurance cover SGD’s?

- Sometimes, depends on the individual policy. Need to check with your insurance company.
- Insurance does NOT cover the cost of any app for a smartphone or tablet.
Severe Stages

GoTalk20+ ($200)

- Simple device
- Easy to use
- Allows user to record his/her own voice for 100 short utterances.
- 5 levels, with overlays
- Computer software for images
Severe Stages

- GoTalk Now app ($79.99)
- For the iPad
- Ability to insert personal pictures and record own speech
Severe Stages

Products by Lingraphica SmallTalk
(free version available)
(For the I-pod touch or I-Phone)

- This application was developed for adults with aphasia (most other devices developed for children)
- Several different apps available for different communication environments
- No ability to change or personalize the features
Severe Stages

Lingraphica SmallTalk

I have trouble speaking, but I can understand you.

I don't feel well today.
Severe Stages

Story Creator by Alligator Apps (free)

For the iPhone and iPad

- Sequenced, narrated slideshow using your own pictures
- No text to speech option
- Fairly simple to program and navigate
Scene&Heard ($50)
(for the iPhone and iPad)

- Users can import their own photographs to create scenes
- Users can then record stories and messages to go along with different parts of the picture
- Easy to use and navigate
- Great for customized communication needs
Severe Stages

Scene&Heard
Locabulary ($130)
(for the iPhone & iPad)

- Allows users to combine location and vocabulary to communicate
- Can use current GPS location to associate with a category
- NOT picture based
- Requires user to construct own sentences
- Can use pre-stored messages
- Can record own voice
Severe Stages

Locabulary

- Moods
- Assistance
- Restaurants
- My Categories

- My name is Megan.
- Let's go to the garden
- Can you drive me there?
- 2 eggs over easy please
- Can we listen to music?
- Goodbye
- Hello
- Yes
INTRODUCTION TO OUR PANEL

Helen & Mark Swartz

Doug & Casey Mackie

Ron & Sally Kinnamon
PRIMARY PROGRESSIVE APHASIA:

- I have a diagnosis of Primary Progressive Aphasia.
- My disease is caused by a shrinking of the lobes in my brain.
- It is a rare disease.
- The aphasia causes loss of language.
- I have difficulty with words, writing, reading and slowed speech.
- Right now, PPA can’t be cured and there are no drugs for PPA.
WORD CARDS:
- I have 90 difficult multisyllabic word cards.
- Identify difficult words
  CELEBRATE
- Divide into syllables & write phonetically
  CELL / ABRATE
- Underline the stressed syllable
  CELL / ABRATE
- Make a sentence using the word “WE WILL CELEBRATE FOR MY BIRTHDAY”
HELEN & MARK: WORD CARDS

- Write synonym for the word VERB-HONOR, PRAISE, BLESS
- Practice reading the word and sentence from the card
- Practice the word by tapping
- Make video with a helper and then practice with video
- The video helper says each word twice, leaving time to repeat
<table>
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<tr>
<td>CELEBRATE</td>
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</tr>
<tr>
<td>EQUIPMENT</td>
</tr>
<tr>
<td>E-QIP / MINT</td>
</tr>
<tr>
<td>I GO TO THE GYM AND USE THE EQUIPMENT.</td>
</tr>
<tr>
<td>NOUN - GEAR, SPORTS, TOOLS</td>
</tr>
<tr>
<td>INVITATION</td>
</tr>
<tr>
<td>IN / VA / TAYE / SHUN</td>
</tr>
<tr>
<td>WE GOT AN INVITATION FOR DINNER.</td>
</tr>
<tr>
<td>NOUN-REQUEST, COME-ON</td>
</tr>
<tr>
<td>POVERTY</td>
</tr>
<tr>
<td>PAW / VER / TEE</td>
</tr>
<tr>
<td>THERE ARE MANY FAMILIES WHO LIVE IN POVERTY.</td>
</tr>
<tr>
<td>NOUN-POOR, NEEDS, HARDSHIP</td>
</tr>
</tbody>
</table>
PICTURE CARDS:

- I have about 40 pictures and writings.
- Take pictures of daily life, social occasions, trips, events
- Write a few sentences about each one
- Talk with other people about the pictures
HELEN & MARK: PICTURE CARDS

Hawaii Trip - March 2014

Gluten-Free Expo March 2014
INTRODUCTION

DOUG & CASEY MACKIE
ABC SPELLER APP
BY TRANSCREATIVE SOFTWARE
DOUG & CASEY: LOCATOR APP

FIND MY FRIENDS APP
Haircut

This is Doug Mackie, I need a haircut - when can I get a hair cut - today or tomorrow.

