



Halton-Peel Community
APHASIA PROGRAMS

Primary Progressive Aphasia

What is it?

What does the diagnosis mean?

360° Perspective

Client, clinician, and caregiver
thoughts and experiences

"I Am" Poems

Individuals from the PPA
community share who they are



Letter from the editors



"Perspective is everything when you are experiencing the challenges of life"

- Joni Eareckson Tada

For the past few years, Halton-Peel Community Aphasia Programs has worked closely with clients diagnosed with primary progressive aphasia (PPA). Receiving a new medical diagnosis can be frightening and overwhelming; your reality and perspective changes.

This magazine is to help guide you through your discovery of PPA. It captures a 360 degree perspective, offers information on resources, and includes recent research pertaining to this brain illness.

Whether you have been recently diagnosed, have been living with it for some time, or are a loved one, we hope you find this resource informative, helpful and enlightening.

We are sincerely grateful for our members, caregivers and community partners for their help and support in creating this resource.

We hope you enjoy!



Ola Kaczorowska

Communicative Disorders Assistant



Vanessa Rotundo

Communicative Disorders Assistant

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Appendix



How to use this document?

Using a document can be challenging. Here are some tips and tricks to make this magazine more accessible!



visual support

you can increase the size of the font by using the zoom in and zoom out feature



Zoom in

Zoom out



auditory support

if reading is challenging, try a text to speech program or app, where you can listen to the written text



Speechify

- Add [Google chrome extension](#)
- Download application



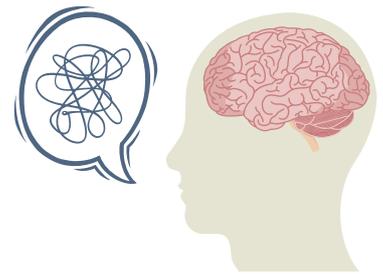
Primary Progressive Aphasia



What is Aphasia?

An acquired language disorder

- caused by **stroke, brain injury or brain disorder**
- masks a person's inherent **competence**
- difficulty getting **messages in and out**



Messages in



listening & understanding



reading

Messages out



talking



writing

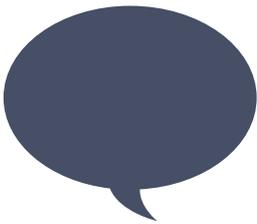
People with aphasia know what to say, but finding the words is difficult.

"I know you know"

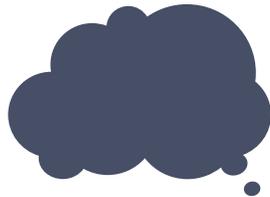


What is Primary Progressive Aphasia?

- Neurodegenerative brain condition
 - Type of dementia
- PPA can make it hard to:



Speak



Understand



Read



Write

Primary impairment primarily with language early on

Progressive gets worse over time

Aphasia language impairment

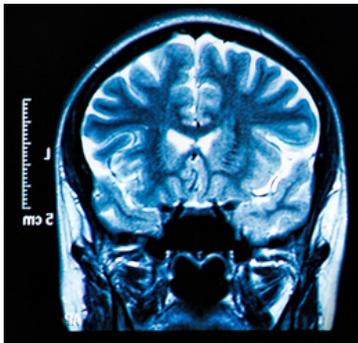
"Not being able to speak is not the same as not having anything to say."

- Rosemary Crossely



What is PPA - Continued -

- Symptoms may start **small** but will become worse over time
 - Primary symptom is **language processing**
 - Difficulty "finding the words"
 - Aphasia symptoms begin **before** cognitive decline



- Cause of PPA
 - buildup of proteins caused by
 - Alzheimer's Disease or
 - Frontotemporal Lobar Degeneration (FTLD)

- People with PPA may have **problems** with
 - finding the words
 - pronouncing or articulating words
 - understanding the meaning of words and concepts
- No two people are exactly the same

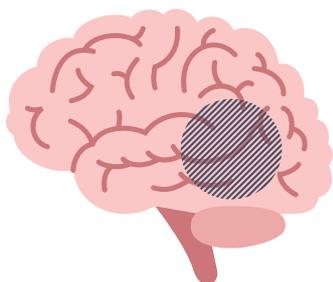


- Over time, individuals may also experience:
 - difficulty **swallowing**
 - movement deficits, lose **balance**, fall easily
 - **personality changes**
 - mutism



Types of PPA

Logopenic variant



Most common of all 3 variants

Produces difficulties with:

- word finding
- understanding long sentences

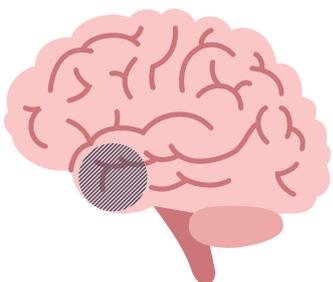
Non-fluent variant



Produces difficulties with:

- speaking fluently (there are pauses / hesitations in speech)
- saying sounds and syllables accurately

Semantic variant



Least common of all 3 variants

Produces difficulties with:

- finding and understanding words
- understanding the meaning of objects and living things
- difficulties recognizing faces of people (less common)

** More general things like “fish” are easier to understand versus “salmon” or mackerel”.

The concept behind the word is starting to disappear



A Life Participation Approach to

Understanding and Supporting People with PPA

Video presentation by Halton-Peel Community Aphasia Programs' team members:



Brittany Clark
Speech-Language Pathologist



Paula-Jane Bellizzi
Social Worker

The image shows a YouTube video player interface. At the top left is the YouTube logo. The video title is "A Life Participation Approach to Understanding and Supporting People with Aphasia and PPA". The video is from the channel "Halton-Peel Community Aphasia Programs" and was uploaded on May 5, 2022. There is a "Watch on YouTube" button and a play button icon. Below the video player, there is a link to watch the video online: <https://www.youtube.com/watch?v=J8ax7nlzISQ&t=1241s>.



360° perspective





Living with Primary Progressive Aphasia

Receiving a diagnosis is a life-changing experience.

