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PPA SUPPORT GROUP MEETING SEPT 7TH 2011

The meeting was attended by 25 group members, including both patients and carers, and a total of 6 associated members of staff. We began with general conversation over refreshments which were provided in the meeting room.

At 1pm, members were invited to visit the Art Therapy room, [next door] which would be available to anyone wishing to partake in the session being provided there by 2 therapists from the London Art Therapy Centre. By 1-15pm the group had re convened accordingly, and those wishing to hear Dr Jason Warren present 'A Research Update on the Progressive Aphasias' had the opportunity to do so.

Dr Warren spoke for approximately 30 minutes, before taking questions until 2pm. Some of the questions/comments raised were;

- 1] Are there standardised questionnaires which are used to gather information from people with PPA or similar diseases. Dr Warren explained that there are, and these tend, when used, to be administered on an annual basis.
- 2] Is it common for people with PPA to hum? And is the humming tendency linked to any research into music recognition?
- 3] Tone of voice was noted as being particularly significant in the effect it has on people with PPA.
- 4] The wisdom in forewarning as many people as possible about potential complications in communication and behaviour was generally accepted as prudent. Trying to reduce the opportunity for conflict by informing receptionists/staff/local shop keepers etc. ahead of any crisis situation was considered a wise move.
- 5] The need for studies of the 'end of life' stage of this and similar diseases was raised. Dr Warren endorsed the need, and accepted that most of the research that he and his colleagues are involved in tended to focus along more specific scientific hypotheses. These were important issues in their own right, as they all help us to understand the nature of the disease more fully. Patients seen in the clinic at the National Hospital for Neurology and Neurosurgery are more typically in early stages of the disease process.

Dr Warren left the meeting, which provided for a natural 5 minute break. There was some movement between the Art Therapy room and the meeting room, before a general discussion and question and answer session was facilitated. Dr Philip Fletcher, who is himself new to the group, introduced the session by outlining his research aims and objectives. These will be presented in a forthcoming newsletter article.

General discussion amongst the group covered many topics including;

- 1] recognition of the need for respite care, but with an acute awareness of the difficulties of letting someone go! How does one know the time has come to accept respite care? The need for good quality care arrangements, where people can be kept active and involved was of paramount concern.
- 2] The term 'dementia' was discussed, along with all the connotations it inevitably implies. In general, members felt that people were patronising once the term dementia had been mentioned. Even in places where you would expect understanding and empathy, people were not particularly aware or practical in their approach. Nurses were listed as a group particularly guilty of this. Melissa Loucas made the point that communication in hospital settings has long been the subject of discussion and debate. The whole 'institutionalisation' processes that accompany any body's visit to a hospital setting, impact even more acutely when the person involved has dementia. **The Royal College of Nurses launched a national commitment to improve the care of people with dementia in hospitals on Sept 21st, following a recent survey of people with dementia and their carers about their experiences in hospital.**
- 3] There was some discussion around terms of reference that might be helpful when explaining to others just what a diagnosis of PPA means. '**Serious neurological behavioural condition**' was generally accepted as all encompassing!
- 4] Realising and accepting that no-one could make this disease, with all its incumbent implications better, was discussed and acknowledged as a potentially very lonely place to be. Carers expressed feelings that no-one seems ter-

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ribly interested in their plight, and that having to fight for services was the last thing most people felt able to do whilst coming to terms and dealing with all that the diagnoses hold. The right to an 'Assessment of Need' and a 'Carers Assessment' was stated as something to be requested of the GP in the first instance.

