



Frontotemporal Dementia Support Group Newsletter

(formerly Pick's Disease Support Group)

For carers of frontotemporal dementia: Pick's Disease, Frontal Lobe
Degeneration, Dementia with Lewy Bodies, Corticobasal
Degeneration and Alcohol Related Dementia

FTD SUPPORT GROUP
FTDSG

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Raising Awareness Event in the House of Lords

We often refer to the critical need to raise awareness of not only FTD, 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 Baroness Sally Greengross and Professor Nick Fox due to attend and welcome an invited list of guests. Baroness Greengross is a crossbench (independent) member of the House of Lords and chairs the All-Party Parliamentary Group on dementia. Prof Nick Fox is director of the Dementia Research Centre, UCL. I intend for this event to achieve an important 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 is not only about memory loss and that it affects younger people too. This event is a support group initiative and one which I hope you see as a platform from which your views will be represented.

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

Frontotemporal dementia [FTD] is a diagnosis which encompasses a range of specific sub-classifications.

People who present primarily with language based symptoms are typically diagnosed with a Primary Progressive Aphasia [PPA] diagnosis, whilst those who present with the more behaviourally focussed symptoms are usually diagnosed with behavioural variant [bv] FTD .

Whilst the FTDSG tends to focus on the needs of carers, family and friends of people affected by a diagnosis of bvFTD, there is also a PPA support group for those affected by the predominantly language based symptoms. This group is coordinated out of the Dementia Research Centre, UCL, London.

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>

In addition to joining us at the annual seminar in March next year, Anna will be speaking at a PPA support group meeting on October 9th 2014, where she will share her understanding in a presentation entitled:

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

If you would be interested in attending this meeting please let Jill know via jill.walton@ftdsg.org or tel. 07592 540 555

Annual Seminar 5 March 2015...save the date!

Our Annual Seminar has been booked for Thursday March 5 2015, in the usual venue: Basement Lecture Theatre , 33 Queen Sq, London WC1N 3BG. Provisional agenda includes expert speakers across a range of FTD related issues:

Growing ideas: How can speech and language therapy help your conversations? Anna Volkmer, highly specialist speech and language therapist, South London and the Maudsley Hospital

Coping strategies for carers: Dr Eneida Mioshi: Department of Psychiatry, University of Cambridge School of Clinical Medicine

Imaging in FTD: Dr Jon Schott, Dementia Research Centre /UCL

The GENetic FTD Initiative Dr Jon Rohrer, Dementia Research Centre /UCL

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

Drug treatments and trials in FTD Dr Cath Mummery, Dementia Research Centre, UCL

FTD: a family's perspective

More information available via the website nearer the time, or from jill.walton@ftdsg.org

'Out of the ordinary'

Cindy Reeve is the FTDSG regional contact person in Cornwall and has been facilitating meetings in the area since 2012. When Truro was launched as a dementia friendly town Cindy found herself involved in an initiative she shares with us here:

It all started back in March when I attended the Dementia Alliance launch of Truro as a dementia friendly town.

One of the activities towards the end of the day was asking various people and organisations to pledge to carry out different activities. So when Tim Roe, the Director of Home Instead Senior Care pledged to hold free sessions for caregivers, I was in like a shot.

The result of my discussions with Tim was a day of workshops geared specifically to the aspects most relevant to caregivers like ourselves who are looking after loved ones with FTD. Our 'out of the ordinary' support group meeting was established. Three months later we all came together in Truro for three workshops. All three were held on one day to cater for the difficulties group members find in ensuring their loved ones are cared for whilst they [the carer] are not at home.

The first session was about capturing life's journey. While we've all heard of life journals, or my life books, I have to admit I hadn't realised how important and useful it could be in helping family relations to appreciate and understand more about what it's like to live with FTD in the family, to say nothing of the usefulness in helping professional caregivers and medics look after our loved ones. A life journal also helps to personalise activities, diminish stress and help manage behaviours, especially those challenging difficult ones.

Needless to say this led very neatly into the next session which was about techniques for handling those challenging behaviours. This opened up lively discussions about some aspects of re-direction that work and some that don't, with all of us acknowledging that we may try a technique one time and it will work and the next time it may not.

It was very interesting to discover how a life journal weaves its way through the techniques for challenging behaviours and how on those difficult days it might prompt reminders about favourite things or topics which may be used to try to ease those difficulties.

