

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

Carer Support Meetings In some areas support group meetings are arranged by regional coordinators. Please see the website www.ftdsg.org or contact regional coordinators directly

London: Carers meetings take place between 11.00am-2pm at UCL Gower St site venue. Contact Jill Walton 07592 540 555 or jill.walton@ucl.ac.uk for details .

Liverpool: Neuro Support Centre, Norton St, Liverpool, L3 8LR : Meetings usually take place between 1pm and 3pm .Contact Mary Dawber on 01625 879 104 or email mary1246@hotmail.co.uk for details.

Yorkshire Yates Wine Bar , Boar Lane, Leeds LS1. Contact ftld1@yahoo.co.uk for details .

South West: Lyme Regis : contact Penelope Roques –01297 445488 for details .

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

Hertfordshire/Bedfordshire: Contact Richard Pleydell-Bouverie on richard@lawrenceend.com or 01438 833022 for details.

Cornwall: Contact Cindy Reeve on 01726 71562 for details.

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

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.

Surrey: Contact Karen on 07525597503 or email Karen.Tapson@alzheimers.org.uk for details.

Stockport: Contact Helen Griffiths 0161 716 4505 for details.

FTDSG Volunteer Regional Contacts For carers, there is often a sense of isolation when

Scotland—Anne Miller 01436268476
milleranne89@googlemail.com

Northamptonshire—Hilda Hayo 07920 819523
hhayo@talk21.com

Yorkshire – Rev. Ronald Carter 01904 610 237
Anne Squires 0113 2947139

London – Mrs Carole Ivey 0207 603 0550

Northern – Mrs Jillian Ramsay 0191 421 4069 m0770 885
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Cambs— Val Freestone 01223 768005
valerie.freestone@addenbrookes.nhs.uk

Manchester/ Stockport—Helen Griffiths
helen.griffiths@nhs.net 0161 716 4505

Herts/Beds—Richard Pleydell-Bouverie 01438 833022
richard@lawrenceend.com

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

Kent/Sussex– Jane Smissen Bell 01323 504156
6bells.jane@gmail.com

West Midlands – Sister Ann Johnson 01743 255856

West Sussex– Jill Butcher 01444 451 837
jillbutcher@onetel.com

Birmingham— Pauline Ross 07815285876
polly.ross@bopenworld.com

Suffolk - Mrs Gillian Gubb 01502 569077

Kirsty O'Dwyer 07887800947 kross38@hotmail.com

Norfolk—Gillian Litson 01263 514624

Kirsty is happy to take calls from anyone whose parent is affected by FTD

South West – Miss Penelope Roques 01297 445 488

Central - Emeline Keown [YoungDementia UK]
01865 747698 Mob: 07909 060430
emelinekeown@youngdementiauk.org

Cornwall—Mrs Cindy Reeve 01726 71562

Lynne Ramsay: acts as a volunteer adviser on funding and services:

Tel 0208 467 1462 email lynnerramsay1@gmail.com



Inside this issue:

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World FTD Awareness Week—October 4-11 2015

As a result of our collaboration with FTD support groups from around the world at the International FTD Conference in Vancouver last year, we are excited to be gearing up for the first **World FTD Awareness Week!** The dates are **October 4 - 11, 2015.**

As October fast approaches, we want to encourage regional contact people and support group members alike to embrace World FTD Awareness Week and consider ways in which you can help demonstrate that we are a strong international community of families and professionals who are working together to advance care and treatments for FTD. Together, we have the chance to fight the isolation and challenges that people diagnosed with FTD and their caregivers experience.

There are many ways to participate in World FTD Awareness Week, and for this first year, events and activities of all kinds are expected from at least ten countries across the globe. Within the United States our sister organisation, the AFTD, will be marking the week with Food For Thought events—their goal being that communities and families in each of the 50 U.S. States will host these awareness/fundraising events. These events may offer inspiration for our own UK-based efforts. Combining fundraising and awareness efforts offers people a chance to learn more about FTD, and at the same time contribute to the momentum of work to fight this disease. (UK-based support group members are welcome to borrow from the materials that the AFTD have developed, which can be found here: <http://www.theaftd.org/get-involved/host-an-event/aftds-food-for-thought>. Specifically, AFTD has produced a toolkit for families that can be found here: <http://www.theaftd.org/wp-content/uploads/2013/03/Food-for-Thought-Toolkit-20151.pdf>).

