



Support for Caregivers of Individuals with Primary Progressive Aphasia (PPA)

What is PPA?

Primary-Progressive Aphasia (PPA) is one of many types of Aphasia and is a type of frontotemporal dementia (FTD). PPA is a neurodegenerative disease that affects the structure and function of the brain and gets worse over time. The main symptom of PPA is ongoing decline in language abilities. The most severe stages of PPA result in the inability to understand or produce spoken or written language. On average, people are diagnosed with PPA at 60 years of age. The age range of those with PPA is 40 to 80 years old. Men are twice as likely to live with PPA as women. About 50% of people with PPA have a history of dementia in their immediate family. About half of those with PPA will go on to develop additional non language behaviors or symptoms over time (for example: memory loss, personality changes). Most remain able to take care of themselves.



PPA Diagnosis and Types

Neurologic, speech-language, and neuropsychological evaluations are commonly done to diagnose PPA. There are three major types or variants of PPA: Semantic, Nonfluent/Agrammatic, and Logopenic. Each one is associated with damage/decline to different parts of the brain, and each has different speech-language characteristics. A speech-language evaluation determines what type of PPA is present and follow-up recommendations are made based on that evaluation in conjunction with the other interprofessional evaluations.



Communication Strategies

Even though PPA progresses over time, these are ways to help individuals with PPA maintain the ability to communicate.

For Individuals with PPA

Keep talking – think about who and what are important to you and keep talking about those people and things

For example: people, places, things, and events

Augmentative and Alternative Communication (AAC)

AAC refers to all the ways we share our ideas or feelings without talking. There are several types of AAC, some with and some without technology.

Without Technology (Low-Tech):

- Gestures and facial expressions
- Written language (pen and paper), pictures, photos

With Technology (Hi-Tech):

- An aided device can be programmed to an individual’s needs: vocabulary should meet daily living needs as well as commands, requests, and desires. An AAC device should be updated as needed.*

For Caregivers

Identify what is important for the person with PPA to communicate about – now and in the future

Examples include people in their lives, things they like, memories of big moments in their lives

Patience

Those with PPA need time and space to form their thoughts and decide what to say. Be patient, especially as the disease progresses.

Simple but Appropriate Speech

Using simple speech can be helpful when talking to an individual with PPA. However, it is important to not oversimplify or “talk down” to the person with PPA.

Identify the Topic at the Beginning of a Conversation

Use gestures, pictures, photos, writing, or drawing and communicate face-to-face in a quiet environment.



Self-Care Strategies

Being given a diagnosis of PPA can be difficult. It is normal to feel sad, scared, and alone. But, you are not alone...
Creating safe spaces and being aware of support options are crucial for everyone involved.

For Individuals with PPA

For Caregivers

Speech and Language Therapy

This can be an important self-care tool for someone with PPA. In addition, those living with PPA and their caregivers can benefit from continuing to learn about the disease.

Spend Time with Yourself

Being a caregiver for someone with PPA can take a lot of time. Be sure to spend time taking care of yourself. Enjoyable activities, as well as down time, can be helpful and refreshing.

Be Patient with Yourself

Living with PPA will lead to some challenges. Each day should be taken with as much patience and forgiveness as possible.

Spend Time with Friends

Due to the progressive nature of PPA, a caregiver may spend most of their time caring for the person with PPA. It is important to protect and maintain relationships outside of the responsibilities as a caregiver.

Let People Know What You Need

For example, counseling options are available – talk to your family and to your interprofessional care team for possibilities.

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Support Groups

Support groups are available for those living with PPA. Support groups may supply education as well as a sense of community. A recommended group is the Support and Education for Early Dementia (listed below).

Support Groups

There are free online support groups for caregivers and family members of people with PPA. A recommended group is the Monthly Online Care Partner Support Group for FTD/PPA (listed below).



Additional Resources:

A related brochure on this website: “Primary Progressive Aphasia (PPA).” (link)

The Association for FrontoTemporal Degeneration

<https://www.theftd.org/what-is-ftd/primary-progressive-aphasia/>

I Am A Caregiver

<https://www.aphasia.org/category/i-am-a-caregiver/>

Monthly Online Care Partner Support Group for FTD/PPA (Free)

<https://www.brain.northwestern.edu/care-and-support/ftd-ppa-support.html>

Providing Care for a Person with a Frontotemporal Disorder

<https://www.nia.nih.gov/health/providing-care-person-frontotemporal-disorder>

Support and Education for Early Dementia

<https://www.brain.northwestern.edu/care-and-support/seed.html>

YouTube Series: Conversations with Caregivers (English / Spanish)

<https://www.youtube.com/playlist?list=PL3BRqTEEZ5z5yjjV19qIL50Vr-CxoWe4>

For more information, please contact:

Dr. Therese O’Neil-Pirozzi, Lab Director

t.oneil-pirozzi@northeastern.edu

Developed by: Annika Briggs & Kira Maidenberg

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