We finished the day with a third session on thoughts and ideas to encourage engagement in activities, helping our loved ones to feel secure and valued. This involves things like stimulating our loved ones' minds, as appropriate to their cognitive levels, while recognising that the simplest of activities can bring fun, laughter and emotional warmth. Physical activity, however light can help maintain co-ordination and muscle strength.

Furthermore, the importance, however difficult it might be, of continuing to maintain social interaction, even if it's only holding someone's hand, was stressed.

Once again information from a life journal weaved a thread throughout the whole of this session on activities. An example given by a member of our group was reference to an activity that went back sixty years to when she and her loved one first went to a swimming pool. Currently this is an activity which is covering the mental, physical and social areas for her spouse.

This session also covered techniques to encourage our loved ones to become more engaged in day to day activities, from taking a shower to assisting with household chores.

Last, but by no means least was the emphasis to take care of ourselves by getting plenty of sleep—yes I know that's not possible, but we still have to be aware of it—taking regular exercise, eating well balanced meals and drinking plenty of fluids are also important. We were also encouraged to maintain friendships which give us some emotional support and spiritual and religious activities if appropriate.

There is no doubt that this was an 'out of the ordinary' support group meeting but everyone who attended the day took away something very specific to themselves as an individual.

Whose to say there won't be more 'out of the ordinary' meetings down here in Cornwall!

Tau Rx Study update

We announced in a previous newsletter that a drug trial for people with behavioural variant FTD was due to be conducted in 12 centres across the UK. The drug, known as LMTM, is being developed by the pharmaceutical company TauRx. Smaller, earlier studies have already taken place and this phase 3 study aims to recruit a larger number of patients to find out if LMTM works in treating some of the symptoms of bvFTD and if the medication is safe.

The study will be clearly explained to people who are interested in taking part and participants will need to be screened in order to ascertain their eligibility for involvement.

The study requirements are that the participant has a diagnosis of bvFTD, is aged 70 or under and that they also have a companion who is prepared to accompany them on every visit to the hospital. There are 9 scheduled visits over one year and a follow up visit at the end of the treatment period. Neither the patient nor the clinician would know if the participant is receiving the active drug during the duration of the trial. This type of study is known as a "double blind placebo controlled trial". Each visit would consist of various types of clinical and cognitive assessments and would take place over one day.

If you are under the care of a hospital site where the study is being conducted, it would be wise to contact them in the first instance.

For patients interested in the **UCLH** centre, contact Justin Kinsella (Clinical Trials Fellow) 0203 448 3668 or Jane Douglas (Trials Nurse) 0203 448 3560

Other sites currently recruiting for this study include:

Southampton [contact Lesley MacKinnon on telephone 01962 825568 or email lesley.mackinnon@hhft.nhs.uk]

Re:Cognition Health [telephone 020 33 55 35 36 or email clinician@re-cognitionhealth.com]

Charing Cross Hospital [contact Ginnette Kitchen on telephone 01203 3135515 or Mob: 00 44 (0) 7903241429]

For more information and for a list of all sites that are recruiting for this study go to:

www.picksdementiastudy.com (Please note that this information is managed by a third-party, MediciGlobal, a market research and marketing agency hired by TauRx to support its clinical trials activities.)

<http://clinicaltrials.gov/ct2/show/NCT01626378> : for a more detailed description of the design of the study, inclusion/exclusion criteria, endpoints, etc.

[Dementia Action Alliance \(England\)](#)

The Dementia Action Alliance are surveying people affected by dementia and professionals to review progress made on delivering the National Dementia Declaration to find out whether current activity is leading to real changes on the ground. Please do consider completing the survey using the link here :

<http://www.dementiaaction.org.uk/impactsurvey>

Carers and Supporters of People Living with Dementia Research Project

Dr Andrew Balmer, a Sociologist at the University of Manchester, is conducting research in order to better understand the experience of caring for a person living with dementia. The focus is on frontotemporal dementia, and in particular on behavioural variant FTD, because these areas are significantly under-studied.

The research aims to answer some sociological questions and also to improve the communication of information between clinical professionals (consultants, doctors, nurses, etc.) and carers of people living with dementia and also people living with dementia themselves.

Andrew would like to speak to carers (and former carers) of people living with (or who lived with) frontotemporal dementia. The research would involve you talking with Andrew for 1-2 hours about your experiences of supporting and caring for a person living with FTD.