Veggie

CALL A TAXI
This is Doug Mackie, I need a taxi to go to the Airport! I need to get to the Airport by 5 PM. At 0 HARA
ADDRESS
1192 SE Birtola Rd, Tequesta FL
33469 - 877-902-5946
1716 Highland Terr, Glenview IL
60025
Birkdale
This is Doug Mackie | on Birkdale
Pan - we have a guest letter
arriving at the front or
back gate.

SIR
What movies are playing in (GV) Jupiter
" are good Pizza's in (GV) Jupiter
" are there good restaurants in (GV) Jupiter
" are good groceries in (GV) Jupiter
" are good steaks in (GV) Jupiter
Find gas near
Show me football scores from Sunday
" " Saturday
Directions to Knollwood Club ??
DOUG & CASEY: PHONE NUMBER VISUAL AID

Jupiter Friends

Dave Toal  561 529 2304
George Reinaldi  561 741 7539
Dave Winters  561 743 0840
Jylr Lunston  561 741 3791
Jeff Harris  561 743 0683
Stan Eagle  561 575 3624
Herb Martin  561 214 3700
John Golen  561 746 3214
Charlie Grandi  561 886 8171
John Osmond  561 745 4440
Bruce Margulis  561 747 6003
John (Dr) Hurley  201 572 8133
Art (Dr) Johnson  561 746 3153
Frank Scamp  561 745 2938
Atilla Karadas General Mgr
Andrew Zaino Dir. of Food/Service
Marty Dyrtysh (Pres)
Difficult Words

Predicate

Scrutinize

Sophisticated

Flooring

Diff Words

Apocalypse

Elusive

Bequeathed

Skepticism

Tranquility
DOUG & CASEY: MULTISYLLABIC WORDS

FADING CUES HIERARCHY:

- FACE EACH OTHER
- DOUG WATCHES CASEY’S MOUTH
- SAY WORD SLOWLY IN CHORUS
- CASEY FADES VERBAL CUES AND MOUTHS THE WORD
- CASEY FADES OUT COMPLETELY
- DOUG SAYS THE WORD INDEPENDENTLY
INTRODUCTION

RON & SALLY KINNAMON
Ron & Sally: Communication Wallet

Drinks

- Decaf coffee
- Iced tea
- Diet Coke
- Martini—Hendrick's gin
  - "up" with blue cheese olives
- Gin and tonic
Dear Jack,

I understand you are coming to the Richardson YMCA 50th year celebration. I am really looking forward to seeing you. It has been a long time! It ought to be a great evening of stories and laughs about the fledging days of the Richardson YMCA.

It seems a good idea to let you know prior to that time that I have been diagnosed with PPA, a brain disease that affects primarily language. Though I understand everything and my intellect is intact, I often cannot express what I know I want to say. Some words are difficult to find, and some can make a jumbled sentence.

So, I didn't want you to feel awkward in our conversations, or to shy away from them.

Because I am HERE--can't wait to see you.

See you soon,

Ron
You already know I have Primary Progressive Aphasia. It is a rare neurological disease, that has robbed me of the skills and strengths I depended on. It is progressive (yes, it is getting worse); it means I have trouble with speaking, remembering names, writing, reading, telling time, etc. But you need to know my intellect is still intact, and so I look forward to our times together and learning all about the workings here. And I hope that in some small ways I can contribute.
Things I might be able to do: staple, stuff, clean up, collate, run some errands, and of course the ubiquitous ping pong, and maybe some other things you may think of.

I hope you won't feel awkward talking to me. But here are some things that might help our interactions:

- Speak slowly, giving me some time to "get it"
- If I am interrupted in mid-sentence, the thought will flee.
- Simple sentences, not complex ones are easier
- Processing what you are saying may take a minute or so, or may need repeating, but be patient, I will get there.
I will surely know who you are, and care about you, but your name will probably escape me--that is just the way it is with this disease.

Sometimes being in a group conversation is difficult. I know there will be some misunderstandings, but we can have some good laughs as we figure it out.

You are each doing wonderful things--I can't do them like I used to, but I would so like to partner with you in your efforts.
I am not going to hide.

I am not going to run away.

I will ---

help others

make a difference

I will not stop being ME!
References

- Kyrana Tsapkini, Constantine Frangakis, Yessenia Gomez, Cameron Davis & Argye E. Hillis (2014) Augmentation of spelling therapy with transcranial direct current stimulation in primary progressive aphasia: Preliminary results and challenges, Aphasiology, 28:8-9, 1112-1130,
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