FTDSG website details can be accessed at <http://www.ucl.ac.uk/drc/ftdsupport> and our just-giving site is easily accessible at <https://www.justgiving.com/FTDSG/>.

Please let us know [jill.walton@ucl.ac.uk] of events you host during World FTD Awareness Week . Send us your photographs and stories...however big or small, and we look forward to taking this initiative forward on a yearly basis. Please let Jill know if you would like to work on World FTD Awareness Week programmes on annual basis.

FTD Impact Survey

Results of an on-line two question survey which asked people diagnosed with FTD, caregivers and family members about the impact of FTD on their lives has been published. Of 828 completed surveys —57 were from people diagnosed and 771 from caregivers and family members.

Through the survey, caregivers and family members were able to identify FTD symptoms that caused the most difficulty on a daily basis. Those most prominently named in survey responses were: problems with language and communication; unpredictable, compulsive, inappropriate behaviour; apathy and loss of feelings for others; loss of judgment and lack of emotional control; and an inability to plan and complete regular daily tasks.

The full analysis can be found on the AFTD webpage under the *For Researchers/AFTD Research Analysis* tab.

Research Fund Update

Dr Camilla Clark is well known to many support group members courtesy of the helpful and well received presentations she has made at recent FTDSG Annual Seminars. Camilla is partway through analysing her research findings in regard to emotion and music recognition in FTD and the holders of the FTDSG Research Fund are delighted to have been able to help fund her to continue in this exciting work at the Dementia Research Centre, UCL.

The Importance of dementia support groups

The following letter was first published as an on-line rapid response article and then as a letter in the BMJ on July 23 2015

Robinson and colleagues refer to non-Alzheimer diagnoses of dementia. These less typical diagnoses pose complex problems for those with the disease and for their families, friends, and carers. When these forms of dementia affect younger people the problems can be even more challenging.

When asking the question: "What constitutes best practice in early intervention?" we must acknowledge that people living with a diagnosis of dementia generally do so in the community, supported by informal caregivers typically made up of spouses, relatives, friends, and neighbours.

Support groups have an important role to play in offering people the opportunity to acknowledge their diagnosis and its consequences alongside peers in a similar position. Apart from the social and emotional benefits of participating, disease specific support groups enable the exchange of valuable professional and personal information and advice.

They are also gateways to understanding and sharing, enabling people to cope better and for longer.

Support groups can extend to provide supportive networks across telephone, internet, and social media platforms, as well as providing the opportunity for one to one peer relationships that are continued outside of formal meetings.

Directing patients and their families to such sources of advice and support forms an important part of the post diagnosis consultation. "Rare dementia support" offers information, advice, and support to people affected by frontotemporal dementia (behavioural variant and primary progressive aphasia), posterior cortical atrophy, familial Alzheimer's disease, and familial frontotemporal dementia.

Distinct from the personal and individual benefit to group members, support groups also fulfil an advocacy role on behalf of their members by raising awareness and representing the needs of people within the group by contributing to debates and discussions at a more strategic level.

Jill Walton registered general nurse, **Natalie Ryan** clinical research fellow, **Sebastian Crutch** professorial research associate, **Jonathan D Rohrer** honorary consultant neurologist, **Nick Fox** professor of clinical neurology
Dementia Research Centre, Institute of Neurology, London WC1N 3AR, UK

[Full response at: www.bmj.com/content/350/bmj.h3029/rr-0. | Robinson L, Tang E, Taylor J-P. Dementia: timely diagnosis and early intervention. BMJ 2015;350:h3029. (16 June.)]Cite this as: BMJ 2015;351:h3875 © BMJ Publishing

Emilie Brotherhood and Prof. Seb Crutch, researchers from the Dementia Research Centre, UCL presented their ideas for a new research project at the FTDSG London Carers' Meeting on 13th July. **Emilie writes:**



Our project 'C-PLACID' (which stands for 'Computational PLatform for the Assessment of Cognition In Dementia') aims to use new technology to assess the different skills which are more typically compromised in rarer forms of dementia such as FTD.

