

## Support Group Meeting February 4<sup>th</sup> 2013

The meeting on February 4<sup>th</sup> 2013 was a joint carer's meeting, held in conjunction with carers from the frontotemporal dementia support group. Around 40 people attended, several of whom were attending for the first time. Dr Susie Henley opened the session by talking about the complex process of accepting a diagnosis of dementia in a friend or family member. She listed some of the processes this inevitably entails and also used the session to explain a new counselling service which she is to be a part of, which will offer a series of counselling sessions for people diagnosed with dementia at the National Hospital for Neurology and Neurosurgery. Whilst this service will not in the first instance be available to all, it is hoped that results will show that people who receive the counselling service benefit from it in a significant way, and that a case can be made to roll the service out more widely.

Susie is a research and clinical psychologist at the Dementia Research Centre, UCL, and a summary of her talk is provided in this newsletter.

After a break for refreshments, we reconvened in smaller groups, in order to contribute to a discussion about the particular specific service and care needs of younger people with dementia. This discussion was preceded by a brief explanation from Robert Holman, a mental health commissioning officer in the London borough of Camden, about the care commissioning process that exists in Camden, which is the borough in which the NHNN is situated. Feedback from the discussions was shared at the meeting, and will be collated, together with feedback from similar styled sessions that have since been conducted with other young onset dementia support groups. The final report will be made available via the support group networks.

The next PPA support group meeting is to be held on June 20<sup>th</sup> 2013, in Wilkins Old Refectory, Wilkins Building, UCL, Gower St, WC1E 6BT from 12noon until 2.30pm. Dr Phil Fletcher will be providing an update on the clinical aspects of PPA at this meeting. Lunch will be provided! You are of course very warmly invited to this meeting...please let Jill Walton know if you are able to join us, via any of the contact details listed overleaf.

## The impact of a diagnosis of dementia on carers

Susie Henley (Clinical Psychologist) spoke about the impact of a dementia diagnosis on carers and some resources that carers might find useful. There are over 670,000 carers for people with dementia in the UK and the amount of free care they give saves the state around £8 billion. Often carers experience difficulty in getting a diagnosis for the person with dementia, because the symptoms aren't well-recognised, and then find they are "left alone" after diagnosis when in fact they really need on-going support and information. And whilst it can be a relief finally to be given a name for what's going on, it can also be very upsetting and make the future seem uncertain.

Susie touched a bit on the social dilemmas that arise when you care for someone with dementia – friends and neighbours often can't see that anything is wrong, don't understand what help you might need, or in the later stages just assume that there's no point visiting. She suggested that it is important not to assume that everyone will react like this though, as this can put you off asking for any sort of help; do try to ask friends and neighbours for what you need and see what the result is. The emotional impact of dementia is also hard – many people go through a wealth of feelings from guilty, angry, and annoyed, to sad and despairing. Coming to a peer support group is one way of realising that it is normal to feel like this, and that many other carers also have those feelings from time to time. Sometimes you can manage these feelings by finding some time to yourself, or letting off steam with a friend, or going out for a walk, but if they become overwhelming and stop you from getting on with what you want to do, there are lots of options that have been shown to be helpful. Your GP should be able to refer you to a form of counselling, of which there are different types to suit different people, and your GP should also be able to discuss whether some medication might help lift your mood, particularly if you feel very down or worried.

More and more research is focusing on carers and their needs. Key messages are that carers need on-going support after diagnosis, and that healthcare professionals must recognise that the needs of the carer and the person with dementia change all the time. National guidelines for carers (NICE) now say that all carers should have an assessment of their needs (which includes assessing for and treating psychological distress if necessary), and should be given education about dementia, peer-support groups and information about benefits and legal matters. Ideally a lot of this initial information should be provided by an NHS clinic, although feedback from carers shows that services really vary in how much they understand about dementia and what information they can offer. Susie listed a number of websites, both NHS and voluntary, that have information about legal, financial, and social support that is available. The importance of peer support groups came up several times, and was reinforced during the meeting as the most useful answers to questions people had at the end of the talk were from the other carers there; and it is great that people feel able to share their experiences with each other at the meetings.

