



Welcome to the January 2016 PPA Support Group Newsletter. We hope that the content is of interest to all who read it; however we are aware of the difficulties in producing information which meets everyone's needs and in a style which they are comfortable to embrace. Please do let us have any suggestions regarding the format of the newsletter and indeed any contributions you wish to make.

As many of you are aware, the cost of operating and running the PPA support group has been primarily funded to date through the Myrtle Ellis Fund: a funding stream which was generously initiated by the family of Myrtle Ellis when she was diagnosed with Posterior Cortical Atrophy in 2007.

We are extremely grateful to the family and to the many fundraisers who have subsequently contributed to keep the fund viable. We currently find ourselves in a position whereby we facilitate 5 disease specific support groups in affiliation to the Dementia Research Centre here at UCL, and after careful consideration and involvement with the Ellis family, believe it is time to re-launch the support group network with a new branding and remit which better captures our extended provision and allows us potential for ongoing growth and development. As such, on Feb 29 2016 – a rare day in itself - the new Rare Dementia Support initiative will be officially launched.

Rare Dementia Support services will be funded by the newly amalgamated Rare Dementia Fund. The Fund is being established within The National Brain Appeal as was the case with the Myrtle Ellis Fund. It will provide funding for the Dementia Research Centre at The National Hospital of Neurology and Neurosurgery, to continue providing support by way of meetings, newsletters, telephone contact networks, websites and access to advice and information for patients and carers dealing with one of the following types of rare dementia:- Frontotemporal Dementia (FTD)

Posterior Cortical Atrophy (PCA)

Familial Alzheimer's Disease (FAD)

Familial Frontotemporal Dementia (fFTD)

Primary Progressive Aphasia (PPA)

It costs over £35,000 a year to provide current levels of support for the five rare dementias - this includes 13 London and 50 regional meetings a year, a part-time support nurse co-ordinator and all associated expenses such as catering, marketing and venue hire. Over 2,000 people (UK and overseas) are currently on support group databases receiving emails and newsletters with around 1,000 attendees across all the meetings. In addition, travel and accommodation bursaries are available to help patients and carers attend the meetings.

In essence and on a practical level, nothing will change for you the service users. At an organisational and strategic level, Rare Dementia Support will allow us opportunities for service development and fundraising which, we believe, will enable us to increasingly meet the needs of people diagnosed with rare or atypical dementia diagnoses.

May I take this opportunity to invite you to the scheduled meetings listed on the back page of this newsletter. I look forward to seeing you or indeed being in contact with you in whatever capacity is most appropriate.

Jill Walton

UCL and UK supermarkets unite to beat dementia with carrier bag funds



UK supermarkets Iceland, Asda, Morrisons and Waitrose have pledged funds from the new levy on single-use carrier bags to support the construction of a new world class dementia research centre at UCL. The Dementia Research Institute will bring together researchers from across UCL and UCLH to lead national and international efforts to find effective treatments and improve the lives of those with dementia. The £350 million project currently has a shortfall in funding of £100 million, and the cash expected to be generated by carrier bag sales from Britain's food retailers has the potential to bridge much of that gap. Initial calculations indicate the project could raise £20m in the first year, depending on patterns of carrier bag usage under the new system. No over-

heads are taken from the sums raised, with 100% of funds going to support dementia research. **Professor Nick Fox, Director of the UCL Dementia Research Centre**, said: 'We are committed to creating a Dementia Research Institute at UCL as part of UCL rising to the challenge set by the PM and the G8 and posed by the scourge of dementia. UCL has made this a key priority. UCL can and will bring unmatched research breadth and depth as Europe's leading neuroscience centre and Europe's leading clinical dementia research, integrated and co-located with the National Hospital for Neurology .

Speaker presentations: PPA support group meeting Dec 3 2015

We were delighted to welcome Chris Hardy and Dr Sharon Savage as guest speakers at the Dec 2015 support group meeting. Chris Hardy, Clinical Research Assistant at the Dementia Research Centre, UCL spoke to the group about speech processing in primary progressive aphasia. Chris explained how speech is processed in the brain before going on to describe what happens to speech processing in PPA and what that means for people affected by it.

Dr Sharon Savage, PhD, Master of Clinical Neuropsychology at the Cognitive & Behavioural Neurology department, University of Exeter Medical School shared current research findings and their clinical application in a presentation entitled "Feeling lost for words? Word retraining programs to help people with Semantic Dementia". Sharon is planning a new research study in 2016 to create an app for word retraining in people with Semantic Dementia and is interested to know how often people with Semantic Dementia might use technology (such as tablets or smartphones) and get opinions on some design features for the app.

The end goal is to create an app that is effective and free for people with Semantic Dementia to use. If you are interested in learning more or contributing your thoughts please contact Sharon on 01392 722816 or s.a.savage@exeter.ac.uk.

Audio recordings of both speaker presentations are available at <https://www.ucl.ac.uk/drc/support-groups/PPA-support-group>



Couples course for people with Primary Progressive Aphasia in Surrey—Feb 2016

Dyscover [www.dyscover.org.uk] is an established third sector provider of specialist, Speech and Language Therapist-led, long term support for people with aphasia. Following the launch of a pilot project aimed at people with primary progressive aphasia in 2015, funding has now been secured to offer the course to other couples affected by progressive aphasia diagnoses. The course aims to help the person with the condition together with a family member or friend to preserve the success and enjoyment of interaction despite their language difficulties.

Six group sessions, spread over 12 weeks and led by two specialist Speech and Language Therapists offer a combination of information, practical help and peer support.

