



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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FTDSG Annual Seminar: Tuesday March 4 2014

33 Queen Sq, London, WC1N 3BG

We would love to welcome as many people as possible to the Annual Seminar. Please confirm your attendance by contacting Jill Walton On 07592 540 555 or jill.walton@ftdsg.org Speakers and agenda to include:

Jacqueline Kindell - a specialist speech and language therapist, providing assessment, treatment and management advice to people with dementia and their carers 'Semantic disorder: implications for daily living'

Jennifer Thompson - Neuropsychologist and Honorary Research Fellow, Cerebral Function Unit, Greater Manchester Neuroscience Centre 'Understanding changes in behaviour'

Hilda Hayo - Chief Admiral Nurse/ CEO, Dementia UK 'Exploring the social context of living with behavioural variant frontotemporal dementia'

Laura Downey - Clinical Research Assistant, Dementia Research Centre, UCL 'Mentalising music in frontotemporal dementia'

Dr Jason Warren - Reader in Neurology, Dementia Research Centre, UCL 'What's on your mind?' Your questions answered'

Cost: £10 for carers £75 for professionals. Discounted rates may apply.

Payment by cheques made out to The Frontotemporal Dementia Support Group [National Brain Appeal] can be sent to 22 Brushwood Drive, Chorleywood, Herts, WD3 5RT . Alternatively, arrange for payment into our account at Barclays bank, 1 Churchill Place, London, E14 5HP. [Sort code 20 82 94 Acc. no. 20646687] copying me in to any payment transactions....

Thank you!

Contact jill.walton@ftdsg.org or tel 07592 540 555 to reserve your place.

Emotional changes in people with FTD

Emotion is one area of psychology that is not particularly well understood. However, there is currently significant research focussing on basic emotional reactivity, empathy and emotional regulation and complex social interactions in people with dementia.

In such research, participants may be shown videos designed to elicit emotions and be asked to self-report how they feel before and after the videos. Studies may also facilitate participants to engage in conversations with their caregivers — who are often spouses or other family members — about controversial topics. Alternatively, music may be used as the medium by which emotional responses are measured, and there is much which the architecture of music sheds on our understanding of the circuits affected by dementia.

The neurological 'circuits' affected by FTD are known to be different to those affected in people with Alzheimer's disease and it is the case that people with different dementia diagnoses react differently in these studies. For example, whilst some people may understand their emotions but are not able to respond appropriately, others are less capable of understanding what they are feeling.

Aligned to this research is the interesting correlation between loss of emotional reactivity in a person with dementia, and the subsequent effect on caregiver stress levels. It is known that the demands of the caregiving role can put caregivers at risk of psychological and physical illness and there is an effort to understand what particular symptoms in people with dementia are most problematic for caregivers' well-being.

Some researchers believe that emotional changes are the most more likely to produce problems and stress for caregivers. "The fact that the person is destroyed by the disease and becomes cold and uncaring makes the whole process much more solitary and isolating for the caregiver." [Robert Levenson, a professor in the department of psychology and head of the UC Berkeley Psychophysiology Lab , University of California]

The implications for people affected by a diagnosis of FTD and all that this inevitably entails are obviously very significant.

Jill Walton

A carer's story.....Anne's husband was initially diagnosed with possible Alzheimer's disease, a diagnosis that was subsequently reviewed and changed to bvFTD. Her story conveys with poignant effect, the harsh reality of a relationship cruelly torn apart by this disease. Now an ex-carer, she is a keen advocate of marriage and relationship counselling organisations, recognising the effects that the symptoms of dementia can have on marital, and family relationships. These effects are often borne out during the years leading up to diagnosis, which when it comes, often brings a sense of relief and an explanation which helps people understand such damaging behaviour for what it is: the symptom of a cruel and unrelenting disease.

'An upright, honest, moral to an almost excessive degree, reserved, almost prudish, English gentleman, not overly demonstrative, Christian, and non judgemental. I loved him deeply and trusted him with my life. People commented on our happy marriage, and were disbelieving when they heard he was divorcing me. It took me a long time to understand and believe that a degenerative brain disease was the cause.

Several years ago I noticed that he was crying a lot and losing interest and skills in his work, and was a potential risk to himself and others when using machinery - something with which he was meticulously careful.

One afternoon, sobbing uncontrollably, he told me in front of our daughter, that he loved another woman that he had met on the train and he was comforted by her because he had had some disappointing medical news (not serious).

