Primary Progressive Aphasia is a rare clinical syndrome. It has only a relatively short history in medical scientific literature. It was described over a hundred years ago but the term PPA, was only coined by Professor Marcel Mesulam in 1982. There has been an explosion of research and knowledge in the field of PPA in the last twenty years but there are still lots of questions.

Sometimes, when we don't have the answers, we look to different, but similar conditions, for insights. There can be helpful information that comes from research and study in other neurological conditions.

This issue, features insights from Parkinsons Disease, Alzheimer's Disease and from the community of aphasia caused by stroke.

Cathleen Taylor

Chat and Support Group

Our next chat and support group at War Memorial Hospital will be at

2pm

THURSDAY 17th JANUARY

Call 9369 0212 for more information
When Fox was diagnosed with Parkinson's Disease in 1991, at age 30, he turned to drinking. "If I couldn't obliterate the problem, I would obliterate myself, or at least my awareness of what was happening," he wrote a few years ago. "Medication for the symptoms, alcohol for the feelings".

A few years later when he quit drinking, he explains that he underwent a transformation. He says he became "kind of weirdly optimistic and positive."

"There's this aphorism that I learned when I quit drinking, which is that my happiness grows in proportion to my acceptance, and in inverse proportion to my expectations," he says.

"The more I expect, the more unhappy I am going to be. The more I accept, the more serene I am."

The word "optimism" comes up repeatedly throughout the interview.

"It's really important for me to stay positive," he says. He traces a lot of this back to his parents - his father was a career soldier - making the most of a tough life with few luxuries. But it's also a practical deal he has made with himself.

"That's the way I look at things - if you focus on the worst-case scenario and it happens, you've lived it twice.

It sounds like Pollyanna-ish tripe but I'm telling you, it works for me."

People with aphasia from stroke sometimes have trouble if unexpectedly alone in public or an unfamiliar place. Because of their speech and language problems, they tell the story of being mistaken for a person who is ill or disoriented from alcohol or drugs. People with aphasia can also be less successful than usual communicating in a stressful situation. When they need their speech and language the most, in a difficult situation, it is at its worst!

Solutions have been developed by the Alzheimers community. The Safely Home program is a joint collaboration between Alzheimers Australia NSW and the NSW Police. It may never be needed but if the situation arises, this program offers an easy solution.

It costs $39 for Alzheimer’s Australia NSW members and $54 for non-members. You can find out more at www.alzheimers.org.au

A woman with progressive non fluent aphasia was recently pulled over by NSW Police for a routine driver breath testing. She was carrying a card in her wallet explaining her aphasia and it proved an invaluable strategy for dealing with what could have been a distressing situation.
Dr Regina Jokel, is a Canadian speech language pathologist and leading researcher in PPA. Her current research focuses on language interventions for adults with progressive aphasia.

At the International Conference on Alzheimer’s Disease (ICAD) in Paris, last year, Dr Jokel and colleagues presented data from their work with three individuals with fluent PPA.

They set out to find evidence that a successful language intervention for people with PPA can induce measurable effects in brain activity. In other words, they wanted to see if there were changes on neuro imaging after language treatment. The individuals in the study had ten one hour session of learning nouns. At the completion of the ten treatments, all improved on naming of the nouns they has practised. Importantly, the functional MRI scan that also followed the treatments, showed increased activation in the left anterior temporal regions of the brains of each individual in the study.

Dr Jokel and colleagues state “This is important….the increased activation noted on post-treatment scans shows initial promise that a non-pharmaceutical intervention is capable of inducing positive changes in neural activation in a progressive disorder”.

Do you care for someone with PPA?

We are conducting research into the experience of persons caring for someone with primary progressive aphasia (PPA). The research is being conducted by Lauren Roche, under the supervision of Dr. Karen Croot, Lecturer in Applied Cognitive Psychology at the University of Sydney.

Through a questionnaire, we aim to build a holistic understanding of what it is like to care for someone with PPA. We hope this information can be used to plan future support for people caring for someone with PPA.

If you would like to know more about contributing to this important research, please contact Lauren Roche, student researcher and Doctorate of Clinical Psychology / Master of Science candidate.

Ms Lauren Roche:
Phone: 02 9351 2647 / 0439 420 064
Fax: 02 9036 5223
Email: lroc4696@uni.sydney.edu.au
Address: Brennan MacCallum Bldg (A18), University of Sydney, NSW, 2006
Do you know someone who would like to be on the newsletter mailing list?
They can contact us by

Phone: 02 9369 0212

or

Email: taylorc@sesiahs.health.nsw.gov.au

If you would like to contribute a story please email or write to:
Speech Pathology
War Memorial Hospital
125 Birrel Street WAVERLEY,
NSW 2024