Aphasia therapy

Let’s make it meaningful

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Presentation aims

- Theoretical frameworks
- Research and best practice
- Goal setting
- Implementing into day to day clinical work
- Case studies
LPAA: Life Participation Approach to Aphasia

- LPAA Aims
  - to promote a philosophy of service delivery that meets the needs of people affected by aphasia
  - confronts the pressures from our profession, providers and funding sources

- Video clip: https://vimeo.com/130329731
Defining the approach

- **Consumer driven** service delivery approach
- Supports individuals with aphasia in achieving their **immediate and longer term life goals**
- Calls for a **broadening and refocusing** of clinical practice and research on the **consequences of aphasia**.
- Focuses on **re engagement in life**...from initial assessment and intervention
- Until the **consumer** no longer elects to have **communication support**.
Aphasia Redefined: Kagan, Simmons Mackie
2013

Now consider the following re-definition of aphasia:

Aphasia is... “a communication impairment that impacts identity and relationships because of difficulties speaking, understanding, reading and writing.”
A-FROM Key principles:

- Based on the LPAA Life Participation Approach to Aphasia
- Follows WHO (World Health Organisation) framework.
- Can be used from day one post stroke
- Emphasis is on a person’s communication strengths
- Quality of life is the ultimate goal
- Incorporates focusing on functional strategies, impairment based activities while relating to real life situations.
CAPE-Roberta Elman

- A framework for people with severe aphasia
  - C = Connect with others with aphasia – groups, befriending, mentoring
  - A = AAC, establish functional communication
  - P = Partner training
  - E = Education and information about aphasia
Aphasia United

- Professor Linda Worrall
- A united voice for Aphasia
- A new peak international organisation
- Aims to bring together the global community

www.aphasiaunited.org
Four areas of action

1. Increasing awareness – designate an international Aphasia day/month

2. Consensus on best practice – 10 Best Practice Recommendations 2015

3. Setting an international research agenda

4. Building capacity – aphasia consumer organisations, across linguistic boundaries, aphasia not through stroke
Australian Aphasia Rehabilitation Pathway

- Receiving the right referrals
- Optimising initial contact
- Setting goals and measuring outcomes
- Assessing
- Providing information
- Enhancing the communicative environment
- Enhancing personal factors
- Planning for transitions
Audrey Holland (Aphasiologist, University of Arizona)

- makes 3 basic assumptions for **living successfully with aphasia**:
  1. It takes time
  2. Aphasia is a family problem
  3. People do not “get over” aphasia; they learn to fit it into their lives.
Setting meaningful goals.

- Include all aspects of the ICF when setting goals. (Worrall et al. 2010)
- May help to use a tool
- Can be challenging with people with severe communication impairment
- Include whanau and friends (Grawburg et al 2013, Pound 2014)
- A-FROM - Assessment for Living with Aphasia (ALA)
- Self assessment scales (SACS)
- Other
Traditional SLT goals

Impairment level
- Increase naming
- Increase use of sentences

Functional:
- Use the telephone
- Write a shopping list
Categories from benefits of groups research.

Rotherham, Howe, Tillard, 2015.

1. Improves communication
2. Improves confidence
3. Provides information about aphasia
4. Provides support
5. Provides a feeling of hope and encouragement
6. Provides an opportunity to help each other
7. Provides an opportunity to feel part of the community
8. Provides a comparison
9. Provides a positive communication environment
10. Provides an opportunity for social contact: companionship
11. Helps to identify with others who have aphasia
12. Provides stimulation
13. Provides an opportunity to utilise skills
14. Provides a sense of worth
“The Center has given us back our lives. The people there are the best. For anyone with aphasia, this is the place to be.”

Ronnie Davis
Center family member
Living Successfully with aphasia  (Brown, Worrall, Davidson, Howe, 2010)

- Doing things
- Meaningful relationships
- Striving for a positive way of life
- Communication, having strategies to communicate
Other key themes in research

- Developing independence
- Social networks
- Support
- Positive self identity
- Set new future goals
Traditional SLT goals

Impairment level
- Increase naming
- Increase use of sentences

Functional:
- Use the telephone
- Write a shopping list
Why??