## Sustaining everyday conversations for couples where one partner has semantic dementia: A case series intervention

Jacqueline Kindell – University of Manchester

Members of the support group are often interested to know about PPA relevant studies and research. As such, we have included this explanation of a study which Jacqueline Kindell is currently undertaking:

I am a speech and language therapist and have worked with people with frontotemporal dementia and their carers for a number of years. Funded through a Dunhill Medical Trust Research Training Fellowship, I am undertaking a PhD study at the University of Manchester to look at everyday conversation in people with semantic dementia, which is a variant of Frontotemporal dementia or Pick's Disease. Much of the work in this area so far has examined performance in test situations; however, in this study, I am looking at everyday conversation difficulties at home. As well as examining conversation, I am looking at the individual's life story and how this frames their conversation; for example, in what the person with semantic dementia likes to talk about. We know from some of the research, that people with this condition often have favourite topics of conversation that are important and unique to them. Following assessment, which will include videotaping talking and interviewing the person and their carer/family, I will be designing an individually tailored support intervention. This approach will help the couple/family to identify the best ways to encourage communication and manage any difficult areas with respect to conversation. I will then assess if this intervention is helpful.

I will be recruiting six couples/families for this project during 2013-2014 from the Greater Manchester area; so far, two families have come forward to take part. Local clinicians such as older age mental health services, memory clinics, neurologists and speech and language therapists are being asked to refer interested individuals into the study. The reason for this is because I want to make sure all the relevant diagnostic tests have been completed, individuals meet the study criteria and the study fits in with any existing treatment or therapy being given locally. Supervisors for this study are: Professor John Keady from the University of Manchester and Professor Ray Wilkinson from the University of Sheffield.

I hope that this study will find out important information about everyday life with semantic dementia so that in the future we can provide the right support and right information at the right time.

If you would like to know more about the 'everyday conversation and semantic dementia project' please contact me:  
Jacqueline.Kindell@postgrad.manchester.ac.uk

### Strategies for people with PPA

Communicating with people affected with FTD can be challenging—for both parties involved. Joanne Douglas has PPA. She has a PhD in Molecular Microbiology and worked as a professor at The University of Alabama at Birmingham (UAB) in the field of human gene therapy. She has written three short pieces containing tips on communicating: one is for people affected with PPA and suggests how they can most effectively use their words and communicate with others, the second is for other people who are trying to speak to someone with PPA. The third piece came about as Joanne continued to experience a decline in her ability to speak, read and, especially, to write. The tips she learned earlier still serve her well and she is continuing to implement those approaches on a daily basis. She has devised some additional strategies which make meaningful improvements to her quality of life as her condition progresses.

Please visit [www.theaftd.org](http://www.theaftd.org), type PPA into the search box on the home page, then scroll down to 'Strategies for people with PPA' to access these accounts.



### Forthcoming meetings

**Summer Meeting: Thursday June 20<sup>th</sup> 2013** Wilkins Old Refectory, Wilkins Building, UCL, Gower St, WC1E 6BT .12noon until 2.30pm. Dr Phil Fletcher will be providing an update on the clinical aspects of PPA

**Autumn Social Event: October 4<sup>th</sup> 2013** 'An afternoon at the British Museum' 2pm-4pm. A specially guided group visit to the British Museum, Great Russell St, London, WC1B 3DG. During a welcome which includes tea and biscuits, museum staff will chat about the museum, tell us what they do and ask us about our group. We will then explore and handle some objects together, linked to the collection. This will be followed by a visit to the galleries, with us being able to choose which gallery we want to see.

**Joint FTDSG/PPA Carers Meeting: Mon Feb 3<sup>rd</sup> 2014** The Old Boardroom, NHNN, Queen Sq., London WC1N 3BG

For more information or to confirm your attendance, please contact Jill Walton 07592 540 555 or email