



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

Inside this issue:

- *Annual Seminar 2014
- *Brain Donation: Brian's Story
- * Brain donation: a members letter
- *Scribe
- *FTD and police contact
- *Rare Disease Plan launched

FTDSG Annual Seminar: Tuesday March 4 2014

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 [provisional] 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 fronto-temporal 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.

Radio 5 live: FTD and police contact

The Frontotemporal Dementia Support Group were pleased to be represented in a Radio 5 Live discussion on Sunday Nov 3rd when Radio 5 broadcast a programme highlighting ways in which people with dementia may have involvement with the police. Two main areas were discussed; restraint and shop lifting.

Police officers were interviewed who commented on the fact that they are increasingly being asked to go to care homes or nursing homes to restrain dementia patients who are often fragile and elderly. They discussed how this could cause injury to the patient and that just sitting talking to them can calm them down. This highlights the need to have enough staff in homes sufficiently trained to cope with these patients and hence avoid the need to call for police assistance.

Patients, particularly those with young onset, frontal lobe degeneration lose their inhibitions and act impulsively. They are often highly mobile and shop lifting is a typical result. Various discussions took place including having a register of diagnosed patients. These patients are vulnerable which again emphasises the need to have a confirmed diagnosis and have mental health nurses available in custody suites.

Another area not included in this programme where the Police are heavily involved is looking for missing patients. patients with any form of dementia may wander continuously and while living in the community can become lost. The police spend millions every year looking for people. These patients are very vulnerable and therefore take a high priority. The stress for family members is indescribable when patients are missing for sometimes days. Anyone with a switched on mobile phone can always be tracked as to where it was last used and hence where to start searching. But patients do not need expensive blackberrys or Iphones as they are likely to lose them. Purposely designed products do exist for patients. e.g. MindMe Locate which can be bought by the public and if the patient becomes lost allows them to be found much faster; thus reducing the stress for all concerned.

Lynne Ramsay

Strategy for Rare Diseases launched November 2013

The long awaited UK Strategy for Rare Diseases has now been published! FTDSG contributed to the consultation process involved in drawing up this document. To achieve the UK-wide vision for rare diseases, there are 51 recommendations which all four countries of the UK have committed themselves to. You can read them at: <https://www.gov.uk/government/publications/rare-diseases-strategy>. Health Minister Lord Howe said: '**For the first time, we are strengthening the links between research and the treatment and care of patients with rare diseases. This is about putting those patients first, with better diagnosis, treatment and support for them**'

Brian's Story by Janet Longman

“How long did Brian have dementia”? A question we, as a family, are often asked. It seems a simple enough question, yet so very hard to answer.....

In hind sight Brian had his condition for a very long time. I refer to it as a “condition” because he was not diagnosed for many years, and it wasn’t until his death that the truth was actually revealed.

With further research, families like ours could have had answers, diagnosis and support at an earlier stage, but without more people donating their brain, this cannot happen.

Our family was like many others, although also very different. I met Brian in Bournemouth in 1966 and we married in 1968. We both worked in banking and enjoyed some extremely happy times together, moving in time to Farnborough, where we had a first child, Clare. Brian at this time worked in London., and eventually his work took us to the Bristol area in 1976 where our second child, Matthew, was born. Life was good. We visited our parents in Bournemouth regularly, spending many happy family times sailing. Time moved on with great family holidays, and a good social life both with close personal friends, and friends through Brian’s business connections. Our children were now both growing up, so I decided to return to work at my local comprehensive school. However, looking back, at about this time I can see that there were things that were just “not right”. Eventually Brian took early retirement and took on various different roles, one of which was voluntary work for the RSPCA. I loved my job and the people I worked with, but social events at this time were becoming difficult. I either didn’t go, or Brian and I went, but I had to be aware of what he was doing and saying at all times. It had come to my attention that Brian was beginning to act in an “odd” sometimes socially unacceptable manner.