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Extend goals to deeper themes

To have conversations. Why?
- To maintain relationships

To use the phone/ text/ facebook?
- To connect with friends

To write a shopping list?
- To maintain role in family
Case Study 1

- JD. 44 year old woman. CVA in March 2014
- Fluent - conduction aphasia
- Most important things in her life
- Cats
- Gardening
Initial goals

- Establish a functional means of communication for JD to access her community
  - Involved increasing written naming,
  - Increasing accuracy of speech
  - Partner training of friends and family
  - Strategies to catch the bus
  - AAC – iPad
  - Meeting others with aphasia
Video clip of JD

https://vimeo.com/143330965
Living Successfully?

- **Next step of goals**: (Sense of worth, sense of hope, opportunity to help others, opportunity to feel part of the community)
  
  - Establishing new friends- aphasia groups, walking the neighbour’s dog, aphasia awareness in the local shopping area.
  
  - Helping others- befriending, volunteer work - gardening with clients at Burwood Hospital.
  
  - Writing/ developing a gardening guide after stroke
JD Now

- Self managing, discharged from SLT,
- The goals are ongoing
- But she is self motivated and can access further therapy through AphasiaNZ groups etc.
Conversation as treatment.

- Conversation is core to every interaction and relationship.
- Advocated and researched extensively; Simmons – Mackie, Kagan, Boles, Whitworth......
- A recent review; Simmons-Mackie, Savage, Worrall, 2014
- Wide variety of published approaches
- Multiple directions for future research in the area in particular to measure outcomes of conversation therapy associated with specific approaches.
Concluded

- It is an essential goal for people with aphasia –

- "To improve conversational skill, confidence and participation."
Benefits of Targeting Conversation

- Natural context
- Positive identity
- 1:1 or in groups
- Addresses couples, relationships
- May involve partner training.
Groups

- SLT led
- Peer led
- Volunteer led

- Therapy groups – time framed
- Conversations groups
- More specific activity – book clubs, Gavel clubs
Group benefits - Rotherham, Howe, Tillard 2015

- 27 Different categories of benefits for PWA and 10 for family members
- Conversational strategies
- Building confidence
- Friendships
- Support
- Psycho-social benefits were extensive
- Information
- New ideas, new activities - stimulation
The project group

- Therapy group
- Peer led
- Goal/ project
- Awareness raising via fundraising
- To attend the Wellington Aphasia conference
Gaining independence

- Setting up a bank account
- Participating in a variety of fundraising activities
- Achieving the ultimate goal - Conference in Wellington
Strong friendships

- Support
- Humour
- Sense of achievement together
- Sense of belonging
- Positive identity
Communication

- Supportive communication environment
- Share ideas and opinions
- Make plans
- Contribute
- Use of email
Case study 2

- PG, man in his 50s, had a left MCA stroke in March 2015. Initially limited verbal output, jargon, lots of spontaneous social utterances. Excellent communicator with facial expression, intonation.

- Initial goals:
  - 1) To participate in conversational using multi modal communication
  - 2) To increase accuracy of speech for family names
  - 3) To increase functional means of communication in everyday situations using high and low tech AAC
Domain 1: Aphasia Severity

- Severe Phonological deficit – phonological therapy
- Resulted in:
  - increased written naming,
  - Improved auditory comprehension
  - Improved conversation
- Reduced reliance on high tech AAC, could use pen and paper more
- Starting to read some words aloud
Domain 2: Environmental factors

- Family and friends need to be able to communicate effectively
- Partner training - individualised to client and family dyad
- Strategies for accessing the community – Aphasia card, Apps on phone, communication charts,
- Returning to family role - Dad, husband - ordering coffee, paying in cafés, paying for petrol
Domain 3: Participation

- Connect with others with aphasia – Aphasia groups – introduced from rehab
  ward.
- Group conversation opportunities
- Positive communication environment
- Use Multi modal strategies

- Life Participation
- Going skiing
- Going on holidays
- Spending time with family and friends
Domain 4: Personal Factors

- **Facilitators:**
  - Motivated
  - Supportive family
  - Resourceful wife – excellent at making aphasia friendly resources!!
  - Sense of humour

- **Barriers:**
  - Mental health concerns
  - Living remotely – dependent for transport initially
Including Whanau

- Evidence that family experience the impact of aphasia significantly. (Grawburg 2013).
- 3rd party disability
- Across all aspects of the ICF, health, isolation, depression, ability to work, change in roles.....
- The effects on the family needs to be considered by SLTs and the goals of the family included in rehabilitation.
Including Friends:

- Carol Pound -2014 – “my friends are my anchors.”
- Increased social networks has a positive effect on health.
- Participatory Action research
- How do working age adult with aphasia define, experience and understand friendship?
Results of the research – Forest of friendship
Reflections for people with aphasia....

