



Welcome to the first newsletter of 2014! The December meeting was an interactive occasion, providing opportunity for people with diagnoses of PPA to discuss thoughts about their diagnosis and exchange strategies they have developed to adapt to their changing needs. Of particular note were the following 2 contributions from the audience:

1] People with any form of cognitive condition can become lost, and/or may be or unable to communicate their meanings or objectives whilst out and about. The stress for them and their families may be reduced by the wearing of a locator device. Purposely designed products do exist, for example: MindMe Locate which can be bought by the public and had been recently trialled by members of the group.

2] A learning programme accessible via a website called [www.react2.com](http://www.react2.com) was heralded as a helpful tool by a member who shared details with the group. Allowing amongst other things, various pictures to be identified with appropriate noises etc., it was proving a very helpful device for this member of the group.

Please do let me have any thoughts regarding agendas for future meetings, or indeed feedback regarding how we can make our meetings as beneficial as possible.

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## Jacqueline Kindell: Semantic Disorder

We were grateful to Jackie for making the journey from Manchester to join us for the support group meeting, during which she presented some of the findings of her ongoing research, combined with a longstanding expertise acquired through her role as a speech and language therapist working with people with dementia.

A brief summary of her presentation is provided here.

Semantic dementia, also termed the 'semantic variant of primary progressive aphasia', is a type of frontotemporal dementia with a progressive and striking receptive and expressive communication disorder (Neary et al. 1998, Gorno-Tempini et al. 2011). In semantic dementia, the central deficit in semantic memory leads to difficulty attaching meaning to, and therefore recognizing and understanding, words, objects, faces, sounds, smells, touch and tastes (Hodges and Patterson 2007).

Most studies examining communication in semantic dementia have concentrated on performance on structured speech and language tasks within experimental settings. However, there is a lack of research looking at natural conversation and the challenges generally in everyday life in this condition. This includes how family members interact with the person with semantic dementia and how the person themselves views their difficulties. There has also been an assumption that the difficulties most prominent on testing are also the difficulties that the person, and their family, finds most challenging in everyday situations.

Given the priority is usually to help the person communicate as well as they are able in everyday situations, then greater understanding of such conversation issues is required in this condition. Jackie's work demonstrates, and indeed her presentation conveyed the fact that even those with significant language difficulties may maintain certain aspects of communication that can be used to 'make connections'. This might be skills with body movement, facial expression, eye contact or even singing. Jackie is exploring these issues in her research.

Jackie also spoke about the need to understand that communication in families living with dementia is as much about emotions as language skills. Adapting to changing communication abilities requires support for the person and their family. This can be particularly challenging for those living with an atypical dementia where appropriate support and accurate information are hard to find.

For advice about communication and other issues in frontotemporal dementia the following 'FTD toolkit' from Australia has some very useful advice, particularly sections 3, 4 and 5: <http://ecdc.org.au/ftd-toolkit.htm>

For those interested in advice for swallowing difficulties the following freely available guides may be of help:

Difficulty Swallowing in Dementia (Peterborough Dementia Group):

<http://www.dementia.jennerhealthcentre.co.uk/documents/Swallowing%20guide%20for%20relatives%20carers.pdf>

Eating and drinking in dementia: A guide for families and carers (Guy's and St Thomas'):

<http://www.guysandstthomas.nhs.uk/resources/patient-information/elderly-care/2300-eating-and-drinking-in-dementia.pdf>

## Lore Windemuth –Wolfson and Linda Yue: The Scribe Project

A new and developing project for people who are no longer able to complete writing projects on their own was described by Lore Windemuth –Wolfson and Linda Yue at the December meeting. SCRIBE provides a creative outlet for people whose illness is encroaching on their ability to complete work like book chapters, articles, scripts, academic papers or personal writings. They may have a physical disability which prevents them from typing and writing or they may have early dementia and need help ordering and structuring their thoughts. Lore and Linda and their small bank of scribes each have specific writing skills that can be matched with the client's particular project. SCRIBE aims to help clients maintain their sense of independence and purpose in life.

The service is borne out of personal experience as, in 2012 Lore's husband Paul was diagnosed with a rare and rapidly progressing form of dementia, which affected his ability to read, write or speak. Writing was Paul's life. Before he became a rehabilitation psychiatrist for the NHS, he'd spent 7 years as a comedy script-writer for theatre, TV and radio. As a doctor he continued his creative writing but was also involved in academic publications.

As Paul became less able to do day-to-day things like cooking or helping with the children, his writing actually became more important to him.

Lore explained that it turned out to be a total godsend when Linda started working with Paul. She had taken on most of the practical work at home and, despite the fact that she knew Paul hated having to ask for increasing help, Lore was finding it stressful to keep the family life going. His work sessions with Linda meant there was something she didn't have to organize or be responsible for and it gave him a greater sense of independence and purpose. All of those things made a huge difference to the state of their relationship. "We managed to stay partners for longer."

Linda explained how she worked with Paul two or three times a week for a few hours at a time. During this time they completed a wide variety of projects. Initially her role was simply to type as Paul talked. Gradually, as his symptoms worsened, Linda made suggestions about wording, did research and helped to edit and structure the work. Towards the end of his life they talked a lot about the subjects and developed themes and ideas more collaboratively.

**How will Scribe work?** The service will offer a half an hour introductory session whereby they will aim to agree with the client what they would like to achieve. They then offer six sessions up to two hours each, in which to complete the writing project(s). At the end of this time they will evaluate progress with the client and may agree further sessions as needed. If attention or concentration are a problem the sessions could be shorter, but the expectation would not be that they would work solidly for the two hours. This time period offers opportunity for pauses.

For more information about the service please email: [scribe@1stframework.org](mailto:scribe@1stframework.org)

## Forthcoming meetings

**Joint FTD/PPA/PCA Carers Meeting:** Thursday 13 Feb 2014: Wilkins Haldane Room, UCL, Gower Street, London WC1E 6BT. 11am – 2pm. Altered intimacy within close relationships, following the diagnosis of dementia will be the focus of this meeting. Guest speaker Jane Youell.

**Hertfordshire regional support group meeting:** March 28 2014: 11am-1pm at The Junction, Christchurch C of E, The Common, Chorleywood, WD3 5SG. An informal event providing opportunity to meet others with PPA.

**Full PPA Support Group Meeting:** Thursday 5 June 2014: Wilkins Haldane Room, UCL, Gower St, London, WC1E 6BT. 11am-2pm.

### **Additional events of interest:**

**Frontotemporal Dementia Support Group Annual Seminar:** Tuesday March 4 2014 9.30am-4pm. 33 Queen Sq., London, WC1N 3BG.

The agenda will encompass a wide range of FTD related issues, with more details available from Jill Walton.

Please contact Jill Walton for further information on any of the above

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