Eventually it became necessary for me to take early retirement to be with Brian, and we decided to move to Cornwall. We had always said we would retire near the sea, where we would be able to enjoy our favourite past times. We started our new life in Golant, Cornwall, with my Mother, our faithful dog (William) and 4 tortoises! Both Matthew and Clare had their own lives by then, but visited often.

In the beginning, I encouraged Brian to be independent and even join some local groups. This didn’t turn out to be a positive experience – more so for me than Brian! He had started to act irrationally and his social skills had deteriorated fast. Such a sad thing to happen to a man who used to be so highly thought of amongst work colleagues and friends alike.

I won’t go into the many occasions that Brian’s behaviour caused concern, but every single one of them affected me, and indeed our family. I am of the understanding that Brian was blissfully unaware of any deterioration in his life, and for this I am truly thankful. The truth of my thoughts will never be known, but I am sure that Brian was not aware of what he was doing.

Looking back, I think I was maybe burying my head in the sand – I just wanted things to be “as they should be”. I wanted our retirement to be the dream that Brian and I had always had. Again, sadly, this wasn’t to be.

In 2003, with encouragement from my children, I took Brian to be assessed at the Nuffield hospital in Plymouth, and he was diagnosed with fronto-temporal dementia. Quite a blow. Reality had finally hit me in the face! Having read up on the true meaning of what Brian had, I really did feel devastated. The prognosis was far from positive. Over time, Brian started to display more and more difficult behaviour. Going out was extremely difficult, yet we still managed a few holidays/short breaks away together with our faithful William. Unfortunately, in time came the physical decline. Brian became doubly incontinent and after a long time of caring for him at home, with my children’s reassurance, we started to look for somewhere Brian could live and be cared for full time. After numerous visits to places and hours and hours of discussion, we found Kernow House in Cornwall. This place met Brian’s needs and it was, undoubtedly the right place for him, but leaving him there that first day was one of the most awful days of my life.

So my life had changed again. Brian settled in so well and seemed totally unconcerned either when I arrived or departed. My journey to see him two or three times a week meant a round trip of sixty miles, but it soon became a way of life. In the beginning Brian was able to go out in the car and I would often take him to local places. Clare and Matthew both had young children by now and Brian used to smile at them and attempt to play ball as they threw it at him, but in reality, he was fading fast.

Brian spent 3 years at Kernow House. During this time our family had discussed the possibility of brain donation; something we all agreed on. It was a very big decision, however, the process is not nearly as daunting as one may think. All the paperwork is dealt with as soon as the family have decided that it is the right thing for them. There are a lot of things to be put into place, and at the time of death, things do need to be acted upon quickly. However, as long as everything is put in place with the appropriate people before hand, there is no reason for this even to be discussed at the time of death.

Brian died in January 2013 at the age of 67, after many years of suffering, more for the family than Brian, as I am still sure that he was unaware of his illness. Clare and Matthew, my children, have given me the most wonderful support over the years, and had been with him in the days leading up to his death, but by fate and fate alone, I was with him when he finally decided to say enough was enough. It was traumatic and extremely

emotional, but knowing that Brian's brain donation would happen comforted us all at that terrible time. We have discovered that Brian most probably had an illness called Progressive Supranuclear Palsy, which is extremely difficult to diagnose and for which at the moment there is no treatment. It is not proven to be hereditary – this is a great relief to our family as we were of the understanding that the previous diagnosis was hereditary and therefore caused concern for all of us.

The knowledge that Brian's brain has proven to be of so much scientific assistance is an amazing thing. What a parting gift to leave – I am sure he would have been very happy about it.

Now it is time for our family to remember the good times, of which there are many. Brian will be missed in so many ways, but will always be in our hearts and thoughts.

Janet Longman

Note from The National: If you or your relative would like more information about brain donation to support research into FTD at The National Hospital for Neurology and Neurosurgery, UCL please feel free to contact Suzie Barker on 020 3448 3218 or at suziebarker@ucl.ac.uk. Alternatively information is available from 'Brains for Dementia Research' which is an Alzheimer's Research trust partnership initiative at bdr.office@kcl.ac.uk or tel 0207 848 8377

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!