To find out more about the course email Rosemary Townsend BSc MRCSLT HCPC registered , at rtownsend@dyscover.org.uk or telephone 01737 819419

Research round-up

Individual experiences of changes in empathy : Bethany Coad

Bethany will be speaking at the Jan 25 2016 London FTDSG carers meeting, and summarises her research interest below:

Changes in empathy and difficulties in recognising and responding to the thoughts and feelings of other people can be an early symptom of frontotemporal dementia (FTD). These changes in how a person with FTD may respond to family and friends can be very distressing and can negatively influence a caregiver's quality of life. Because of this, researchers are making an effort to understand the changes in empathy that occur in FTD and the impact that these changes have on individuals who live with and care for people with FTD.

Beth Coad is a PhD researcher at Cardiff University and is talking to family members about their experiences of empathy changes in FTD and the impact these have had on them and their caregiving experience. Interviews can be conducted in-person or over the phone/skype at a time and location convenient to the participant. Beth is willing to travel, ideally conducting interviews within the Midlands, Wales and the south of England.

If you would like more information on this project please contact Beth on 02920 870478 or via email at: Coadbm@cardiff.ac.uk

Hyper sexuality Study: Natalie Tayim

Natalie is a PhD student working with Prof Jason Warren, an eminent UCL clinical and research neurologist :

Neurological disorders can sometimes be associated with changes in the desire for sex. In some disorders, the desire for sex can increase, but in others, desire for sex can decrease. This can cause significant problems for some patients and their partners/carers. However, because this is such a sensitive topic, such problems are often underreported.

A study that has been set up at Queen Square in collaboration between the DRC and Department of Urology seeks to further our understanding of this important issue, and hopefully lead to improved treatment. This will be done by investigating:

- (1) the prevalence of any changes in sexual desire in neurological disorders;
- (2) the physical, psychological and cognitive factors associated with such changes;
- (3) the impact of these on the patient and their carer.

After this, it is hoped to develop a suitable psychologically-based treatment for people affected by changes in sexual desire.

This study aims to understand the changes in sexual behaviour that may occur in dementia and the impact this has on carers. This will be done using a semi-structured interview and questionnaires.

Participants will be asked some general questions about the health of the person with dementia and their sexual behaviour. Participants will also be asked about how changes in the sexual behaviour of the person with dementia has impacted them.

It is hoped that the information gained from this study will help improve our care for people with neurological disorders and their carers. It is hoped that this research will inform :

- (1) our understanding of the predisposing, precipitating, and prolonging factors involved in the development of hyper sexuality, to reveal predictors of the disorder; and
- (2) the development of a psychological intervention for people affected by hypersexuality, to reduce distress and promote wellbeing.

If you would like more information about this study, please contact the researcher, Miss Natalie Tayim, at 07490 090010 or email at natalie.tayim.12@ucl.ac.uk



[MEF]

MYRTLE ELLIS FUND

supporting rare dementia

The PPA Support Group is funded and supported by the Rare Dementia Fund, as part of The National Brain Appeal (Charity number 290173). For more information on the work of the Fund or to make your own contribution to the running costs of the PPA Support Group, please contact The National Brain Appeal on 020 3448 4724.

Alternatively visit <https://campaign.justgiving.com/charity/tnba/rare-dementia-support>

FTDSG Annual Seminar Thursday March 10 2016.....save the date!

Provisional agenda includes:

An overview of FTD and the Pippin study - Dr Ian Coyle Gilchrist

Emotion recognition in FTD - Dr Charles Marshall

Disease stages in FTD: common deficits and management tips - Prof. Eneida Mioshi

'What's On Your Mind..?' a question and answer session Prof. Nick Fox

'No laughing matter: why do patients with FTD like (or stop liking) the things they do?' Prof. Jason Warren

Cost including lunch: £10 for family members £75 for professionals [concessions available]

Contact Emilie Brotherhood e.brotherhood@ucl.ac.uk or 020 3448 3609 to book your place

Your contributions.....

'Following your snippet about tracking devices I bought my sister a smart phone and installed Familo on it. I've given her a new GiffGaff SIM card for the new phone so that she can carry on using her old phone for phone calls and texts and told her to charge it every night and carry it everywhere. Familo tells me and other family members if the battery drops below 2% and when she leaves home. For instance, I was notified she left home the other evening and walked to her daughters. I'm not convinced she always takes it out with her, so it's not perfect, but it does take a little of the stress away. It's a collaborative project between the University of Dresden and Dresden City Council so it's free and there are no adverts or efforts to sell you more products. It's not specifically for dementia but I think it covers most requirements.' Details available at - <https://www.familo.net/en/>

Forthcoming Support group meetings:

PPA Support group meetings: 21 April 2016 and 21 July 2016 [bvFTD carers meeting Jan 25 2016]

Joint support group meeting: July 7 2016. Medical –Legal Issues : James Malby is a solicitor specialising in Private Client law and is experienced in the preparation of Lasting Powers of Attorney and Advance Statements. He advises on all aspects of their use, benefits, registration and other issues that often arise. James will give a presentation to help dispel some myths and outline the benefits of making these documents and the processes involved. More details nearer the time.

The above meetings take place in rooms within UCL , Gower St, London WC1E 6BT, All the above listed meetings are scheduled from 11am -2pm, with coffee available from 10.30am and lunch provided. Exact room details, agenda details and reminders are circulated nearer the time.

Regional meetings Tuesday 12 January 2016, Totteridge Community Centre, Totteridge Drive, Totteridge, High Wycombe, Buckinghamshire, HP13 6UG 10.30am -12.30pm.

Frontotemporal Dementia Support Group Annual Seminar: an all day series of presentations by experts across the FTD field will be held on **March 10 2016** at 33 Queen sq, London, WC1N 3BG. See this newsletter for agenda information

DISCLAIMER: Please note that you assume full responsibility and risk when attending support group meetings, and also in the use of the information contained on our website, in our newsletters and at support group meetings.