What it was like receiving the diagnosis of PPA:

- making me very sad and very depressed at times
- do not want to upset my family or friends by making them have to work for me -- I want to be the helper, not being a burden to my family or friends. Sad that PPA can affect people so early in their lives
- it was a challenge to connect with other medical people that are VERY familiar / understanding / researching in PPA
- sad that there is not drugs/treatment to help stop or decrease the affect of PPA

What the journey with PPA has been like so far:

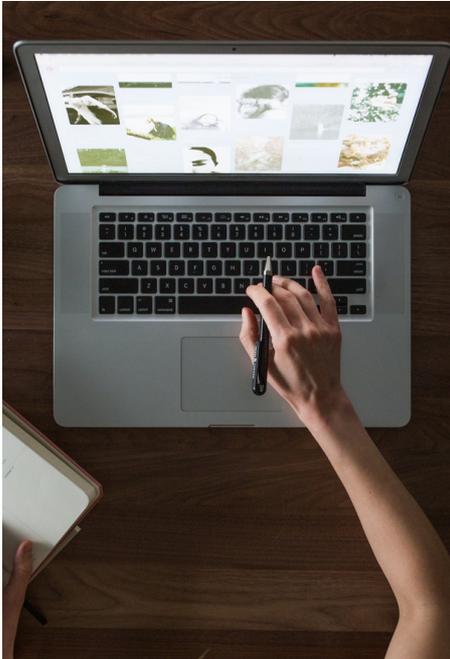
- 'slowly' losing the ability to speak, write
- allowing me time to prepare for my death
- every day exercising physically and mentally to try to remain as good as long as I can

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Living with Primary Progressive Aphasia

- Continued -

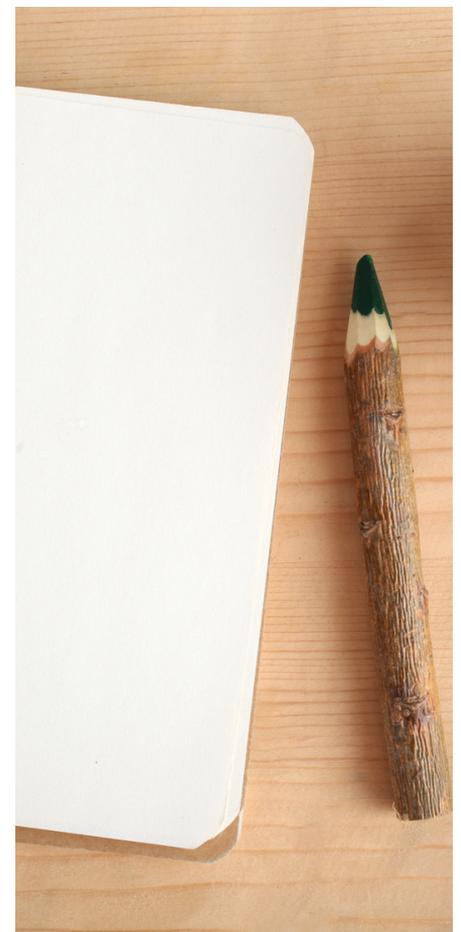


What the journey with PPA has been like so far (continued):

- researching regularly to try to find what might help me, and offering areas/researchers my involvement into research
- pleased that I was able to connect with H-PCAP in Burlington in 2018 and after starting there they grouped those with PPA to have a chance to meet one another and have sessions with one another

What has helped:

- I do think keeping a list of words that I have trouble remembering how to say or define and then practising every day with a couple of those pages I have (I do have many pages now) - does help me to remember the definition or how to say it
- using the transcranial direct current stimulator every day ([Dr. Jed Meltzer at Baycrest Hospital, Rotman Research Institute, Baycare Center](#)) got for me (using it since Sept 2018) to help stimulate the brain. It is under research for it's usefulness
- using the laptop or iPad to write down words to get help with spelling, pronouncing





Being Diagnosed with Primary Progressive Aphasia



What was it like receiving the PPA Diagnosis?

My name is Elaine, I am 78 years old. My husband George and I have been married for 54 years and we have three children and six grand children. I was a Registered Nurse for 31 years, retiring from my last position as Assistant Director of Care at a not for profit long term seniors care facility. About five years ago my family expressed concern about a hesitation in my speech and worried that I may have suffered a mini stroke. My youngest daughter took me to the emergency department at Oakville Hospital. After hours of extensive tests and scans, the neurologist gave me the diagnosis of Primary Progressive Aphasia.

I had never heard of PPA and I looked it up to find out more. I learned that it is a form of dementia. This hurt me because I was used to dealing in my career with alzheimer's patients in long term care and I knew what the diagnosis meant for me. It was not painful and disfiguring but it slowly progresses. Since the diagnosis I try to keep my spirits up for the sake of my mental health and for my family.



Being Diagnosed with PPA - Continued -

I find PPA frustrating. In my mind I know what I want to say, I understand everything happening around me. I used to be a social person, never afraid to strike up a conversation with a stranger in line at the grocery store but I have stepped away from social interactions with strangers. I cannot drive myself anymore, carry on a conversation over the phone, read out loud, sing, or speak sentences that are more than a few words. I feel most relaxed when in the company of my immediate family and friends who know about my diagnosis.

The most difficult thing about having PPA is slowly losing my ability to talk and having to rely on my family for everything.

My greatest fear is having to move into a long term care facility for the remainder of my life and having no independence.

My husband George, my family, the speech pathologist and participating in online programming like book club have helped me.





"I am" poem

When diagnosed with a health condition, it can sometimes consume you and become a part of your identity. It's sometimes hard to remember who you were before your diagnosis.

It's important to remember and tell yourself that:

"I'm still me"

Our members capture this beautifully with their "I am" poems.





I am...

01



I am a mother and a Baba
 I wonder and hope everything will be alright for my grandchildren
 I want to get better
 I feel grateful for my husband's support
 I try to be happy
 I am a mother and a Baba

02



I am a good housekeeper and a great grandmother
 I wonder about PPA and how to fix it
 I want to be independent
 I feel happy
 I try to be happy
 I am a good housekeeper and a great grandmother

04



I am a wife and a nurse
 I wonder if my husband will always be willing to help me out
 I want to be independent and not be a problem for others
 I feel content
 I try to think of others
 I am a wife and a nurse

05



I am a dreamer and a grandfather
 I wonder about the future of my grandchildren
 I want to be independent
 I feel knowing (engineering)
 I try to do engineering
 I am a dreamer and a grandfather



I am...

06



I am a grandmother of 5 and a gardener
I wonder about the future of my grandchildren
I want to be as independent as I can
I feel grateful for my two families that help me and are always there for me
I try to learn new things on my iPad
I am a grandmother of 5 and a gardener

07



I am a daughter and a healthcare giver
I wonder about what research and treatment will be available for PPA
I want to not be a burden to anybody
I feel fortunate and unfortunate
I try to do the best I can, for as long as I can
I am a daughter and a healthcare giver

08



I am a grandmother and a great grandmother
I wonder if there will be a cure one day
I want to go hiking
I feel sad and a bit overwhelmed
I try to not be lonely
I am a grandmother and a great grandmother



Helping your loved one

After a lengthy assessment with a neurologist, my sweet mom was diagnosed with PPA in the fall of 2019. In addition to the many communication challenges evident at that time, mom was also experiencing other PPA symptoms including depression, and fine motor loss.

At first, mom's diagnosis was somewhat of a relief, as it enabled our family to understand the notable changes that mom was experiencing. However, it did not take long for a deep sadness to sink in. Questions started to surface.