- Talk to peers with aphasia
- What has helped them stay in touch with friends?
  - Make an effort
  - Get out of the house
  - Let people know early on e.g. send a card
  - Take me out from rehabilitation – prioritise relationships too
  - Don’t make assumptions about negative reactions - Check whether self or other exclusion
For family members

- Family are hugely important but friends are important too
- Don’t exclude friends, act as a bridge
- Stay in touch with your own friends
- For your own wellbeing and as an important friendship resource to the person with aphasia
- Inform yourself and your family but also equip friends with information - About stroke and aphasia
- Balance your role as anchor with the space and opportunity to explore different post---aphasia identities
Cultural Considerations:

- “For Māori, language is precious. And without it we are a bit lost”: Māori experiences of aphasia
- Karen M. McLellan, Clare M. McCann, Linda E. Worrall & Matire L. N.
it was impossible to fully separate the impact of aphasia in one’s life from the impact of the stroke overall

2 pairs of themes:

1) “Grieving for what is lost” – “Recognising what we have got”
2) “It is hard” – “Choosing how to respond”
Clinical implications:

- Aphasia can have a profound effect on Maori families
- changes in relationships and roles.
- However for Maori, the person's status did not change in their whanau or hapu.
- For example. One man continued his role on Sports and Marae committees,
Clinical implications

- SLTs need to recognise the loss associated with aphasia for Maori.
- Provide appropriate assistance for dealing with negative emotions.
- SLT can guide whanau members to support the PWA in continuing their roles in their whanau and community.
- Further research is ongoing in the area of Maori perspectives and aphasia
The effect of aphasia on social relationships
Fotiadou, Northcott, Chatidaki, Hilari (2014)

- Stroke and aphasia can negatively impact a person's ability to maintain healthy relationships
  - with friends
  - with family
  - with the wider network
Aphasia Blog talk

- 10 relevant blogs
- Participants aged between 26-69
- Living in the community
- Were at least 1 year post stroke
- 6 women, 4 men
Results

- Aphasia was a consistent thread affecting all parts of a person's network.
- Harder to have:
  - In-depth conversations
  - Express opinions and thoughts
  - Feel less included in conversations
  - Resulting in feelings of frustration and depression
Family

- Changes in activities
- Changes in family dynamics
- Loss of autonomy - “I'm not allowed out alone!”
- Parenting limitations “now the husband is the playmate, reader and explain it all person”
Friendships

- Friends were important
- Difficulties in maintaining pre-stroke friendships
- Physical disability also a barrier to going out eg to restaurants
- Not initiating visits
- Environmental factors - background noise
- Embarrassment of aphasia
- Over time the responses evolved and changed as people adjusted and their communication improved.
Wider social network

- In this study, wider network was conceptualized as neighbours, co-workers, community members
- *Reduced participation:*
  - Avoidance
  - Fatigue
  - Public transport, bathrooms, eating and drinking….all too hard
New and positive interactions

- Some participants became motivated to be more active in their wider community:
  - Aphasia, stroke, religious groups
  - New friendships
  - **Social media** - “learnt to just be me”
  - Assisted in promoting participation - e.g connecting with other parents
Benefits of expressive writing

- Research demonstrates positive psychosocial benefits in engaging in expressive writing -
  - “tell your stroke story”
- Blogging has been shown to provide an expressive outlet
- Act as an emotional release
- Provides a story of the recovery journey
- Feel connected to others
Conclusions

- Every person with Aphasia is different
- Can tailor therapy to meet their own meaningful goals using A-FROM
- Involve whanau, friends as much as possible - train strategies
- Use groups early in rehab, not just a discharge destination
- Connect with others with aphasia
- Social media helps connect with wider community