I was utterly disbelieving, we knew that he had been treated for depression a few months earlier, so thought that was part of the problem. I asked him was it a sexual relationship and aghast he said "no nothing like that". I then asked why did he tell me then in front of our daughter, and he said that someone local had seen them together and was blackmailing him. Sadly, this woman he had met, who was in fact a prostitute, was I think the black-mailer, and from that moment on, put him up to the many dreadful things that he did to both me and the children. Caring at this stage was not part of the scenario. As far as I was concerned, he didn't love me any more. I was, as he said second best, but I would always be his best friend. I cried myself to sleep almost every night, and couldn't believe that our marriage was at an end; we had worked together farming so well, won competitions and been complemented on our partnership.

He moved into a small cottage next door, but still expected to be fed and have his washing done. I continued doing all of this because in the depths of my mind something intuitively said "carry on". In due course I stopped feeding him, about which he was very angry.

The prostitute had left messages on my phone and had also spoken to me, saying what her occupation was, and that she didn't love him and that he was too old and obsessed with her. I asked her how much money she had taken and she told me.

I saw him every day, he was working for our son, farming, but had lost many of his tractor driving and stock handling skills. Part of me was mean enough to enjoy witnessing this, because it confirmed what I knew: something was wrong.

He changed to a new doctor because he was convinced that I was being told everything by my [previously our] GP. His new GP told him later and after he was diagnosed with ALZ, that there was nothing wrong with him! I feel that if I could have been involved at that stage we could have prevented the divorce and that perhaps some drug intervention would have modified his behaviour.

He moved in with some friends at this stage. Sadly they never understood his problem and in fact turned many people against me, unkindly saying that when my GP advised I visit a STD clinic, that my solicitor must have suggested it as a means of claiming more money in the settlement.

HE was having more and more hospital visits by now because of other physical problems, skin cancer being one, [which, in the end killed him], and I took him to almost every one: radiotherapy, a huge operation on his scalp, followed by chemotherapy.

At this stage the friends with whom he had been living, could no longer cope. I had suggested some time earlier that they would find him too much. They said he was difficult to motivate, that his driving was not good, but that he didn't have dementia! They told me [after his death], that they had even asked the staff at the hospice what was wrong apart from the cancer, and had been told there was nothing else wrong! I could do nothing else but contact the hospice and report this, because if it was true, it was a possible breach of patient confidentiality.

They took the matter very seriously. The same "friends" also told me that he had visited the prostitute, who was in the Midlands, again. When I asked why they had let a vulnerable man make this journey, they said it was his business. So the ignorance around dementia is a real issue and carries multiple safeguarding and protection issues. Friends often struggle to accept a diagnosis they can't relate to.

So caring kicked in full time: trying to get him to eat, to drink, to shower. I would medicate him before the nurses came (initially I took him to the surgery but the dressings became so complicated that it was better that he was at home to sleep off the morphine rather than being driven home).

We had been divorced for about 6 months at this stage. His mobile phone revealed that the prostitute and another woman were in contact still.

Because of his dreadful head wounds and the FTD symptoms, he was finally admitted to a Hospice 38 miles away.

The FTD showed itself as lack of insight and motivation, fortunately the sexual promiscuity had subsided, however I did have worries for the nurses at the hospice. It seems he had passed that stage and there were no comments, and his personal care was well covered by the wonderful nurses at the hospice. I always tried to be there at a dressing change to try and distract him. He didn't watch the Olympics, which would normally have been very much enjoyed. He would sometimes say that he knew he had done wrong but didn't deserve this cancer, and I would always reply that his cancer was not a punishment, but that he had FTD and he couldn't help what he did. He even acknowledged at times that he put people against me, and asked how to put it right (insight?) I would ask him to tell someone the truth - he couldn't --FTD?

Towards the end I would cry all the way to the hospice and all the way back. He was so troubled, I asked for an increase in all his medication and the chaplain and social workers to talk to him. They did everything I asked.

And the end is so poignant; he asked me to re-marry him. I said I would but I wanted to liaise with the doctors so that, for this decision and occasion, I knew he had capacity. Having been examined by doctors and the chaplain, and subsequently putting the C of E at Lambeth Palace in a flat spin, (they too were wonderful) we were married 5 days later in the hospice chapel with children and grandchildren there: the two little girls aged 3 and 7 carried sunflowers.

