

### **‘Living Independently with Aphasia’**

*Among all the passion of the speakers at this multidisciplinary conference, Samantha Miles found the contributions from people with aphasia and a call to evaluate whether our current intervention has meaning for the rest of a client’s life particularly enlightening.*

The Speech and Language Therapy Aphasia Action Group at Portsmouth City Teaching Primary Care Trust delivered their second multidisciplinary aphasia conference ‘Living Independently with Aphasia’ in May 2008. The refreshing passion of the speakers created an enlightening and encouraging day. Key themes centred on the drive to increase service users’ empowerment and involvement, and public awareness of aphasia.

- **Depression and aphasia**

**Dr. Chris Code** discussed the prevalence, diagnosis and impact of depression in stroke survivors. He observed that neurological changes occurring post-stroke may be misleading and reduce the validity of using DSM\* criteria to diagnose depression. Clinicians should take into account reduced energy, weight / appetite changes, disrupted sleep, and the effect that impairments of voice and facial movement have on the ability to communicate a range of emotions. He presented research demonstrating the importance of satisfactory interactions with others to achieving happiness, and commented on the high correlation of social isolation and depression. Severity of aphasia was shown to have the greatest impact on social activity. Other studies have demonstrated the importance of positive emotional states for effective rehabilitation outcomes. This research supports the need for access to ongoing speech and language therapy intervention for people with chronic aphasia.

- **Out and about**

Dr Code quoted research suggesting that, on average, only 5 per cent of the general public had heard of aphasia. He found that people with moderate aphasia spend 20 hours outside the house each week, accessing community facilities and retail outlets, and much less time accessing health services. One factor in choice of shop was the communication barriers experienced. However, no single type of barrier stood out as more common, and the type of shop did not affect the type of barrier experienced.

- **Public awareness**

Aphasia reduces the ability to be empowered in life. Dr Code cited research demonstrating how supported conversation training for those who work within service industries improved the communicative effectiveness of people with aphasia. He suggested that supported conversation training and awareness-raising was invaluable to the participation, wellbeing and communicative effectiveness of people with aphasia. Rehabilitation must strive to increase empowerment by improving access to resources and enabling people to take part in decision making and problem solving, and to interact effectively to get what they want. Empowerment for people with aphasia clearly cannot be achieved without targeting public education and awareness.

- **Annual reviews**

**Dr Jane Williams**, consultant nurse in Stroke care, discussed the impact of the National Stroke Strategy  
<http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyA>

[ndGuidance/DH\\_081062](#)) on people who have aphasia. She commented upon work still to be done, including the key requirement of annual multidisciplinary stroke reviews.

- **Increasing access**

Dr Williams observed that one third of stroke survivors experience communication problems. Historically, this client group has not had access to participation in service development. Dr Williams emphasised that it is *everybody's* responsibility to improve public and professional awareness of stroke, and to increase the involvement of people who have experienced a stroke in decisions about design of the service. She commented on local and national initiatives to increase access to information via the internet, such as <http://www.pompeystrokes.co.uk>. The development of this website was supported by Joanna Kerr, speech and language therapist, as part of her master's project. She facilitated three focus groups to identify what information people with stroke and with aphasia wanted to see on the website. The participants then sorted the topics they had raised to identify how best to organise the website information.

- **Intensive community intervention**

**Sarah Easton**, Team leader for the Portsmouth Community Stroke Rehabilitation Team, spoke passionately about the success of this inter-disciplinary model for stroke rehabilitation. The team was created from realignment of costs following the closure of an 18 bed stroke ward. It offers intensive community intervention for an average 'length of stay' of 35 days.

Sarah described the model as an "evolution of culture", increasing therapists' knowledge and leading to the development of core skills for all team members. She explained how intervention within the team aims to empower clients towards independence. Clients are supported to take the risks and make the mistakes that will allow them to learn strategies that have real meaning and value in their lives. Outcome measurements are based on the level of independence achieved by the client.

Sarah called for clinicians to evaluate whether our intervention currently has meaning and value for the rest of the client's life, and to consider the multiple variables of personality, environment and expectations affecting participation. She placed the team's approach in the context of clinical advances and recent legislation regarding stroke care, showing how the team meets the call for comprehensive, patient-led rehabilitation. She demonstrated how the team has reduced the number and level of care packages, and improved links with health services and voluntary providers.

