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PPA SUPPORT GROUP MEETING FEB 6TH 2012

On February 6th, members of the PPA support group met together with carers from the Frontotemporal Dementia Support Group [formerly Picks Disease Support Group], in a pilot joint meeting.

The meeting began with informal discussion around issues which were of relevance and importance to people attending. There was significant helpful exchange of information and advice between group members, which included, amongst others, the following topics:

- The need for information and advice regarding benefits, at diagnosis
- The impact that counselling can make on a carers ability to cope. Cruse was mentioned as a good resource, [www.crusebereavementcare.org.uk], but most GP practices have a counsellor attached to them, and should be willing to refer patients as appropriate
- The importance of keeping a daily record of behaviour and care needs over a period of a fortnight, in order to be able to accurately assess, present and justify needs to care providers
- Noting the value of respite care
- Alzheimer's Society literature was noted as being particularly helpful: Visit alzheimers.org.uk/
- The Princess Royal Trust for Carers was also noted as a beneficial source of information, help, advice and discussion for carers: Visit www.carers.org/
- The need to always be looking ahead to care needs, and trying wherever possible to avoid having to make big decisions in a moment of crisis

Very significant was the tangible relief felt by many people present, just at realising they were not alone in the situations they were facing.

After lunch, Dr Phil Fletcher delivered an informative presentation , in which he explained the classifications of diseases within the diagnosis of Frontotemporal dementia. A summary of his presentation is provided overleaf.

Dr Jason Warren joined us for the afternoon session, and the meeting ended with an informal question and answer session which they kindly co-hosted.

Feedback from both groups of carers was very positive, and I will be arranging another joint meeting on February 4th 2013. In the meantime , I draw your attention to the carers' meetings that the FTDSG regularly hold, and extend a very warm welcome to anyone wishing to attend them. Often informal in nature, they do facilitate the opportunity to meet with others in a similar position, and thereby exchange news, views and feelings [view the meetings calendar at www.pdsg.org.uk]

The meeting on Feb 6th really demonstrated how much of an overlap there is with regard to many of the care issues relating to Frontotemporal dementia and the classifications of diseases it encompasses.

Looking ahead, I plan to provide the Frontotemporal Support Group newsletters to the PPA Support Group members, with additional PPA specific material attached. I very much hope that this will provide people with access to additional useful information. We will work towards the completion of an FTD specific assessment of need, which carers can use in order to assess and record care requirements, and we will look at ways in which we can provide important factual information at as many points of contact for carers, as possible..

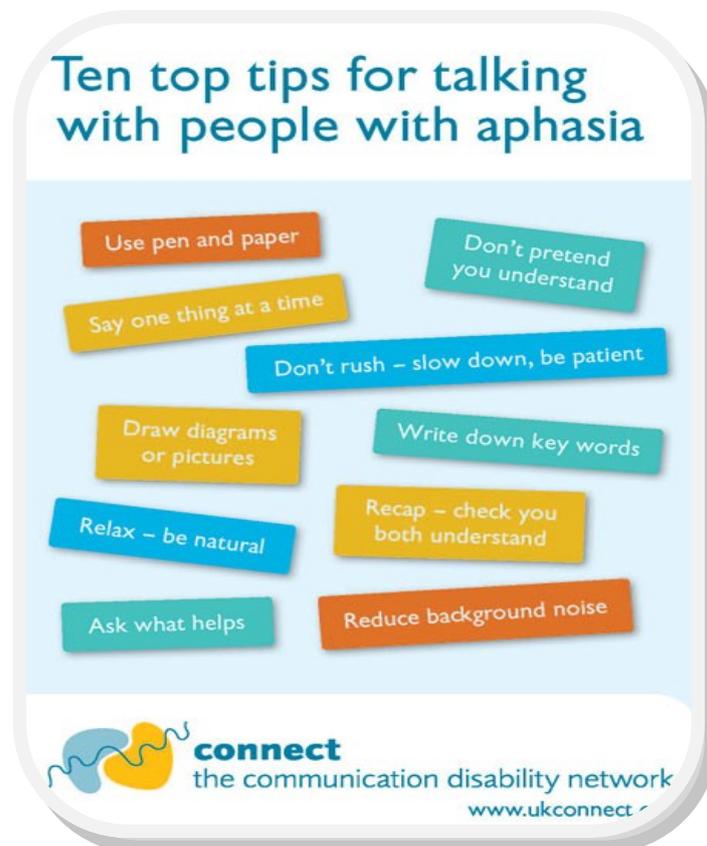
The **Aphasia Alliance** is a **coalition** of key organisations from all over the UK that work in the field of aphasia that have united to **raise awareness** of aphasia.

Connect is one of 11 member organisations within that coalition. It is a charity for people living with aphasia, which they define as a communication disability which usually occurs after stroke or brain injury.

In the case of people in the PPA support group, the aphasia they experience is the result of degenerative brain disease, and whilst this presents many issues which are not common to others who experience aphasia as a result of injury or stroke, there can be some common ground, particularly in the earlier stages of the disease.

We are currently working with the staff at Connect, to establish links between their network and our group, and a recent article in their October 2011 Newsletter included an interview with Rita Harris. During 2003 Rita became aware that her speech was becoming more hesitant and she was having difficulty articulating words. The result of investigations and brain scans, was a diagnosis of Primary Progressive Aphasia.