If you would like to get further information on how to take part in the research then please contact Andrew directly.

Andrew.balmer@manchester.ac.uk

Tel 07737512634



Members of the Longfei Summer Camp 2014

Fundraising Appreciation

Members of the Longfei Taijiquan Association of Great Britain have been incredibly kind in agreeing to focus their fundraising efforts on our behalf again this summer.

We take this opportunity to thank them and indeed to extend our appreciation to all who have fundraised for and donated to the FTDSG. We are grateful for your support and your commitment to the group.

Forthcoming Carer Support Meetings :

London: Carers meetings will take place between **11.00am-1.30pm** and will conclude with a visit to local restaurant for lunch for those who wish to stay on: Mon Dec 1 2014 [Venue: Wilkins Haldane Room, UCL Gower St , WC1E 6BT], Thurs Feb 26 2015 , Mon April 27 2015, Mon July 13 2015 [Venue :Wilkins Front Main Quadrangle]. Contact Jill Walton 07592 540 555 or jill.walton@ftdsg.org for details closer to meeting dates.

Liverpool: Neuro Support Centre, Norton St, Liverpool, L3 8LR : 18 Sept, 27 Nov 2014. Please contact Mary Dawber on 01625 879 104 or email mary1246@hotmail.co.uk . Meetings usually take place between 1pm and 3pm

Yorkshire Yates Wine Bar , Boar Lane, Leeds LS1: Next meeting Nov 14 2014. E-mail ftld1@yahoo.co.uk for details of forthcoming meetings.

South West: :Lyme Regis : contact Penelope Roques –01297 445488 for details of forthcoming meetings

South West: Arundel Arms, Lifton, Devon PL16 0AA : contact Penelope Roques –01297 445488 for details of forthcoming meetings

Hertfordshire/Bedfordshire: October 2 2014 Contact Richard Pleydell-Bouverie on ropb@easykey.com or 01438 833022 for details

Ely: The Masonic Hall, Silver Street, Ely, Cambs, CB7 4J Sept 30 2014, 11.30am-1.30pm

Cornwall: October 9 2014 12noon-2pm Contact Cindy Reeve on 01726 71562 for details

Cambridge: Contact Val freestone at valerie.freestone@addenbrookes.nhs.uk or Tel 01223 768005 for details.

Scotland: Carer support group meeting takes place on the second Thursday of the month .Contact Anne Miller at milleranne89@googlemail.com or Tel 01436 268476 for details

FTDSG Regional Contacts For carers, there is often a sense of isolation when faced with the distress and burden that frontotemporal dementias cause. The FTDSG puts you in touch with people who understand:

Scotland— Mrs Anne Miller milleranne89@googlemail.com tel 01436 268476

Yorkshire— Rev. Ron Carter 01904 610 237 and Ann Squires 0113 2947139

Northern— Mrs Jillian Ramsay 0191 421 4069-mob. 07708 857438

Trent— Mrs Janet Carpenter 0116 239 2913 [Also the contact person for Carers of Alcohol Related Dementia]

Mersey and North West— Mrs Mary Dawber 01625 879 104 email mary1246@hotmail.co.uk

Manchester/Stockport—Helen Griffiths and Mark Perry 0161 716 4505

West Midlands— Sister Ann Johnson 01743 255 856

Central— vacant

Northamptonshire —Rob Hasker (email by preference) Roberthasker1985@hotmail.com or 07889875422

Cambridgeshire— Valerie Freestone valerie.freestone@addenbrookes.nhs.uk or Tel 01223 768005

Hertfordshire/Bedfordshire— Richard Pleydell-Bouverie (email by preference) ropb@easykey.com or 01438 833022

Suffolk— Mrs Gillian Gubb 01502 569077

London - Mrs Carole Ivey 0207 603 0550

Southern [Hants, Wilts] - Mrs Jenny Mackie 01722 336 352

Southern [Surrey, Sussex] - Mrs Val Bywater 01420 362 123-Mob. 07792 721853

Norfolk - Mrs Gillian Litson 01263 514624

Kent— Tina Stirling 01892 723130 email tinastirl@tiscali.co.uk

South West— Miss Penelope Roques 01297 445 488

Cornwall— Mrs Cindy Reeve 01726 71562

Lynne Ramsay: Volunteer adviser regarding funding and services

Tel: 0208 467 1462 Mob. 07760 224 396