- What is this?
- Why mom?
- How will mom manage?
- How fast will PPA progress?
- Will mom have pain?
- What help/support/direction can we get?
- How can we promote awareness of PPA?



By way of the internet, "The Aphasia Support Group" and mom's neurologist, many of my questions were answered. Shortly thereafter, I recognized my new role as one of mom's primary care givers.

As our new "mother and daughter" roles progress, I continue to cherish every day we have together. At times, it is not always easy. It saddens me to think about how difficult and frustrating this challenge must be for mom. As well, I often struggle when I think about the progression of mom's disease and what will entail. It is difficult to see mom change and realize I am losing the mom I know so well.

However, I also know, that I desperately want to continue to stay close beside the person she has become and help her live the best life she can.



Helping your loved one - Continued -

Some ways we like to help are:

- Monitoring ongoing safety concerns
- Assisting with lifestyle changes and support as needed
- Monitoring and supporting health issues
- Encouraging and providing frequent social visits to prevent isolation and loneliness
- Playing word games
- Assisting with virtual support calls
- Dancing
- Laughing
- Sharing feelings
- Developing communication booklet
- Organizing various exercising programs
- Arranging friendly visitor program and other external support groups
- Assisting with home, personal and business care as needed
- Creating awareness of PPA
- Most of all....LOVE



Today, almost 3 years after her diagnosis, mom continues to live on her own with assistance. Although there have been signs of disease progression, mom continues to remain cognizant, works hard to engage in conversations, loves to spend time with her family, loves to watch TV, is motivated to keep moving and maintain as much independence as she can.

She is an amazing mom!



Learning about PPA

Growing up I would have described my Mom as an eloquent speaker, extremely intelligent, driven, compassionate and highly organised. She read books like others eat candy, would speed knit while watching TV, always cooked amazing meals and could make anything green grow with her touch. She worked full time while practically raising three kids alone due to my Dad's work commitments. Despite her hectic schedule my Mom always had time to help us with our homework, drive us to and from where we needed to be, read to us and advocate for us when we needed her to. Friends, neighbours, family also relied on my Mom for her sound advise and words of wisdom. It wasn't until I had a family of my own that I truly understood the personal sacrifices she made for all of us and what an amazing woman she is.

After my Mother was diagnosed, I did some research about PPA and it broke my heart to learn that essentially there was nothing that could be done to improve her condition. I learned that her voice and ability to communicate with us would gradually slip away. The hardest thing for me is knowing that she knows EXACTLY what we mean and say but she just can't respond and more often than not of late we can't understand what she is trying to tell us. My parents have had the same phone number for as long as I can remember. There are times when I miss hearing my Mom's voice and will call their phone when I know nobody will answer just to hear her voice on the answering machine.

My parents, husband Eric, I and my kids recently moved in together and are awaiting the completion of a newly built bungalow which will have all the amenities my Mom needs. I don't think that had my Mom not been diagnosed with PPA we would have ever considered moving in together. Although it has been very hard to watch my Mom go through this I would not give back the time I have gotten to spend with my Mom and watch her with my kids. My Mom has an amazing smile and has kept her sense of humour. Her laughter and positive presence is what gets us all through this.



"Although it has been very hard to watch my Mom go through this I would not give back the time I have gotten to spend with my Mom and watch her with my kids."



Neurologist's Perspective

Dr. Carmela Tartaglia



Speech and language are the basis of all our interactions. What if you woke up one day unable to say: "I want," "I need," "I love," or maybe no longer able to understand those words. It seems unfathomable and yet thousands of people can't express themselves because they can't say or remember the words, and others worse yet, no longer understand them. It's frustrating for the patients and sometimes even more difficult for those around them.

In dementia, the focus is on memory loss, but language impairments are the main symptoms in many neurodegenerative diseases. Primary Progressive Aphasia (PPA) is a family of three neurodegenerative diseases (a brain disease that affect cells in the brain) where language problems are the prominent feature. Over time, however, these patients develop other problems that include memory deficits as well as motor impairments in some cases.

Speech and language problems are not always easy to detect as we all communicate differently and much can be said through nonverbal cues. In thinking about language impairments, one needs to recognize that there is something wrong with a person's speech or comprehension. This can be especially difficult when it concerns a loved one since, when you know someone well, you automatically fill in any gaps or overestimate how much they have understood.

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In my clinic I often encounter caregivers or family members that haven't really grasped the extent of the language problem in the patients and are stunned when the person cannot answer basic questions I ask them. The following are basic clues that may alert you to impaired speech and/or language, and the person should seek medical attention as there may be a primary language disorder:

- Speaking less.
- More hesitant in their speech.
- Stops partway through sentences.
- Uses incorrect words.
- Frequently uses “thing” or “stuff” instead of the correct word.
- Often asks you to repeat yourself but their hearing has been checked and is fine.
- Asks you what something means when they obviously should know such as “what is salmon,” “what is weather”.

The 3 PPAs are quite different, two of them, nonfluent variant PPA and logopenic variant PPA affect expression of language while semantic variant PPA affects language comprehension. These diseases are much less well-known than Alzheimer's or Parkinson's disease and so often are diagnosed very late or misdiagnosed. The cause of these illnesses is the destruction of brain cells, in logopenic variant, the cause is Alzheimer's Disease pathology while nonfluent variant and semantic variant are caused by frontotemporal lobar degeneration, a different type of neurodegenerative disease.

The inability to communicate leads to frustration, distress and caregiver burnout with the final result of inability to care for the patient at home. With few programs for people with language problems not due to stroke, many such patients and their families are left without resources. Communication is essential for quality of life for both patients and their caregivers. Every effort must be taken to preserve communication for as long as possible.



Dr. Carmela Tartaglia
Neurologist



Our laboratory at Baycrest Hospital in Toronto studies language processing in healthy volunteers, as well as rehabilitation of language disorders caused by brain damage. We study stroke-induced aphasia as well as primary progressive aphasia. Although these two disorders have different causes, they do have much in common in that both involve some brain tissue being destroyed by the disease, but also some tissue that is affected by the disease but not destroyed. We examine changes in the electrical activity of this “at-risk” brain tissue and develop techniques to improve its function using interventions like noninvasive electrical stimulation, in which a small amount of electrical current is applied to the brain to make it more active. We have found that people with stroke and PPA both show similar abnormalities in their brain’s electrical activity [1-3](#), and that stimulation can make the activity more look normal while improving language function as well. [4,5](#)

