

Welcome to the PPA Support Group Newsletter. Please see overleaf for details of forthcoming meetings and kindly confirm your attendance to Jill Walton at [jill.walton@ftdsg.org](mailto:jill.walton@ftdsg.org) or 07592 540 555. I am pleased to confirm that we are now able to make the presentations delivered by speakers at our support group meetings, available as audio recordings to download via our website link. As such, the presentation made by Luke de Visser, Senior Speech and Language Therapist, at the June meeting entitled 'Communication strategies to use with people with PPA which may increase success and enjoyment of conversation' is now available at <http://www.ucl.ac.uk/drc/support-groups/PPA-support-group>

Additionally, the Annual Seminar which was hosted by the Frontotemporal Dementia Support Group earlier this year is now available for audio download via the Frontotemporal Dementia Support Groups website <http://www.ftdsg.org/audio/lectures2014/> Jackie Kindell's presentation may be of particular interest to people managing a diagnosis of semantic dementia.

Luke's recent presentation made reference to various iPad applications [apps] which people may find helpful as an aid to communication. They included:

- 'Predictable'; a text to speech application for iPad, iPhone and iPod touch, for which more information is available at [www.therapy-box.com](http://www.therapy-box.com)
- 'Pages'; for which more information is available at [www.apple.com/uk/ios/pages](http://www.apple.com/uk/ios/pages)
- 'Proloquo2go'; for which more information is available at [www.assistive.com/product/proloquo2go](http://www.assistive.com/product/proloquo2go)

Prices for the above apps range from less than £10 to around £150, and people may justifiably feel cautious about spending money on a programme ahead of knowing whether it will be helpful. It is worth asking the manufacturer about trial period availability, and also worth enquiring locally, through speech and language therapists or social workers, about grant provision for equipment and/or software.

Apart from the cost associated with technologically assistive devices, there may be reluctance around embracing these devices, and an uncertainty about how to best operate the software. Whilst I can't vouch for the suitability of the references highlighted over the page, they may be of interest to anyone considering embarking on an investment.

I do still have copies of Jackie Kindell's recently published case study 'Living with Semantic Dementia: A Case Study of One Family's Experience' available and can supply to anyone who would like to receive it, by email or hard copy.

I have previously referred to the critical need to raise awareness of not only PPA, but rarer types of dementia in general, and the unique challenges faced by younger people embracing these diagnoses. I am delighted to confirm that a raising awareness event which will focus on exactly these issues is being arranged. It will take place in the House of Lords on December 9 2014 with both Baroness Sally Greengross and Professor Nick Fox due to attend and welcome an invited list of guests. Baroness Sally Greengross is a crossbench (independent) member of the House of Lords and the All-Party Parliamentary Group on dementia. Prof Nick Fox is director of the Dementia Research Centre, UCL. I will of course keep you updated and intend for this event to achieve the primary objective which is to have key players leave the event with a mind-set they didn't have before they came: principally that dementia affects younger people too. This event is a support group initiative and a platform upon which your needs can be represented.

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. I look forward to seeing familiar faces and welcoming new people alike at the meetings listed overleaf.

Jill Walton 07592 540 555 or [jill.walton@ftdsg.org](mailto:jill.walton@ftdsg.org)

## Growing ideas: how can speech and language therapy help your conversations?

Anna Volkmer is a highly specialist speech and language therapist, working at South London and the Maudsley Hospital. She will be presenting at the British Aphasiology conference later this year, and has a long standing interest in PPA having written and published on the subject. References to her work can be found at:

<http://www.jr-press.co.uk/cognitive-communication-difficulties-dementia.html>

<http://www.britishaphasiologysociety.org.uk/conferences>

Anna has agreed to come and join us at the PPA support group meeting on October 9<sup>th</sup> 2014, where she will share her understanding in a presentation entitled: **Growing ideas: how can speech and language therapy help your conversations?**

Please see overleaf for details of the October 9<sup>th</sup> meeting.

## Information Technology and Assistive Technology Devices

In a recent study looking at opportunities for people with dementia being supported to use computers, Sarah Kate Smith from the School of Health & Related Research at the University of Sheffield worked with people with dementia, enabling them to use various IT devices uploaded with familiar activities including dominos and jigsaws as well as interactive applications enabling members to illustrate their creative flair.

Although the study was not specific to people with a diagnosis of PPA, some of these devices were able to be personalised to the individual's needs and requirements, in a way that might be relevant for our group members.

The study concluded that people living with dementia do not lack the desire to interact with contemporary IT devices, but rather lack the opportunities to trial them, and as such, her recommendations of ideas for activities using computers include:

- 'We can do IT too' is written by Nada Savitch and Verity Stokes and published by Speechmark. The point is made that as computers and other digital gadgets such as cameras and phones are part of our lives, so it is important that people with dementia engage with these IT driven activities. The book focusses on using computers as part of activity programmes for people with dementia and is available from Amazon via <http://www.amazon.co.uk/We-Can-Do-IT-Too/dp/0863888321>
- 'iPad engage' is an organisation which aims to inspire creativity through ipads using various digital apps. It is directly focussed around individuals living with dementia, with the purpose of improving engagement and digital confidence.

For more information see <http://ipad-engage.blogspot.co.uk>

### Websites of interest

The following websites have been listed in previous newsletters, but remain of potential interest to our members:

[www.ftdtalk.org](http://www.ftdtalk.org)

[www.youngdementiauk.org](http://www.youngdementiauk.org)

<http://www.ppaconnection.org/>

### Forthcoming Meetings

**1] East Sussex Regional PPA support group meeting** on Wednesday September 17 2014

12noon -2pm

Venue: The Ostrich Hotel, Station Road, Robertsbridge, East Sussex, T 32 5DJ

An informal meeting for people affected by a diagnosis of PPA, their family and friends.

**2] Full PPA support group meeting** on Thursday Oct 9 2014

11am-2pm [ coffee available from 10.30am]

Venue: Wilkins Front Quadrangle Events Venue on the UCL Gower St site.WC1E 6BT.

We are delighted to be joined by a guest speaker Anna Volkmer who is a Highly Specialist Speech and Language Therapist. Anna is presenting at the British Aphasiology conference later this year, and has a long standing interest in PPA having written and published on the subject.

**3] Joint carers meeting** on February 26 2015

11am-2pm [ coffee available from 10.30am]

Venue: Wilkins Front Quadrangle Events Venue on the UCL Gower St site.WC1E 6BT.

We are expecting 2 guest speakers at this meeting;

**Angela Sherman** will be talking about continuing healthcare funding applications. You can find out more about the organisation she directs at [www.caretobedifferent.co.uk](http://www.caretobedifferent.co.uk)

**Dr Eneida Mioshi:** Department of Psychiatry, University of Cambridge School of Clinical Medicine, who will be talking about coping strategies for carers, amongst other things

**4] FTDSG Annual Seminar** on March 5 2015

9am-4pm

Venue: 33 Queen Sq, London, WC1N 3BG

A whole day event, with speakers delivering presentations on a range of FTD related subjects. Agenda to be confirmed nearer the time.

**5] Full PPA support group meeting** on Thursday 30 April 2015. Details to be finalised.

Please confirm your attendance to Jill Walton at [jill.walton@ftdsg.org](mailto:jill.walton@ftdsg.org) or 07592 540 555