



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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Annual Seminar

The FTDSG Annual Seminar took place on March 4 2014 and was attended by around 100 people. The input from the guest speakers is of course an important part of this event, and we are grateful to all the presenters who helped make the day a success. As important as hearing the expert opinion of the speakers is the opportunity to meet with others who are facing similar circumstances to your own, and who understand what it is to embrace all that a diagnosis of FTD inevitably entails. We recognise that attending the event is not possible for some people, and are pleased to announce that audio recordings of the presentations will be available via our website www.ftdsg.org

How would I know? What can I do?

A new guide for carers which provides advice on how to help with pain and distress in people with dementia, has been published by NCPC as part of the Prime Minister's Dementia Challenge.

'How would I know' offers a range of top tips to help carers and health and care professionals identify whether someone with dementia may be in pain or distress, advice on what may be causing this and a range of possible solutions. It follows on from NCPC's 2011 publication, Difficult Conversations for dementia, which provides advice on how to talk to people with dementia about their end of life wishes.

More than 35 million people worldwide and 670,000 people in England have dementia, with the number expected to double in the next 30 years. An estimated twenty one million people in our country know a close friend or family member with dementia. One in three people aged over 65 will have dementia by the time they die. And as life expectancy increases, more and more people will be affected.

Simon Chapman, Director of Policy and Parliamentary Affairs at the National Council for Palliative Care said:

"When people with advanced dementia experience pain or distress they may behave in ways that people caring for them find difficult to cope with, and also find it hard to say what is troubling them. This is why it is so important to know how to spot signs of pain or distress and what can be done to help them. With almost half of us having a close friend or family member with dementia we really hope that this new guide provides valuable assistance."

Alistair Burns, the National Clinical Director for Dementia said:

"Too often pain or distress in people with dementia may be overlooked or viewed as an unavoidable part of their illness rather than something that can be alleviated. This excellent new guide from the National Council for Palliative Care will be incredibly helpful in helping people to better understand the realities of living with and caring for somebody with dementia".

You can download the leaflet from http://www.ncpc.org.uk/sites/default/files/How_Would_I_know.pdf

Alternatively it is available to buy from shop.ncpc.org.uk

UCL feature in the Governments dementia agenda

In addition to the recent visit to UCL by Health Secretary Jeremy Hunt, UCL has received more than £8.5 million as part of the £20 million made available by the government for research into dementia. 'We desperately need to find better treatment for these devastating diseases – and at the same time we must improve the care and support for the growing number of families that will be affected' says Nick Fox, Professor of Clinical Neurology. Prof Fox's work focuses on diagnosis and treatment for dementia while other projects at The National Hospital for Neurology and Neurosurgery and the Institute of Neurology are tackling dementia in a range of ways. 'Research at The National, the Institute and elsewhere at UCL covers the whole spectrum from basic science to health service research – and research into dementia requires investment across this spectrum', explains Prof Martin Rossor, director of the National Institute for Health Research's dementia and neurodegenerative research network.



Professor Nick Fox (left) and Dr Selina Wray with health secretary Jeremy Hunt at the UCL Institute of Neurology

‘A triumph in raising awareness’

Patricia Marland’s husband Robert has been diagnosed with young onset FTD for over eight years. Sufferers of FTD are extremely vulnerable and unfortunately Robert was manipulated by a friend to the point that the police had to be involved.

Patricia is deeply concerned by how easy it is for the unscrupulous to influence people with FTD which may lead to problems within family relationships, cause financial worries or become a risk in the nursing home setting.

Consequently, she decided to instigate a bid to change the law to protect vulnerable people particularly those suffering from FTD or some other form of dementia.

Patricia Marland started her campaign by collecting 11,000 signatures to a petition which was handed to the Vale of Clwyd MP Chris Ruane. Mr Ruane forwarded the petition to Mark Drakeford AM, Minister for Health and Social Services in Wales and Care Minister Norman Lamb. Collecting 11,000 signatures over 4 months involved walking many streets and talking to thousands of people.

Next came the petition: apparently 100,000 signatures are needed to make it effective. This is an enormous total and many people and organisations were contacted to add their support and sign up.

Patricia has now heard from Paul Haynes Welsh Government Business team who says that the Social Services and Well-being (Wales) Bill provides for the first time a coherent legal framework for adult protection in Wales.

The Bill will require local authorities to make enquiries, or to ask others to make enquiries, where they suspect that an adult in their area who has care and support needs is at risk of abuse or neglect. The purpose of the enquiry is to establish what, if any, action is required in relation to the case. It will also include duties on relevant partners – including the police and health service – to report to the local authority when it suspects that person may be an adult at risk. It is envisaged that this duty would likely lead to increased reporting and would often act as a trigger mechanism to the duty to investigate.

Mrs Marland is continuing to raise awareness by having articles printed in lots of newspapers and her story really pushes home the need for change in the law and we hope the Bill is implemented with as little delay as possible.

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.

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 Palsey, 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.

New Websites

Three new websites have been launched recently, and may be of interest to our members:

- The key goal of a new website, set up by Jon Rohrer and colleagues, is to provide jargon-free research updates on FTD for all people in the FTD community.

www.ftdtalk.org

- YoungDementia UK has launched a new website to offer information aimed specifically at young people who have been diagnosed with young onset dementia and their family members, friends and professionals. It is full of advice and information on living well with the condition as well as inspiring stories, many written personally by people who are living with young onset dementia. It also includes a young onset dementia specific support service listing, and a resource section full of useful blogs, books and websites relating to young onset dementia. UK Director, Tessa Gutteridge said, “Having spent our first 15 years developing a range of young onset dementia supports in Oxfordshire, it's high time, we thought, to move up a gear. We want to make more use of what we know and contribute to a better quality of life for people with young onset dementia. We hope our new website will be our first step to providing support for people on a national basis.” We hope to develop the website further in the coming months and would love to know what you would like to see added. To share any thoughts you have about our website, please email web@youngdementiauk.org

www.youngdementiauk.org

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- There are also several websites and publications which focus specifically on the needs of children and teenagers when coming to terms with a diagnosis of dementia in a family member or friend. Most recently launched is 'AFTD Kids and Teens' Launched by the Association of Frontotemporal Degeneration this resource is designed to meet the unique needs of children and teenagers who have a parent or friend with a diagnosis of FTD.

www.aftdkidsandteens.org

- A fourth website which may also be of interest is the longer standing IMPPACT, which is a site offering resources, support and updates on collaborative PPA research.

[:http://www.ppaconnection.org/](http://www.ppaconnection.org/)

Forthcoming Carer Support Meetings

London: The following carers meetings will take place between **11.00-am-2.30pm** in **The Foyer Seminar Room, Institute of Neurology, WC1N 3BG** and conclude with a visit to local Italian restaurant for lunch;
Mon June 2 2014, Mon Sept 8 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 fld1@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: Contact Richard Pleydell-Bouverie on ropb@easykey.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 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— 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