Our lab works on both brain stimulation and purely behavioural interventions, and we have been working towards making both of these things available to people in their own home. [6](#) During the pandemic we focused a lot on the behavioural work, and conducted a study involving online treatment software that aims to maximize the efficiency of automated picture naming drills through adapting to users’ performance. [7](#) A new project that we are beginning looks at the benefits of training that emphasizes response speed instead of just accuracy. Overall we find that therapeutic techniques, both behavioural and biological, have similar effectiveness in both post-stroke and progressive aphasias. However, PPA patients do have unique needs as a population with a rare, incurable, and progressive disease. Therapy focused on the language impairment is helpful, but more holistic support groups addressing multiple aspects of life with the disease can have a greater impact. [8](#)

Anyone interested in volunteering for research can email us at toronto.language.studies@gmail.com

Social Worker's Perspective - In the Hospital



My name is Maria Martinez. I am a Social Worker at the University Health Network (UHN) Memory Clinic since 2007. I feel very lucky to be working with an interprofessional team in our outpatient setting. The UHN Memory Clinic is comprised of different health care professionals (behavioural neurologists, geriatricians, geriatric psychiatrists, a nurse and an occupational therapist). This Clinic provides assessments, diagnosis of cognitive changes, symptom management and support for people who have been diagnosed with a dementia, including Primary Progressive Aphasia (PPA). Biomarker testing and clinical trials are also offered, if indicated.

My experience working with people who have been diagnosed with PPA has been a very positive one, mostly due to patients and families who are often relieved to be offered a diagnosis, which would include the specific type of PPA. As a Social Worker, I provide education and support to the patients and their families following a diagnosis and at any point during the illness trajectory.

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In the hospital - Continued -

Working with people who have PPA can also be very challenging. At the UHN Memory Clinic, we often follow our patients over many years. During this time, it can be difficult to witness the patients' declining language capacities and progressive cognitive impairment which may include changes to their behaviour and personality. It can be difficult to see our patients continue to lose their ability to read and write, speak and/or comprehend what they hear. People living with PPA and their families would greatly benefit from learning effective communication strategies as well from ongoing education, counselling and linkages to available resources in their community, such as support groups and educational workshops.

One of the challenges I face as a Social Worker working with people with PPA is the ability to find appropriate resources for speech therapy. Unfortunately, our Clinic does not have a Speech Language-Pathologist and so we rely greatly on external resources. As PPA is a neurodegenerative condition, language abilities will change over time but speech therapy can often teach people with PPA to learn new communication strategies. There are several Aphasia Programs in Ontario that offer specific programming for people with PPA. The feedback that I have received from people and their families who participate in these programs has been extremely positive. They feel well supported and encouraged to continue using their conversational skills. They also enjoy the ability to socialize, even during these difficult times living with COVID. Living with COVID and living with PPA can be very isolating so providing support to the person with PPA and their families is of the utmost importance. I have learned very much about PPA from the team that I work with as well as from our patients and their families. They have reinforced the need to be patient and empathic in our work together in order to enhance quality-of-life for those living with PPA.

To learn more about the referral process, please click the image





Support and Counselling



As the Social Worker for the H-PCAP, I provide one-on-one support and counselling to individuals with PPA and their families. I also facilitate a monthly PPA Support Group (with the support of our amazing volunteer). In working with people with PPA my clinical focus is to address the psychosocial aspects of living with PPA which includes looking at the person in their environment.

My goal is to:

- Educate individuals and family members about PPA
- Support people in coping with the diagnosis
- Provide opportunities to connect with others with PPA
- Support communication between individuals with PPA and others
- Improve quality of life for people with PPA
- Help people with PPA reveal their competence and abilities to others
- Promote involvement in rewarding social activities
- Share information about other programs and research studies





Social Worker Perspective

- Continued -

The research indicates that “it is important to support existing relationships and encourage continued participation in social groups, community activities, religious activities and hobbies” [1](#) as this is crucial in helping persons with PPA preserve their identity (beyond the diagnosis). It also reduces the risk of isolation and improves quality of life for persons with PPA.

For this reason, I encourage individuals to engage in activities (including non-verbally demanding activities such as exercise, and music therapy) and to connect with other people.

Through our Peer 1:1 Support Program, I match individuals with PPA with another group member with PPA, for weekly conversation. This is in the form of weekly phone calls or meetings on Zoom or in person (when permitted). This provides individuals with the opportunity to practice their speech, and also to connect with someone else who understands the challenges, and to support each other.

What stands out for me in working with people with PPA, is the importance of an individualized approach, understanding that PPA, like other forms of aphasia, affects every one differently. As a result, the type of support and amount of support needed, depends on the individual and their own strengths, and the amount of informal and formal support they are currently receiving. I meet the client/person where they're at in their journey and follow their lead in terms of supporting them.

In working with individuals with PPA I have had the privilege of supporting people from all different backgrounds and to get to know them beyond their diagnosis.

What I am most impressed by is their strength and resilience. Even though it may be difficult for them to say what they want, they all have a voice and many interesting stories and life experiences to share. I see each of them working hard every day to maintain their ability to communicate and to live their best lives.



Speech, Language, and PPA

Speech-language pathologists, or SLPs, are registered health professionals who have expertise in the assessment, treatment, and management of speech, language, communication and swallowing disorders. They help to improve, maintain and support communications skills and swallow function in individuals with Primary Progressive Aphasia.

Often, one of the first ways a Speech-Language Pathologist supports individuals with PPA, is by educating the client and family about how Primary Progressive Aphasia can affect speaking, understanding, reading, writing and swallowing, and what support is available.

An SLP will conduct assessment using a variety of tools (which might include a personal interview, observation, administering standardized and non-standardized tests) in order to evaluate the person's speech and language skills, functional needs, and determine their areas of strength and weakness. This information will help to identify treatment goals and ensure that those goals are meaningful, functional, and support a person's quality of life.



- Continued -

Given the progressive nature of PPA, planning for the future early on in treatment is essential. With PPA, treatment takes on a more phased approach, where the SLP monitors the person's communication needs, re-assesses skills when needs change, and modifies treatment goals over time. Treatment will look different depending on the stage of PPA that a person is in. In the earlier stages of PPA, treatment might focus on vocabulary, where a person practices naming, describing, reading and writing words that are meaningful to them to help learn strategies for finding words.

In the middle to late stages of PPA, treatment might include training effective compensatory strategies or creating a personalized communication aid to help support communication when barriers and breakdowns occur. Augmentative and Alternative Communication, or AAC, is used when a person cannot consistently rely on their speech to communicate. AAC systems include low-tech supports, such as using paper and a pen to communicate, to high-tech supports, such as using an electronic device that speaks programmed sentences.





- Continued -

Sometimes, over time, people who have Primary Progressive Aphasia may experience difficulty swallowing. This is called dysphagia. A person may have difficulty chewing food or they may start to have coughing or choking episodes when they swallow food or liquid. SLPs are trained to assess swallow function and improve swallowing safety by making various recommendations, including diet texture changes and safe swallowing strategies.