After reading a recent article in the Guardian newspaper, Pete Shilson, a member of the FTDSG supplied this letter which he had written to the Guardian:

'Thanks for your article in G2 today about brain donation. You focused on the need for brains for research into autism, only briefly mentioning other research needs. There is also a need for brain donations for dementia research. My wife has frontotemporal dementia. Both she and I have arranged to donate our brains to dementia research after our death. As you said brains from people with no diagnosed condition ('normal brains') are needed in greater quantities so that researchers can detect differences between them and diseased brains. For the reasons you discuss, dementia research is also hampered by people's reluctance / squeamishness to donate. Perhaps you could return to this subject at some point.

My wife's condition is rare. An issue that you also might find interesting to investigate is the problems that people with rare conditions and their carers have in raising the profile of these conditions which, by definition, most people may not have encountered. My wife's first consultant psychiatrist had never come across a case of FTD before.

You may already be aware of it but could I point you to Rare Disease UK? One of the problems for all people suffering from a rare condition is how to raise awareness that these conditions exist. The total number of people suffering from all rare medical conditions is large but the number with just one of those conditions is, by definition, small. This is increasingly recognised, e.g. <http://www.raredisease.org.uk/>, a website that makes the point that "1 in 17 people will be affected by a rare disease at some point in their life".

A road less rocky...

We [FTDSG] strongly commend to you the recently published Carers Trust report: '**A road less rocky: supporting carers of people with dementia**'. Those of you who are receiving this newsletter via email will be able to access it as an on line document at

<http://www.carers.org/news/new-report-carers-people-dementia-not-receiving-support-they-need> but otherwise, as it is too bulky for us to incorporate or post, it is obtainable upon request by writing to Carers Trust, 32 –36 Loman Street, London SE1 0EH, Tel: 0844 800 4361. Although some of the findings are based on a relatively small sample survey, it does provide a wealth of information as the result of an extensive and relevant literature search, which is helpful. Having read through the document, it is encouraging to see that there is on-going research evidence to back many of the objectives of the support group.

Secondly, this resource to help school children learn about dementia is of significant interest, in part for the information it contains but also for the references it links to. I think this is a very important and a useful resource – and we should advertise it as widely as possible.

http://www.alzheimers.org.uk/site/scripts/news_article.php?newsID=1826

Scribe is a writing and editing service for people who can no longer complete written projects on their own. This may be due to a life limiting condition, a physical disability or because they are in the early stages of dementia and need help structuring their thoughts. Examples of writing projects include: work related articles or book chapters, creative pieces like essays, scripts and stories or letters intended for relatives and friends. Some clients might simply want help with editing, as they dictate, others might need help with word finding, interpretation or ordering their thoughts before they are put on paper. At the end of six sessions progress is evaluated with the client and further meetings may be agreed as needed. Scribe will be represented at the FTDSG Annual Seminar and is currently looking for a small number of 'trial clients'. More information on Scribe can be found at www.1stframework.org/scribe/



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 Tues 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 0845 458 3208/jill.walton@ftdsg.org for details.

Liverpool: Neuro Support Centre, Norton St, Liverpool, L3 8LR : 21Nov 2013, Thursday 9 Jan, 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 –01297445488 for details of forthcoming meetings

South West: Arundel Arms, Lifton, Devon PL16 0AA : contact Penelope Roques –01297445488 for details of forthcoming meetings

Hertfordshire/Bedfordshire: Contact Richard Pleydell-Bouverie on ropb@easykey.com or 01438 833022 for details of forthcoming meetings

Cornwall: 23 Jan 2014 Contact Cindy Reeve on 01726 71562 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:

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

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

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

North Wales-Mr Roy Jones 01248 351 537

South Wales-Mrs Pat Coulson 01792 883 684

Lynne Ramsay: Volunteer adviser regarding funding and services

Tel: 0208 467 1462 Mob. 07760 224 396