He died really at peace, (which I knew he would) 5 days later. That morning the hospice phoned to say would I go in as quickly as possible because he was asking for me. I was so pleased that he asked for ME, that healed some wounds.

Yes I am still hurt at some of the things he did, and by people who think he would have behaved as he did, had he not had a degenerative brain disease. But he couldn't help it. I am proud of my children and grandchildren who steadfastly supported us both, and I am proud of me because I did not reject him when he needed me most. Caring and loving are wonderful emotions but oh! ..so painful.

Reflecting on it all there were 6 years of hell, of hoping things would be right, frustration at some of the doctors who didn't know enough. Further reflection tells me of the signs that were there years before that, nothing as single incidents, but put together they were indicative of things starting to go wrong. I pray that tests will be discovered and treatments initiated to save families and patients from this dreadful disease.

Incontinence Management in FTD

Unlike Alzheimer's disease, reasons for bowel incontinence in FTD are complicated, and strategies to manage it must consider the cognitive, behavioural and communication impairments in FTD as well as addressing as many of the potential causes as possible. A new educational resource is available at www.theaftd.org. Alternatively email jill.walton@ftdsg.org if you would like a hard copy of this document.

Your contributions

This section of the newsletter is for members to have the opportunity to contribute any helpful hints, experiences, or points you want to raise...email jill.walton@ftdsg.org.uk, Tel 07592540555 or post to 22 Brushwood Dr, Chorleywood, Herts, WD3 5RT. Longer articles are also welcome!

 A website which looks to be a good starting point for someone who is worried about financial issues relating to care. It covers many other issues which may be of concern to Support Group members: <http://www.housingcare.org/finance-advice.aspx>

When a dementia diagnosis is made, the grieving for the emotional/memory ties lost can start almost immediately because of the certainty that the situation will continue to progress. In a way, this means that carers, family and friends may have a bereavement 'apprenticeship'. When death occurs the adjustment may not be so bad as you have had to contend with in the preceding years. For people caring for someone with FTD, I would say live every minute focusing on what you CAN do and prepare yourself in gentle ways for totally losing that lovely person.

In my journey through this illness there have been three things that have caused the most concern to me.

- ◆ 1. Obtaining funding to assist me.
- ◆ 2. Drug management of the more challenging symptoms. There seems to be no clear research into dealing with the condition now, with emphasis on finding a cure for the future.
- ◆ 3. Finding a suitable care home for my husband without a cohesive list to refer to.

Do others agree?

BMJ Patient Partnership Strategy Recruiting Peer Reviewers

The BMJ relies on peer reviewers for opinion on the quality and usefulness of an article., informing the editors decision about whether to publish it or not. The BMJ is currently inviting people to join its panel of patient reviewers, providing a perspective on the patient focussed aspect of particular manuscripts, drawing on your experience of a particular topic, condition or intervention. Please right click on the text box below to open the link for more information

 [Detailed guidance for patient reviewers.docx](#)

Forthcoming Carer Support Meetings

London: Joint FTDSG and PPA support group carers meeting Thurs Feb 13 2014 ,11am—2pm : Wilkins Haldane Room, UCL, Gower St, WC1E 6BTJ.

Annual Seminar March 4 2014, 9.30—4pm, Lecture Theatre,33 Queen Sq, London, WC1N 3BG.

The following carers meetings take place between **11.00-am-2.30pm** in **The Old Boardroom of the National Hospital for Neurology and Neurosurgery, Queen Square, WC1N 3BG** and conclude with a visit to local Italian restaurant for lunch; **Mon 2 June 2014, Mon Sept 8th 2014, Mon Dec 1 2014**

Contact Jill Walton 07592 540 555 or email jill.walton@ftdsg.org for details.

Liverpool: Neuro Support Centre, Norton St, Liverpool, L3 8LR : 20 March, 22 May, 24 July, 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 Meetings: Yates Wine Bar , Boar Lane, Leeds LS1:. 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: March 11 2014 , 10am –12.30pm. Contact Richard Pleydell-Bouverie on ropb@easykey.com or 01438 833022 for details

Cornwall: 10 April 2014, Contact Cindy Reeve on 01726 71562 for details of this and forthcoming meetings

Cambridge: Wednesday 24th of March 2014 ,for details contact valerie.freestone@addenbrookes.nhs.uk or Tel 01223 768005

Ely Golf Club : Date in April to be confirmed Contact jill.walton@ftdsg.org 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— Mrs Sue Smith [YoungDementia UK Mon-Thurs] -01235 522 382

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