5] In response to carers complaints that GP's didn't seem to know about the disease, Dr Phillip Fletcher explained that it is a rare disease, which many GPs will never see, and certainly not see on a frequent basis. Whilst it is difficult for any one GP to be aware of all the unusual diseases he/she may come across, there is a need to increase awareness generally and specifically around dementia and its types. **The Pick's Disease Support Group is currently launching a 'Raising Awareness' campaign, which, once piloted may be of interest to this PPA Support Group!!**

6] Admiral Nurse services were discussed and clarification requested in terms of their availability. We can confirm that whilst practical provision is indeed available only in some geographical locations, the helpline service is available to all. Telephone **Admiral Nursing DIRECT** on 0845 257 9406

or contact via: www.dementiauk.org/what-we-do/admiral-nurses

7] There was a positive response to the suggestion of re-instating the newsletter, with a request for any information/ advice/guidance to be included in it. To that end, I invite you to send any contributions you wish to make to:

jill@pdsg.org.uk or by post to 22 Brushwood Drive, Chorleywood, Herts, WD3 5RT

ART THERAPY WORKSHOP

We were well served by the 2 art therapists supplied by the London Art Therapy Centre; The session operated on a 'drop in' basis, with Marcia and Yafit operating very flexibly around our needs. They suggested that clients think about a significant moment in their life, and try to represent it through art. To this end, they provided a selection of mediums, ready made images and stimuli to get people started. Whilst some people spent most of the meeting time in the Workshop, others drifted in and out, sometimes accompanied for a time by carers.

All work was available to take home at the end of the session, and I sensed that the session had run smoothly and been generally well received.

END OF LIFE ISSUES

Call it what you may, planning for the inevitable decline towards end of life is often painful and traumatic. When the person you are planning with and for has dementia, then the process can be even more complicated and painful.

In a recent Alzheimer's Society publication, [Living with Dementia June 2011] an article entitled 'Being Prepared' outlined the benefits to thinking and planning ahead. Putting people with dementia more in control of their lives, reducing stress on families and carers later down the line and increasing the chances of a 'good death' are amongst the benefits listed. Peter Ashley, a member of the Dying Matters Coalition, and himself diagnosed with Lewy Body Dementia is quoted as saying "People are scared. They don't want to talk about dying.. They think of today, not tomorrow. Thinking about what's going to happen later when you lose your capacity can be a disincentive to planning ahead. But if people can overcome these problems they might be able to see the merit in it".

As a result of several conversations over recent weeks with members of this and other support groups, we wish to bring to your attention the following publications:

www.dyingmatters.org.uk has lots of information about planning ahead

<https://www.respectourwishes.com/>

www.endoflifecareforadults.nhs.uk/publications/planningforyourfuturecare

Also, the Alzheimer's Society have just published factsheet 463: Advance Decision

The General Medical Council has written advice and policy documents with regard to Advance Planning and is apparently aware of the need to incorporate the very specific issues that arise when a person has dementia. They can be accessed via:

www.gmc-uk.org

Go to the home page and then select 'Guidance on Good Practice'; then enter 'Advance Directives' into the search keywords box at the top right of the page

ON ANOTHER NOTE...the Alzheimer's Society public policy team wants to hear about your experiences of planning for end of life, end of life care itself and the emotional and ethical issues this brings up. If you would like to be involved, please contact Martina Kane via martina.kane@alzheimers.org.uk or call her on 0207 423 3580.

Dr Jason Warren is a Wellcome Trust Senior Clinical Fellow and Reader in Neurology, Dementia Research Centre, Institute of Neurology. He is currently involved in several research projects which focus on Primary Progressive Aphasia. He has summarised the presentation he gave at the September 7th meeting here:

Research update in the progressive aphasia

The progressive aphasia remain the focus of a major research effort, both at our Centre and in many other specialist centres in the United Kingdom and internationally. Key recent developments include:

- * Identification of clinical, psychological and brain scan features that predict particular diseases across the progressive aphasia spectrum
- * Mapping of the nerve fibre tracts that link brain areas together into specific networks in each of the major progressive aphasia syndromes
- * Building models of how these networks of nerve cells malfunction to help understand how the pathological process leads to damage (and ultimately, to symptoms)
- * Mapping of the changes in brain function that occur in progressive aphasia while the brain is working (e.g., listening to sounds), in comparison to healthy older control subjects
- * Improved understanding of the diversity of non-language impairments in the progressive aphasia, especially in the perception of environmental sounds, voices and music, behaviour and emotional comprehension
- * Agreement by an international panel of experts on criteria for use by neurologists and research scientists in diagnosing different subtypes of progressive aphasia
- * Establishment of the first international consortium of specialist centres (led by the Dementia Research Centre) to study the earliest markers of disease activity in people at-risk of genetic forms of progressive aphasia and other forms of frontotemporal dementia

Together these research directions have substantially advanced our understanding of the pathological processes and genetic abnormalities that cause progressive aphasia, the nature of the brain malfunction that causes symptoms and the range of symptoms that patients develop, how best to measure the brain changes caused by these diseases, and how to distinguish these diseases from one another and from other dementias such as Alzheimer's disease.

