Aphasia Access Conference 2017

SERVING THE UNDERSERVED: PRIMARY PROGRESSIVE APHASIA SERVICES IN THE LIFE PARTICIPATION MODEL

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Keeping Conversations Alive: Spotlight on the *Living Your Best* Life Education and Support Group For Clients and Families living with Primary Progressive Aphasia

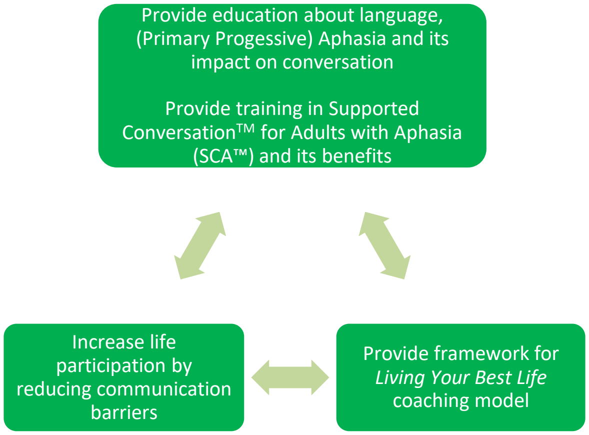
Living Your Best Life – Supporting Couples to Keep Conversations Alive

The *Living Your Best Life* education and support program is offered as the signature program for clients with PPA and their families at the Aphasia Institute. During initial assessment, client needs, abilities and identity are explicitly discussed in order to inform clinical decisions regarding individualized programming options.

As is the case for assessment and the majority of PPA programming at the Centre, *Living Your Best Life* is delivered by a Speech-Language Pathologist (S-LP) and a Social Worker (SW); due to unique nature of the PPA journey, a high level of skill in Supported Conversation for Adults with Aphasia (SCA™) and counselling are required. When available, it is recommended that support personnel (e.g. Communicative Disorders Assistant/Speech-Language Therapy Assistant) contribute to the program as co-facilitator or to develop program resources as needed.

Goals and Objectives of the Program

Design of the *Living Your Best Life* program was guided by principles of the Life Participation Approach to Aphasia and the Framework for Outcome Measurement in Aphasia (A-FROM). The specific goals of the program include:



Provide education about language, (Primary Progessive) Aphasia and its impact on conversation

Provide training in Supported Conversation™ for Adults with Aphasia (SCA™) and its benefits

Increase life participation by reducing communication barriers

Provide framework for *Living Your Best Life* coaching model

Design of the Program

Clients with PPA and their families gain education and are able to practice SCA tools and strategies to reduce the barriers created by aphasia in the four domains of the A-FROM. Additionally, embedded within the service model is the consistent use and modeling of transformative language to enable active thinking and actions (i.e. language of *life* as opposed to *loss*).

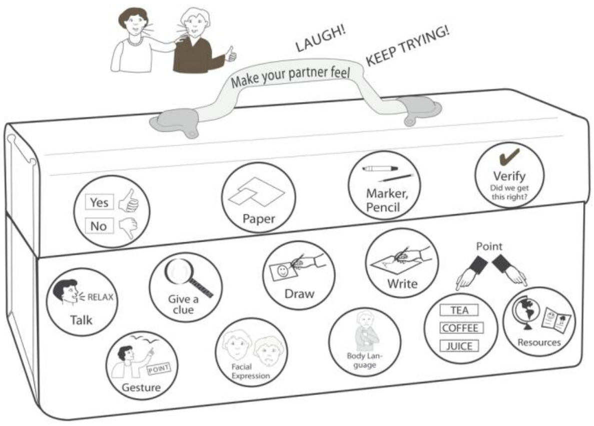
The program is a designed to be seven weeks in duration, and it is broken into two major components:

- **Component I (4 weeks) -** Provide education about PPA and training in Supported Conversation for Adults with Aphasia embedded within the *Living Your Best Life* coaching model. Clients with aphasia may participate in the Community Aphasia Program (CAP) simultaneously while learning the tools and can incorporate them into practice week by week.

The agenda for **Component I** program includes:

- Becoming a Group
  - Your Journey with PPA
  - Group Expectations and Goals
  - Identity and Strengths
- Deconstructing Aphasia
  - What is Language?
  - What is Aphasia?
  - SCA Toolbox
- Keeping Conversation Alive
  - Partnerships
  - Focus on 'the conversations'
  - SCA in context
- Living Your Best Life
  - Defining Quality of Life
  - Inviting Others Back In
  - Continuing the Journey

Clients and families living with PPA may have difficulty understanding their challenges in the context of a predominantly stroke-based population. The following resources have been particularly helpful, regardless of aphasia severity:



Stroke	Primary Progressive Aphasia
Sudden	Slow
Physical changes common	Physical Changes less common
No change over time	Changes over time
No change in memory	Changes in memory common
COMMUNICATION affected	**COMMUNICATION affected**
SOCIAL CHANGES	**SOCIAL CHANGES**

- **Component II (3 weeks) -** Partners are provided with a facilitated caregiver support program and introduction to community resources (e.g. Alzheimer's Society). Concurrently, members with PPA continue in CAP conversation groups in order to practice skills and build community

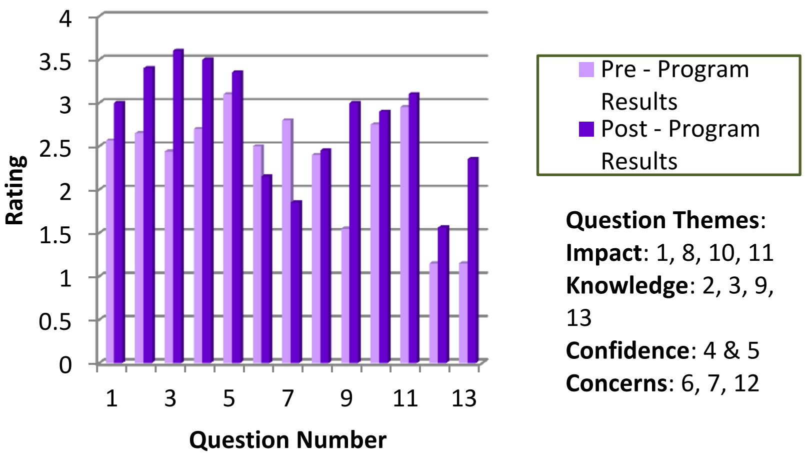
Impact of the Program

At the beginning and end of the four-week couples component, participants independently complete an aphasia friendly survey. The themes represented by the questions include: impact of PPA on their life; knowledge about aphasia and supported conversation; confidence sharing their journey with others; and concerns for the future. Survey questions are listed below, followed by recent group responses.

LYBL Group Survey Questions:	
Q1	Today, which one is you?
Q2	I understand what primary progressive aphasia means
Q3	I understand how aphasia causes communication breakdown
Q4	I know what to tell others about primary progressive aphasia
Q5	I am comfortable telling others that I am affected by PPA
Q6	I have concerns about my communication skills
Q7	I am concerned about other abilities (memory, multitasking, prioritizing)
Q8	My family and I are able to have important conversations
Q9	My family and I know how to help each other communicate
Q10	My family and I adapt well to change
Q11	My family and I are able to focus on quality of life
Q12	I have fears about how PPA will continue to affect my life
Q13	My family and I know which community supports are available to us

Themes represented:

Impact **Knowledge** **Confidence** **Concerns**



Question Themes:
Impact: 1, 8, 10, 11
Knowledge: 2, 3, 9, 13
Confidence: 4 & 5
Concerns: 6, 7, 12

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