Many of you are aware that the changes in a person's social skills before and after the diagnosis of behavioural variant FTD can be a dominating and challenging feature. As yet, we haven't found a way of measuring these changes in social skills in a way that is true-to-life and which accurately reflect the stories we hear from carers, family members and friends in clinic, about the reality of living with behavioural variant FTD.

Developing a way of measuring these changes in social skills and the differences between people with and without FTD could eventually increase the possibility of an earlier and more accurate diagnosis.

One area of new technology that Seb and I would like to use to assess and measure change in social skills is 'Virtual Reality'. Virtual Reality technology involves computer simulated scenarios and characters (who you can 'look at', 'walk towards' and 'chat with') who appear and interact within the scene. The idea is to create various true-to-life scenarios (e.g. within a pub or café setting) which contain realistic characters and interactive opportunities, and see how people with and without FTD interact within the scenes. As the research is still in the initial phase, we asked the carers who attended last month's meeting to help us in the design of the Virtual Reality scenarios. We kick-started the discussion in the meeting's afternoon session by inviting carers to share with us any examples that they felt epitomised the experiences and behaviours of their close relatives/friends who live with FTD. This generated a very insightful discussion, and we are intending to build on some of the experiences that were shared as they create and pilot the Virtual Reality scenarios.

We hope to have some of these Virtual Reality scenarios ready for you to experience by the beginning of 2016. This research is open to people with and without a diagnosis of bvFTD. If you would be interested in taking part, or have any questions about the C-PLACID project, please do not hesitate to **contact Emilie on e.brotherhood@ucl.ac.uk**

Empathy: the emotional glue that holds relationships together....

Empathy, the 'emotional glue' in relationships that lets us understand the feelings, needs and concerns of another, is an early casualty in FTD. Loss of empathy [as we saw demonstrated in the survey referred to on Page 1 on this newsletter] is often a distressing symptom for spouses/partners, family members and friends.

People with FTD often make uncharacteristically insensitive comments. They can be self-centred in their actions, have flat, emotionless facial expression and there is often a blunting of emotional warmth and insensitive emotional responses to others.

Patterns of empathy loss differ among people with FTD depending upon the specific brain regions affected.

Jill Shapiro has researched and published on this subject extensively and makes the distinction between cognitive empathy [understanding another's perspective and recognising what one should feel] and emotional empathy [showing emotions appropriate to the situation appreciating what one actually does feel].

Other behavioural symptoms associated with FTD may intensify empathy issues. For example lack of insight/self-awareness, apathy, and loss of impulse control.

Because many cognitive abilities remain intact, caregivers sometimes question whether an individual is "acting this way on purpose." Recognizing empathy loss as part of the disease process is often difficult. Changes in other behaviours are more obvious and observable to others, but empathy affects the private relationship between individuals. Because a person with FTD may appear "selfish," "mean" or "uncaring" caregivers, family members and friends often "personalize" the lack of connection and feel hurt, sad or angry.

It is important to recognize that loss of empathy and the inability to connect emotionally are primary symptoms of FTD.

Acknowledge the hurt, sadness and anger that you may feel when your partner no longer reacts in expected ways. Use counselling and get support to help you as the caregiver or friend process emotions. Educational resources and FTD support groups may also help.

Remember: your feelings are valid, important and deserve attention. It might help to try and develop new ways of relating to the person with FTD without expecting a reciprocal response. Keep your side of the relationship open by introducing topics and activities of interest to the person (i.e., pets, sports, television programs) and share what works with other family members and friends.

Be prepared to hold on to and appreciate unexpected moments of insight or connection with the person.

For access to Jill Shapiro's presentation on loss of empathy in FTD please see page 40 **in the AFTD 2015 Education Conference booklet**. A **December 2014 handout** from AFTD's Partners in FTD Care resource for health professionals also provides helpful guidance.

A personal 'thankyou'....

Dear All

A big, big thank you to everyone who contacted me regarding my husband Peter Stephenson and our fight for CHC, without your support and stories I am not sure I would have had the energy to continue fighting.

I am so pleased that I did try again and using your wonderful advice and ideas I have just found out today that we have been granted CHC, which is to be back dated to May 14, I burst into tears. It was not until that moment I realised how important it was to us and all the emotions flooded out. The poor lady on the end of the phone did not know what to say to me

Anyway a very big thank you from the bottom of my heart. I wish you all well.

With Love

Miranda