Communication Partner Training is another important component in therapy. Communication happens between two people, and it is vital that communication partners (including caregivers, family members and friends), learn how to support conversation by communicating effectively with the person who has PPA. Examples of strategies include acknowledging communication difficulties, using a slightly slower rate of speech, simplifying speech, writing keywords, using picture supports, and verifying that a message has been understood. Learning how to effectively communicate with a person who has Primary Progressive Aphasia increases their opportunities to participate both in conversation and in life and decreases their feelings of loneliness.

As two speech-language pathologists who work directly with those affected by Primary Progressive Aphasia, we feel privileged to be part of their care team by supporting them in accessing communication and safe swallowing, and being continuous advocates for them along their journey with PPA.



Brittany Clark
Speech-Language Pathologist



Julie Curran
Speech-Language Pathologist



PPA Treatment Options

Primary Progressive Aphasia (PPA) is a degenerative disease and while there are currently limited medical treatments to stop or slow the degeneration process, there are non-pharmacological interventions that may offer a significant benefit and increase the quality of life for people living with PPA.

While we cannot stop the degeneration of PPA, we can help create systems to maintain independence and socialization. Behavioural gerontology is focused on examining the interaction of the biological variables associated with aging, especially with degenerative diseases like PPA, with the environmental variables available to us. In general, we use this approach for many age-related changes, for example, if you are having difficulty seeing far away (age-related deterioration) we introduce glasses (environmental manipulation) or perhaps you are forgetting to take your medication (age-related deterioration), so you begin using a pill planner (environmental manipulation). For people with PPA, we are often examining factors that may facilitate or hinder their desire and ability to participate in their everyday life. For example, crowded and noisy environments can be very challenging for people with PPA. While one's inclination may be to stop going out to restaurants with friends and family, a simple environmental modification that enables the individual to still participate in this type of enjoyable activity is to ask for a table that is near the edge rather than in the middle of the dining room or choosing times when the restaurant is less busy to go out.

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These are simple strategy that enable the person with PPA to engage in enjoyable activities while still honouring that PPA can make communication challenging. Behavioural gerontology is focused on ways that we can change the environment to better suit the individual's needs and offers strategies to support individuals as they are aging to maintain their sense of self. Increased engagement in life is associated with not only a longer life expectancy, but it can slow the rate of progressive symptoms and increase one's quality of life.

The primary impairment for those with PPA is often related to language and communication, and yet recent evidence suggests that these patients are not being informed that there are therapy options available to them. This is likely due to misinformation that therapy is not appropriate because of the progressive nature of the disease. Therapy for PPA should include a focus on enhancing quality of life, maintaining daily life skills, implementing memory and language programs, preserving one's social connections and prolonging independence. Overall, the main goal of therapy is to help the person with PPA and their family develop strategies to maximize their communication skills and slow down the degenerative process of the disease, not to regain lost language abilities.



Shawna Fleming
Board Certified Behavioural Analyst
Evergreen Communication Therapy



Resources



H-PCAP Support Groups



Monthly PPA Support Group

Some of the topics covered in our monthly PPA Support Group include:

- Understanding PPA
- Family & Social Supports
- Tips for talking to others
- Dealing with depression
- Mindfulness activities
- Guest speakers
- Community Programs and Services



Monthly Caregiver Support Group

Some of the topics covered in our monthly Caregiver Support Group include:

- Grief and Loss
- Caregiver burden
- Coping with stress
- Mindfulness activities
- Guest speakers
- & more

We also offer a weekly PPA Conversation Group!

Contact us or visit our website to complete your referral.

For more information, contact:



Paula-Jane Bellizzi
Social Worker
paula-jane@evergreen-therapy.ca



Supportive Conversation Strategies

Supported Conversation for adults with aphasia (SCA™) was developed by the [Aphasia Institute](#). Using these strategies helps build a communication ramp for those with language disorders.

Encouraging conversation helps the help people with aphasia get their message in and get their message out in a valued manner.

Everyone with aphasia is unique. It's important to find the strategies that work best for each person with aphasia. When a communication breakdown occurs, start by using gestures then add more techniques as needed.

Techniques to help “Get the Message In”:

- Use short, simple sentences
- Use a slightly slower rate of speech
- Expressive tone of voice
- Use meaningful gestures and facial expressions
- Repeat or re-phrase
 - E.g., “Are you retired? – pause – “Are you no longer working?”
- Write down key words
 - Use black markers and print neatly, do not use cursive or CAPITAL letters
- Draw pictures or search for images on a device
- Point to objects, pictures, or other communication aids
 - Such as calendars, communication books, iPads

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Supportive Conversation - Continued -

Techniques to help “Get the Message Out”:

- Ask one question at a time
- Ask yes/no questions
- Offer choices (include “other” as an option)
 - E.g., “Do you want coffee, tea or something else?”
- Write down key words for the person to choose by pointing
- Encourage best mode of responding – speaking, writing, gesturing, pointing, drawing, etc.
- WAIT. Give the person time to respond.

Verify:

- Repeat back what you understood
- Ask yes/no questions
 - E.g., “This is what I heard.... Is that what you meant?”
- Ask for a clue if there is something that you don’t understand
 - E.g., “Can you draw it for me?” “Can you show me?”
- Expand on incomplete messages
- Summarize the main idea of their message when appropriate
- Don’t forget to also verify the person with aphasia has understood your message
- If needed, verify comprehension in 2 ways (e.g., spoken words with written key words)

Interested in learning more?

Caregivers, family, friends, community partners, and healthcare professionals are invited to attend our free virtual training session. Facilitated by Speech-Language Pathologist and Communicative Disorders Assistant.

Email info@h-pcap.com to register for an upcoming training session.



Rare Dementia Support (RDS) Canada is a support service for Canadians affected by rare or young onset dementia, including primary progressive aphasia (PPA). The service is led by Nipissing University and funded through a generous donation from The Hilary and Galen Weston Foundation. RDS Canada provides:

- Tailored information and learning resources for people living with rare or young onset dementia, family and friends, and professionals.
- Individual, family and group support.
- Canada-wide services provided by a team of practitioner specialists, researchers, educators and individuals with lived experience.
- Learning through research to address the support needs of people affected by rare and young onset dementia.

RDS Canada provides support in partnership with Rare Dementia Support UK, a world-leading service provided by University College London Dementia Research Centre and funded by the National Brain Appeal in the UK.

At RDS Canada we understand that dementia is a cluster of various disease and can impact more than memory. Rare and young onset dementia, like PPA, brings a unique set of complex challenges based on atypical symptoms, a person's age and role in life at the time of diagnosis. RDS Canada offers support and an opportunity to take part in a virtual community with other people affected by PPA and other rare and young onset dementia.