- **Partnership projects**

**Ruth Niewenhuis** described three *Projects in Partnerships with People with Aphasia*, a series which has been running since 2005.

One project encouraged people who have aphasia to volunteer as support workers to facilitate groups for recent stroke survivors. Outcome measurement included the Quality of Life Scale (Hilari, 2003) and semi-structured interviews pre and post groups. Ruth found that people with aphasia needed more rest breaks, and needed time to de-brief. Timing of therapy delivery and planning meetings had to be altered

to accommodate this need. Additionally, creative opportunities for participation had to be considered.

The second project focused on Partnership Working in Practice. An aphasia friendly video study day was held on 'Partnership working'. This was well attended, and received a highly positive evaluation from delegates. Speakers who had aphasia reported increases in self-esteem and confidence. This successfully promoted collaboration between people with aphasia and NHS and voluntary agencies.

Lastly, Ruth fed back on the Bim Bhowmick bursary, awarded to her by the Stroke Interest Group of the British Geriatrics Society, Wales. This involved using 'expert patients' with aphasia to teach medical staff how to communicate effectively with people who have aphasia. The project used video teaching sessions of conversations between doctors and staff from a stroke unit and people who have aphasia, as part of medical training. This innovative technique was an effective way to target the acknowledged need for multidisciplinary education in supportive communication.

- **Challenge for medics**

**Dr Alison Hatfield**, consultant in rehabilitation medicine, discussed the difficulties associated with delivering medical intervention to patients who have aphasia. Problems can be ignored or misdiagnosed, and it can be difficult to get consent for procedures or establish resuscitation wishes. She commented on the difficulties of using many of the standard, non-aphasia-friendly assessments to diagnose depression. She discussed communication strategies, also advocating a fuller clinical examination, shorter assessment sessions and increased multidisciplinary team liaison.

- **Personal journeys**

Two stroke survivors who have aphasia gave first-hand accounts of their personal journeys through the NHS system.

**Peter** was admitted to a hospital outside the Trust and transferred to local services on discharge home. He is a highly articulate man. His wife spoke of the distress she felt at seeing someone who had achieved so much throughout his life struggling with things he previously found so easy. She was hurt that people could no longer see the man she knew. Speaking of the pressures of her role she said, "I was not only physically caring for him but speaking for him as well."

Peter spoke of the difficulty in obtaining accessible information and regaining independence. He asked, "why call aphasia aphasia?" His inability to pronounce the term certainly made the point! It made me wonder if we should use a term that allows our users to communicate their own diagnosis? Does the academic debate regarding the 'a' versus 'dys' suffix matter, if our service users can't access either? With so few of the population having heard of aphasia, is now the time to launch a newer, more accessible term?

Peter explained how technology was an obstacle towards his independence. He feels that, while many people have poor communication skills, it is still easier to speak to a real person. He described the difficulty of making customer service phone calls and the struggle to process and retain information given in automated menus. Supported conversation training (as mentioned by Dr Code) will not overcome this barrier.

**Angela** was admitted to a general ward as a stroke ‘outlier’, and then self-discharged home. She felt she may have remained in hospital if she had understood she had a chance of going to a stroke rehabilitation ward. The professionals involved felt the information had been given to her, but that was not her perception. She said, “Information didn’t register when I was in hospital. I needed a simple book with key facts.” Angela continued, “I was too scared, lost and upset to talk to my family.” Do we make sufficient allowance for the information overload facing people who have had a stroke?

The conference evaluation forms show that first-hand accounts are the most powerful and moving presentations. While professionals strive to provide co-ordinated care, client perspectives indicate there is still work to be done. Their stories showed the importance of increasing user involvement, and engagement with ‘expert patients’.

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#### **Reference**

Hilari K. (2003) *The Stroke and aphasia quality of life scale - 39 item version*. London: City University (Pack includes: the SAQOL-39 instrument, the SAQOL-39 manual and a scoring sheet.)

*\*DSM stands for Diagnostic and Statistical Manual of Mental Disorders, a handbook from the American Psychiatric Association*