

Serving the Underserved: Primary Progressive Aphasia Services in the Life Participation Model Catherine Low S-LP, Lorraine Podolsky S-LP, Elisha Nesci CDA

What is PPA

- Primary Progressive Aphasia (PPA) is an uncommon type of frontotemporal dementia marked by language loss
- Symptoms of aphasia initially present in isolation but lead to progressive changes in other cognitive skills
- By the time diagnosis is confirmed, the journey of dread and changing identity has already occurred

The Aphasia Institute's Contribution

- The Aphasia Institute, at its roots and core values, has been providing hope, and access to life participation for people with stroke based aphasia
- The challenge in offering service for people with PPA and their families is to be creative and expand current offerings to this vulnerable minority population
- There is added value in recognizing that providing hope and access to life participation goals must be approached very differently

The

In contrast to a diagnosis following a stroke, the elusive nature of PPA often means that arriving at a diagnosis may take years

Journey

People living with PPA experience difficulty navigating the healthcare system and accessing appropriate resources and services

With

Clients are under-referred for comprehensive language assessment or traditional language intervention

Clients often arrive at the Institute still processing the impact of the diagnosis, feeling anger, shock, social isolation, and a sense of hopelessness or lack of control

PPA

A-FROM in Action

- PPA services at the Aphasia Institute are driven by the principles of the Life Participation Approach to Aphasia (LPAA) and the Living with Aphasia: Framework for Outcome Measurement (A-FROM) model
- A-FROM is used to distinguish the language impairment from other domains
- Clients and families are entitled to services that lessen the impact of aphasia on relationships and participation in meaningful activities
- Reframed hope, and maximized life participation are explicit goals of all services offered to those living with PPA while the aphasia remains the dominant concern
- Although individuals with PPA are encouraged to participate in various Al programs, one program is designated specifically for PPA - Living Your Best Life

References and Acknowledgements

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Keeping Conversations Alive: Living Your Best Life Programs for People Living with PPA

In order to be inclusive of all PPA members and address the unique needs of caregivers, program offerings have been re-evaluated to accommodate individuals on a case-by-case basis



Service to clients with PPA and their families is more intensive, requiring flexibility and careful clinical judgement related to the nuanced and changing needs of this population and their families.



This service model restores relationships by fostering the skills and confidence needed to have and 'keep conversations alive' for as long as possible (e.g. End of Life decisions, and future care

Living Your Best Life **PPA Education** and Support Group Community **Aphasia**

Ongoing Caregiver Support Group

Bridging

Services

Personal What gets in the way **Your Life Environment** Modified from Kagan et al 2008

Participation

Telepractice

Family Circle Intervention

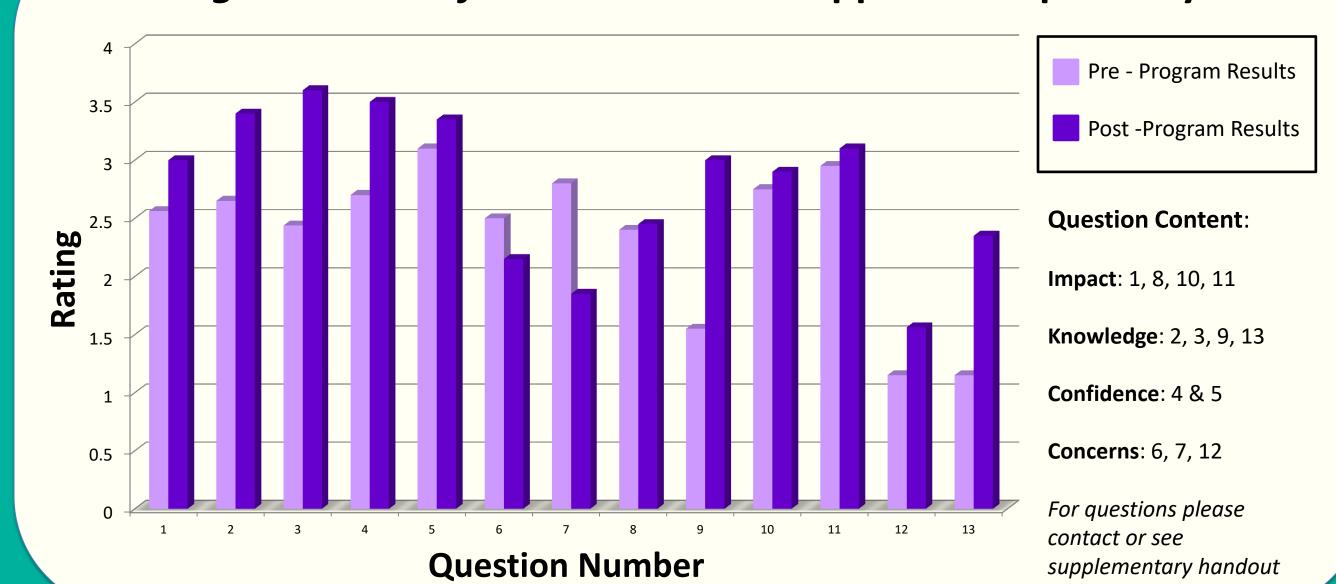
Program

Your Life

Life Story

Program

Living Your Best Life Education and Support Group Survey



Living Your Best Life PPA Education and Support Group

- The Living Your Best Life Education and Support group is the signature service offered for families impacted by PPA
- Running for a total of seven weeks, the program is divided into two major components: education and training, and emotional support
- Content is delivered through formal instruction, and collaborative learning is enriched by peer interaction
- PPA-specific support groups ensure that caregivers feel empowered to adapt to the evolving care and relationship dynamic
- Participation expectations are contracted which include 'check-ins' with staff every six weeks
- Discharge occurs when the clients' needs extend beyond the capacity of direct services offered at the Aphasia Institute

Reduced Stress and "started **Psychological Strain** demonstrating that sense of confidence **Supports Unique Needs of** in her day to day Caregivers activities" **Supports Renegotiation of** "You realize **Identity of PPA Couples** that you are not alone" **Supports Necessary and Difficult Conversations** "It has been our biggest step forward and the most **Peer Support and Learning** significant improvement (Richness of Group) to our *personal* communication in the past year" **Increases Community** Engagement "This program **Communication Practice** has been the gem in my journey" **Bridge to Other Services**

Future Development

- Generate Aphasia Friendly resources around topics such as;
 - End of life decisions
 - Renegotiation of future care and planning
- Further explore integration of people with PPA within the larger Aphasia Community
 - Anxiety about future changes
 - Difficulty identifying with those who have stroke-based aphasia
- Continue to examine timing of services throughout the course of PPA and program suitability
- Expand partnerships with relevant agencies and other clinical professionals to create bridging of services on the continuum of care