To access information RDS Canada offers a no fee membership. Anyone affected by rare or young onset dementia, as well as professionals and researchers are welcome to become a member. Once registered you will be contacted by a staff member and offered a connection for individual to group support. [Click here to register](#) for a membership.

New Virtual Support Groups:

- Words Together: A support group for Canadians diagnosed with PPA, and other rare dementias, who are in early stage. This group is an opportunity to connect with others with shared experiences and enhance post diagnostic support plans.
- The Road Less Travelled: Our journey with grief and loss: A program for families and friends of people living with PPA and other rare dementias.
- Family and Friends: This open support group is for anyone who is a family member or friend to a person living with PPA and other rare forms of dementia.

Learning Opportunities:

- Web-based educational program for family members caring for someone with PPA. Contact [Adetola Grillo](#)
- Knowledge Exchange Seminars

Contact us to find out our current offerings.

Prepared by:

Jen Gordon MSW, RSW
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Follow: Instagram or Twitter @RDSCanada

Memory Clinic

University Health Network



Click on image to access referral form



[Memory Clinic Referral Form - University Health Network](#)

399 Bathurst St., 5WW Toronto, ON. M5T 2S8

Phone: 416-603-5232

Fax: 416-603-6402

A referral is required to be seen at the UHN Memory Clinic. The referral needs to be completed by a physician and available information needs to be sent with the referral. This may include lab work (blood work results) and diagnostic tests such as brain imaging. There are exclusion criteria as well.

Patients with the following conditions, will not be accepted:

- Under 55 without a family history of early onset dementia, a language disorder or a marked change in personality/behaviour
- Developmental disorders/delay
- Major traumatic brain injuries
- Active history of alcohol and/or substance dependence or abuse
- Active psychiatric illness
- Has already been diagnosed with a dementia disorder

Once the referral is received, it is triaged by one of the behavioural neurologists. If the referral is appropriate and complete, it will get assigned to one of three neurologists or the geriatrician. It may also be forwarded to geriatric psychiatry if the referral is more appropriate for them to complete the assessment.

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UHN Referral Process - Continued -



In person, then the neurologists will also complete a neurological assessment and examine their gait. For cognitive testing, many health care providers in the clinic may administer paper and pencil tests. The physicians, residents, RN, social worker and research student are all administering these tests.

For screening and to track change over time, we administer the MOCA (Montreal Cognitive Assessment). There are different versions and it is also available in different languages. We will use interpreters when needed. For initial assessments, we use the TORCA (Toronto Cognitive Assessment) as it is more comprehensive than a MOCA. Both tools contain different components that assess different brain functions:

- Short-term memory
- Visuospatial abilities
- Executive functions
- Attention, concentration, and working memory
- Language
- Orientation to time and place

Prepared by: Maria Martinez
Social Worker





Augmentative and Alternative Communication (AAC) & PPA

Communication is the essence of who we are. Augmentative and Alternative Communication (AAC) refers to communication tools that add to or replaces a person's speech. AAC offers strategies to help someone with PPA be a more effective communicator and maintain their social self for as long as possible. We use different forms of AAC all the time, gesturing thumbs up to tell someone 'good job' or using facial expressions to tell someone you're angry, or perhaps you send text messages or emails. These are all forms of AAC - AAC is any form of communication that doesn't involve speaking.

One of the primary symptoms of PPA is the gradual onset of word finding difficulties, object naming and comprehension. AAC provides a set of tools and techniques that the individual with PPA and their family and friends can use to facilitate communication. Early in the PPA journey, someone may be focused on improving or maintaining word finding skills or decreasing the use of filler words, like uhs and ahs. There may also be a focus on learning alternative strategies that can be used when word finding difficulties occur like writing or gesturing the word or using a communication book. Also during this time, communication partners can learn strategies to support communication and how to best support their partner.





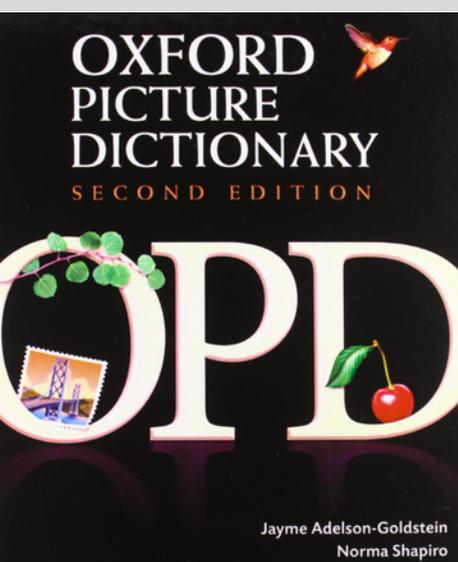
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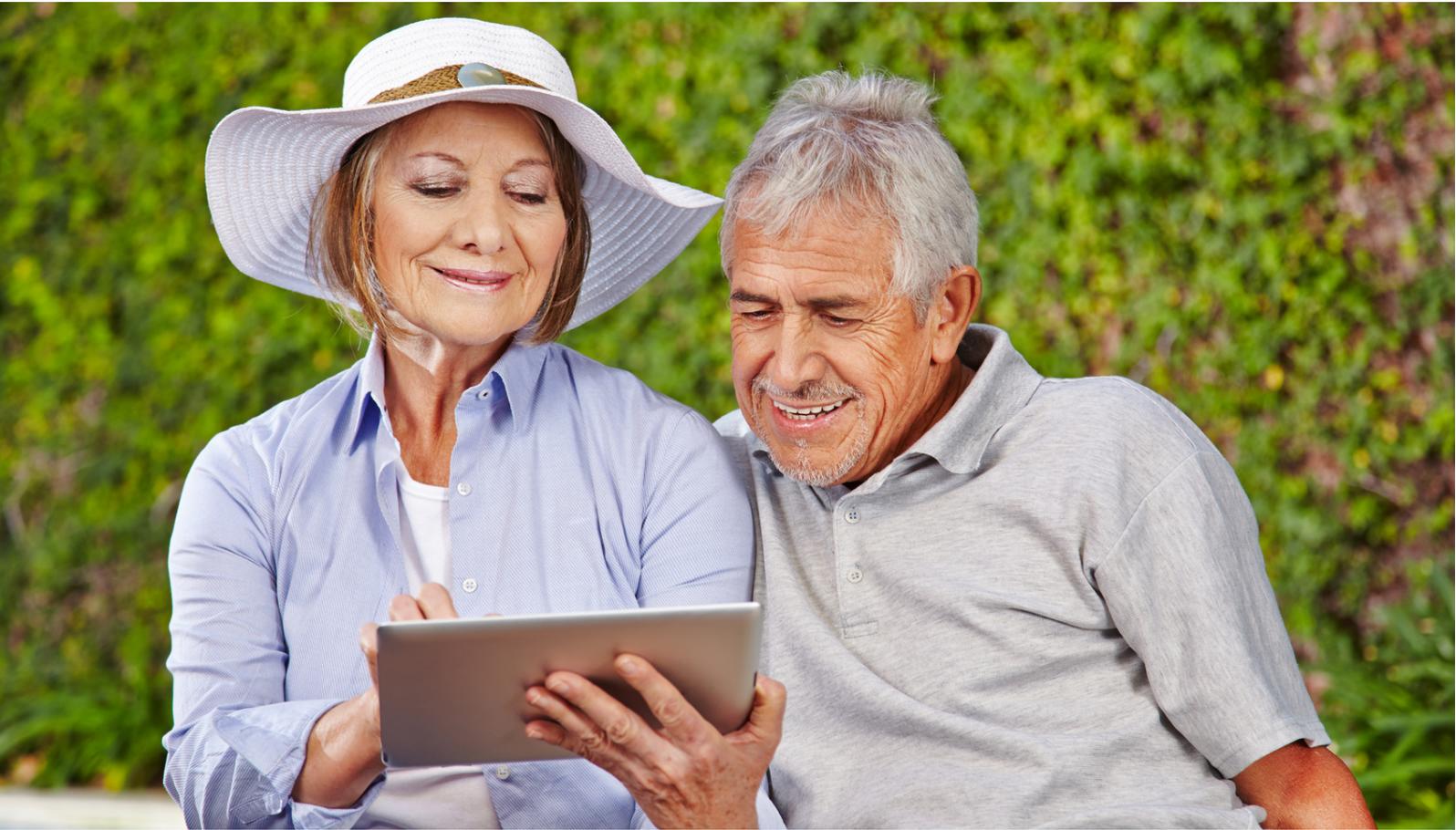
A multi-modality communication approach is often recommended for individuals with PPA. A multi-modal approach allows the person to get their message out using vocal speech but also using gestures, facial expressions, writing and/or a communication book or device. As the person's ability to communicate vocally decline, due to the progressive nature of the disease, they may rely on these alternative strategies more and more. It is important to practice using these tools early on, so that they are reliable as the disease progresses.