This detailed information is an essential step toward effective treatments: such treatments will depend on accurate identification of target diseases and accurate measurement of the effectiveness of interventions, ideally from an early stage when structural brain damage is still minimal and there is potential for reversal of damage. Future progress will depend on collaboration between specialist centres to pool expertise and patient numbers, and close cooperation between neurologists, psychologists, and basic scientists; and above all, on the continuing generosity and fortitude of our patients and families.

We would like to offer our sincere thanks to all our research subjects and their supporters, and to our funding partners, the Wellcome Trust, the Medical Research Council and Alzheimer Research UK.

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!**



NATIONAL KEY SCHEME FOR TOILETS FOR DISABLED PEOPLE



One of the practical, social problems facing carers of people with dementia is managing the use of public toilets. These are rarely unisex thereby making it difficult for a partner to assist with any practical help required during toileting activities. Access to a toilet designed for disabled people, providing more room and provision to assist can be of enormous benefit to those caring for a person with dementia.

RADAR believes that everyone who experiences ill-health, injury or disability should have the same freedom and independence as all other citizens.

One important part of freedom is having the confidence to go out, knowing that public toilets will be available that are accessible and meet your requirements..

If accessible toilets for disabled people do have to be locked, providers are asked to join the **NKS**, which involves fitting standard locks to their toilets and making keys available to disabled people. This has now been adopted by over 400 local authorities. Almost 8000 toilets have been fitted with the NKS lock. The scheme is also used by a number of other organisations including the National Trust, transport undertakings, shopping centres and some pub companies. Purchasing a NKS key, therefore allows access to NKS public toilets throughout the country.

For those who are unable to obtain an NKS key in their own locality, RADAR supplies keys at a charge of £3.00 (if collected and on declaration of a disability), £3.50 (if supplied by post and on declaration of a disability) or £4.11 (if the declaration is omitted)

The required declaration is simply a stated reason outlining why you are requesting a key...for example: 'I would like a key for my wife who suffers from dementia'.

REMITTANCE can be sent to: RADAR, 12 City Forum, 250 City Road, London EC1V 8AF.

Alternatively contact RADAR via: Tel: 0207 250 3222 Fax: 0207 250 0212 Minicom: 0207 250 4119

E-mail: radar@radar.org.uk

Useful Links

Various organisations were discussed at the last meeting as being 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.

<http://www.thrive.org.uk/> Thrive is a small **national** charity that uses gardening to change lives. 'We champion the benefits of gardening, carry out research and offer training and practical solutions so that anyone with a disability can take part in, benefit from and enjoy gardening.' ...Six years ago at 57 Denise was diagnosed with dementia and their plans were shattered. Now Denise is dependent on Stuart for all her needs, cannot express herself and barely understands the world around her. Denise and Stuart were both keen gardeners and when Denise used to come to Thrive once a week they both felt the benefit...

REST-BITE is a Camden based Alzheimer's Society initiative. It is a chance to meet others in similar situations and access information and support. Activities include; physical exercise with a Physiotherapist, music and singing and lunch followed by a massage. Contribution on the day is **£3.00 per person** attending inclusive of all the above. If you are interested in joining us at REST-BITE on Thursdays please call Muriel on: 0207 833 8369 or 07929981445

Forthcoming Meeting Dates: On Monday 6th Feb 2012 we will be trialling a 'carers only' support group meeting. Similar meetings have been requested and beneficial amongst some of the other Support Groups we are involved with. We intend to cover areas relating to loss and bereavement, as well as providing a clinical information update. The June meeting will see a return to the usual format. Details regarding venue and times will be circulated later in the autumn, but put the date in your diaries!