Much of the practical advice and information provided by these organisations is of interest and potential value to our members, as the flier below demonstrates:



Another interesting link, which one of our members described during a recent visit to clinic, is the twitter site twitter.com/aphasiaboard, which facilitates 'forum' style communication between people.

Visit www.ukconnect.org and www.aphasiaalliance.org for more information!

FTD : A Simple Classification!

At the meeting on February 6th, Dr Phil Fletcher provided a clear overview of the way in which Frontotemporal dementia can be grouped. He described FTD as something of an umbrella term, under which there are several sub classifications.

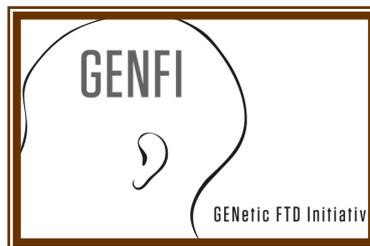
Approximately 50% of FTD is characterised initially by progressive behavioural/personality decline. These changes in personality, behaviour, emotions and judgement are what we describe as behavioural variant FTD. Picks' disease comes into this category of FTD.

Progressive language decline, in which people initially present with changes in language abilities, including speaking, understanding, reading and writing, form a range of conditions which are grouped under the Primary Progressive Aphasia diagnosis. Semantic dementia, progressive non fluent aphasia and logopenic aphasia come under this category of FTD.

Whilst earliest symptoms may be very focal and isolated, as the disease progresses, so degeneration of cells and function becomes increasingly global, with later stages of the behavioural variant and the PPA form of FTD sharing many common symptoms.

There are other variants of FTD, some of which can present with progressive motor decline and difficulties with physical movement. These include Corticobasal Degeneration, Progressive Supranuclear Palsy, FTD with Parkinsonism amongst others.

Phil Fletcher is a Research Fellow at the Dementia Research Centre, NHNN.



Are you part of a family with a genetic form of frontotemporal dementia or primary progressive aphasia?

We are just starting a new study of genetic FTD and PPA. Anyone who is a first-degree relative of someone with a genetic form of FTD or PPA would be eligible to be in the study (a brother, sister, son or daughter). The genes we are specifically looking at are **progranulin** and **tau** and also people with motor neurone disease in the family. We are also studying people who are affected with genetic FTD or PPA. The study involves some psychology tests, a brain scan and a blood test over the period of a day.

If you would like any further information please contact:

Dr Jonathan Rohrer (University College London) - j.rohrer@ucl.ac.uk, Dementia Research Centre, UCL Institute of Neurology, Box 16, National Hospital for Neurology and Neurosurgery, Queen Square, London, WC1N 3BG

or

Dr James Rowe (University of Cambridge) - james.rowe@mrc-cbu.cam.ac.uk, MRC Cognition and Brain Sciences Unit, 15 Chaucer Road, Cambridge, CB2 7EF.

Email addresses required please.....In order to keep running costs to a minimum, and to facilitate ease of communication, it would be helpful to have as many email addresses of PPA Support Group members as possible. Please contact me at jill@pdsg.org.uk with your email contact details. **Many thanks!**



PPA Support Group Meeting May 11 2011

The next PPA meeting will take place on May 11 2012, at University College London, WC1E 6BT. The college site we will be using for this meeting is accessed via the Malet Place entrance. Malet Place is just off Torrington Place, which in turn is just off Gower St. There is a large Waterstones bookshop opposite the entrance.

We will meet in a room called Malet Place Eng. 1.04 which is reached by entering the building via the Malet Place entrance. The security officer on the door will be aware of the meeting, and can direct you to the room. Please phone me on 07592 540 555 if you need assistance!

Malet Place is a few minutes walk from both Euston Square and Goodge St underground stations.

We will meet at 12 noon for sandwiches and drinks, which we hope will allow for informal introductory conversation. Dr Jason Warren will co-host a question and answer session from 12-30pm until 1-30pm. Following this session, Luke de Visser, a speech and language therapist will deliver a presentation, describing the role of the speech and language therapist in PPA, to the group.

A second room has been reserved, and we have arranged for musical workshop activities, to be provided by professional musicians, for anyone preferring to engage in this activity whilst Luke delivers his presentation.

The meeting will conclude by 2-30pm.

Please know that you are warmly invited to this meeting, and do not hesitate to get in touch with me for more information, or to confirm your attendance!

Jill Walton jill@pdsg.org.uk tel 07592 540 555

If you would like further information about the support group, or would like to submit any articles for inclusion in this newsletter, please contact jill@pdsg.org.uk, or telephone 07592 540 555.

The Dementia Research Centre can be contacted at dementia.ion.ucl.ac.uk or at .Dementia Research Centre, Box 16, The National Hospital for Neurology and Neurosurgery, Queen Square, London, WC1N 3BG. Tel: 020 3448 4773

Useful Links

Various organisations are potentially beneficial to our members. Here are some of the links to those organisations. Please do let me know of others for circulation amongst our group, via this newsletter:

<http://www.speakability.org.uk/> Speakability is the **national** charity dedicated to supporting and empowering people with Aphasia and their carers.

www.pdsg.org.uk Information for carers of people with Frontotemporal dementia

www.ukconnect.org A charity for people living with aphasia

www.aphasiaalliance.org A coalition of 11 member organisations, all linked to aphasia

alzheimers.org.uk Information and advice on many aspects of dementia

www.carers.org Information, help and advice for carers.

www.dementiauk.org Support for family carers, professionals and people with dementia