Many people are familiar with many modes of AAC including the use of gestures, facial expressions and writing. Often, people are less familiar with low- and high-tech options that can support communication. For low-tech options, you may create a customized communication book. Communication books can be a great way to support communication - each page in the book is customized to the individual and should focus on words that are important to that person. You may include a map of the world, to talk about travels or an alphabet board so that the person can point to the first letter of a word they've forgotten. A calendar and family tree are useful components. AAC should and can be used in combination with speech to support conversation and help people with PPA to maintain their social self.



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For high-tech options, there apps or features that can be added to a smart phone or tablet to facilitate communication. Text-to-speech is a feature that can be turned on, on many smartphones or tablets, that enables the person to type out a message and then the device will ‘say’ the message out loud for others to hear. Another option is installing an app on your smartphone or tablet that is meant to be used to communicate, such as Linggo or TouchTalk. A speech-language pathologist can help individuals and their families to develop strategies and tools to help the person with PPA get their message out and get messages in.



Shawna Fleming
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Evergreen Communication Therapy

Additional Community Resources

The Association for Frontotemporal Degeneration

Information and Support for people living with FTD as well as caregivers



www.theaftd.org



info@theaftd.org



1-866-507-7222



The Alzheimer's Society of Canada

- Support and counselling; wellness programs; education programs
- Young onset support group may be appropriate
- No Doctor referral needed



1-888-343-1017 - to talk to intake worker



www.alzhn.ca (Burlington, Hamilton, Niagara)



www.alzheimer.ca (national office)

National Aphasia Association

Information and support for people living with different types of aphasia including PPA



<https://www.aphasia.org>



Aphasia Institute

A range of programs for people living with PPA and their families

 (416) 226-3636

 aphasia@aphasia.ca

 <https://www.aphasia.ca>



The Mesulam Centre for Cognitive Neurology & Alzheimer's Disease (Northwestern University)

- Offer monthly support groups for family members and care partners of people living with dementia. During the pandemic, we are offering these groups through Zoom
- Offer three support groups based on diagnosis or age of onset: Primary Progressive Aphasia (PPA), Frontotemporal Dementia (FTD), and Younger-Onset Dementia
- New care partners are always welcome to join the group. There is no fee to participate

For Care Partners of Individuals Living with PPA

This monthly support group is for family members and care partners of people living with primary progressive aphasia (PPA), and is held on the first Monday of each month from 4:30 - 6 p.m. (CT)

If you have not been to the group before and would like to join, please contact Darby for a brief telephone screening:

 Darby Morhardt, PhD, LCSW

 d-morhardt@northwestern.edu

 312-908-9432

Clinical

Research



Clinical, Anatomical, and Pathological Features in the Three Variants of Primary Progressive Aphasia: A Review

Maxime Montembeault, Simona M. Brambati,
Maria Luisa Gorno-Tempini and Raffaella Migliaccio

Abstract

Primary progressive aphasia (PPA) are neurodegenerative diseases clinically characterized by an early and relatively isolated language impairment. Three main clinical variants, namely the nonfluent/agrammatic variant (nfvPPA), the semantic variant (svPPA), and the logopenic variant (lvPPA) have been described, each with specific linguistic/cognitive deficits, corresponding anatomical and most probable pathological features. Since the discovery and the development of diagnostic criteria for the PPA variants by the experts in the field, significant progress has been made in the understanding of these diseases. This review aims to provide an overview of the literature on each of the PPA variant in terms of their clinical, anatomical and pathological features, with a specific focus on recent findings. In terms of clinical advancements, recent studies have allowed a better characterization and differentiation of PPA patients based on both their linguistic and non-linguistic profiles. In terms of neuroimaging, techniques such as diffusion imaging and resting-state fMRI have allowed a deeper understanding of the impact of PPA on structural and functional connectivity alterations beyond the well-defined pattern of regional gray matter atrophy. Finally, in terms of pathology, despite significant advances, clinico-pathological correspondence in PPA remains far from absolute. Nonetheless, the improved characterization of PPA has the potential to have a positive impact on the management of patients. Improved reliability of diagnoses and the development of reliable in vivo biomarkers for underlying neuropathology will also be increasingly important in the future as trials for etiology-specific treatments become available.

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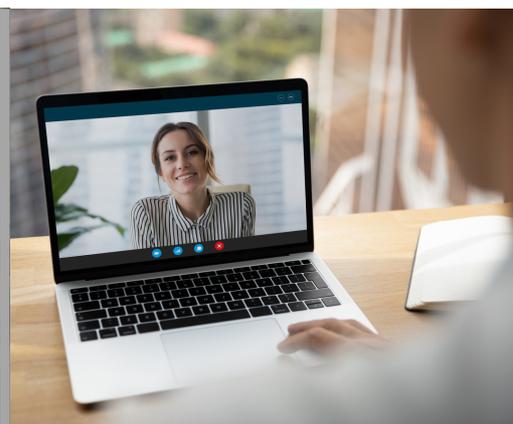
Investigating the utility of teletherapy in individuals with primary progressive aphasia

Heather R Dial, Holly A Hinshelwood, Stephanie M Grasso, H Isabel Hubbard,
Maria-Luisa Gorno-Tempini and Maya L Henry

Abstract

Primary progressive aphasia (PPA) is a neurodegenerative disorder characterized by progressive deterioration of speech and language. A growing body of research supports the utility of speech and language intervention in individuals with PPA, although access to these services remains limited. One potential means of increasing treatment accessibility is the delivery of treatment via telemedicine. Evidence supports the use of teletherapy in stroke-induced aphasia, but research examining the application of teletherapy in PPA is limited. In the current study, a non-randomized group comparison design was used to evaluate the feasibility and utility of treatment delivered via teletherapy relative to treatment administered in person for individuals with PPA.

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A Systematic Review of Transcranial Direct Current Stimulation in Primary Progressive Aphasia: Methodological Considerations

Silke Coemans, Esi Struys, Dorien Vandenborre, Ineke Wilssens, Sebastiaan Engelborghs, Philippe Paquier, Kyrana Tsapkini, Stefanie Keulen

Abstract

A variety of tDCS approaches has been used to investigate the potential of tDCS to improve language outcomes, or slow down the decay of language competences caused by Primary Progressive Aphasia (PPA). The employed stimulation protocols and study designs in PPA are generally speaking similar to those deployed in post-stroke aphasic populations. These two etiologies of aphasia however differ substantially in their pathophysiology, and for both conditions the optimal stimulation paradigm still needs to be established. A systematic review was done and after applying inclusion and exclusion criteria, 15 articles were analyzed focusing on differences and similarities across studies especially focusing on PPA patient characteristics (age, PPA variant, language background), tDCS stimulation protocols (intensity, frequency, combined therapy, electrode configuration) and study design as recent reviews and group outcomes for individual studies suggest tDCS is an effective tool to improve language outcomes, while methodological approach and patient characteristics are mentioned as moderators that may influence treatment effects. We found that studies of tDCS in PPA have clinical and methodological and heterogeneity regarding patient populations, stimulation protocols and study design. While positive group results are usually found irrespective of these differences, the magnitude, duration and generalization of these outcomes differ when comparing stimulation locations, and when results are stratified according to the clinical variant of PPA. We interpret the results of included studies in light of patient characteristics and methodological decisions. Further, we highlight the role neuroimaging can play in study protocols and interpreting results and make recommendations for future work.

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Group intervention for individuals with primary progressive aphasia and their spouses: Who comes first?

Regina Jokel, Jed Meltzer, J.D.R., L.D.M., J.J.C., E.A.N., C.D.T.

Abstract

Primary progressive aphasia (PPA) is a neurodegenerative dementia in which language impairment is the first and most dominant symptom. There is a considerable dearth of interventions for PPA although language rehabilitation has made headway in managing the disorder. Thus far, no comprehensive services have been proposed for PPA clients and/or their spouses. This paper describes the first structured group intervention program designated exclusively for people with PPA and their caregivers. This pilot project originates from a clinical service and presents supporting evidence for initiation of a larger study to establish an evidence-based intervention for PPA. A 10-week intervention program comprised working on language activities, learning communication strategies, counselling and education. Outcome measures administered to participants and their spouses before and after the intervention were compared showed improvements in quality of communication and coping skills in the PPA group compared to controls. Qualitative comments from all 10 participants in the active treatment group highlighted the necessity of intervention that is tailored specifically to the PPA population and addresses the needs of both individuals with PPA and their caregivers. All participants in the intervention group contributed to the study and are also co-authors of this paper.

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Slowing is slowing: Delayed neural responses to words are linked to abnormally slow resting state activity in primary progressive aphasia

Kielar A, Shah-Basak PP, Deschamps T, Jokel R, Meltzer JA

Abstract

Neurodegenerative disorders are often characterized by neuronal "slowing," which may be assessed in different ways. In the present study, we examined the latency of neural responses to linguistic stimuli in participants diagnosed with primary progressive aphasia (PPA), as well as changes in the power spectra of resting state activity, both measured with MEG. Compared to both age-matched and younger controls, patients with PPA showed a delayed latency of 8-30 Hz event-related desynchronization (ERD) in response to semantic anomalies. In addition, resting-state MEG revealed increased power in the lower frequency delta and theta bands, but decreased activity in the higher alpha and beta bands. The task-induced and spontaneous measures of neural dynamics were related, such that increased peak latencies in response to words were correlated with a shift of spontaneous oscillatory dynamics towards lower frequencies. In contrast, older controls showed similar task related ERD latencies as younger controls, but also "speeding" of spontaneous activity, i.e. a shift towards faster frequencies. In PPA patients both increased peak latencies on task and increased slow oscillations at rest were associated with less accurate performance on the language task and poorer performance on offline cognitive measures, beyond variance accounted for by structural atrophy. A mediation analysis indicated that increased theta power accounted for the relationship between delayed electrophysiological responses and reduced accuracy in PPA patients. These results indicate that the neuropathological changes in PPA result in slowing of both task-related and spontaneous neuronal activity, linked to functional decline, whereas the speeding of spontaneous activity in healthy aging seems to have a protective or compensatory effect.

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A neurocognitive computational account of word production, comprehension, and repetition in primary progressive aphasia

Ardi Roelofs

Abstract

Computational models have elucidated word production, comprehension, and repetition in poststroke aphasia syndromes, but simulations are lacking for primary progressive aphasia (PPA) resulting from neurodegenerative disease. Here, the WEAVER++/ARC model, which has previously been applied to poststroke aphasia, is extended to the three major PPA variants: nonfluent/agrammatic, semantic, and logopenic. Following a seminal suggestion by Pick (1892/1977) and modern empirical insights, the model assumes that PPA arises from a progressive loss of activation capacity in portions of the language network with neurocognitive epicenters specific to each PPA variant. Computer simulations revealed that the model succeeds reasonably well in capturing the patterns of impaired and spared naming, comprehension, and repetition performance, at both group and individual patient levels. Moreover, it captures the worsening of performance with progression of the disease. The model explains about 90% of the variance, lending computational support to Pick's suggestion and modern insights.

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Halton-Peel Community
APHASIA PROGRAMS

Clients & Caregivers

Baycrest

Dr. Jed Meltzer



Dr. Tartaglia &
Maria Martinez



Evergreen

Communication Therapy for Survivors



Jen Gordon



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