



FTD SUPPORT GROUP
FTDSG

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

**Vivienne Hughes describes her daughters experience*

**Requests for help with research*

** Facebook site raises awareness of FTD*

**Your Contributions*

**PDSG name change*



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PDSG Name change....

Hopefully not too radical a development and one which reflects the advances in our understanding since the time the group was established. After consulting with Professor Nick Fox and others, we have taken the decision to become FTDSG. An acronym for Frontotemporal Dementia Support Group we hope that the name more accurately reflects the diagnoses of the people we are seeking to reach.

When the group was originally formed, Pick's disease was the most commonly diagnosed of the 'unusual dementias' we were seeing at the time. We now understand Frontotemporal dementia to be an umbrella term, within which there are several sub classifications of diagnosis, of which Picks disease is one.

Changing the name of the group has afforded a natural opportunity for us to re visit our aims, objectives and the range of dementias we have tried to incorporate in the past. Corticobasal degeneration is currently very well provided for in terms of information, advice and support by the Progressive Supranuclear Palsy Association [PSPA]. The PSPA are in agreement that we mutually signpost and link our groups, in order to direct people to the most appropriate resources. There was some concern voiced at the prospect of signposting Lewy Body Dementia to Parkinson's UK and other Lewy Body support groups, but we do sense that as long as these dementias are well signposted from our site to other relevant ones, nothing is actually lost in the process. I will liaise with these groups, and the Motor Neurone Disease Association [MNDA] in order to establish and maintain on-going communication and links.

Unable to find an alternative 'home' for Alcohol Related dementias, we will continue to support these enquirers, and perhaps try to establish further links to other sources of information, advice and support. If anybody has any views or suggestions in respect of taking any of these suggestions forward, I would be delighted to hear from you.

ANNUAL SEMINAR 2012

The PDSG Annual Seminar took place on March 7th 2012. We are as always, immensely grateful to our speakers for giving their time and sharing their expertise, and we trust hat we have shown our sincere appreciation to all involved. Of particular mention must also be Mr Peter Davis, who kindly provides all of our printing and publication requirements, and Mr Roberto Salina who maintains the web site for us. We are indebted to them both and thank them for the valuable contributions they voluntarily make to the support group.

Diary date: Annual Seminar 2013 ...FRIDAY March 8th 2013

Forthcoming meetings of interest

MAY 19th 2012: Alzheimer's Research UK FTD Meeting. In Manchester, an afternoon of short talks on FTD. Contact stephen.chewgraham@manchester.ac.uk or tel.07787 002307

SEPT 5-7th 2012 The *8th International Conference* on Frontotemporal Dementias . Contact www2.kenes.com/ftd

To the Picks Disease Support Group:

Thank you for your emails and newsletters over the past few years.

I would like to tell you the story of my daughter's battle with FTLD. I feel not is much known about it and everyone tends to put it under the banner of Alzheimer's.

Elizabeth was a first class photographer, in business with her husband with 2 studios in Leeds and was Chairman of the Yorkshire branch of Master Photographer's Association for several years. At the age of 52 she was diagnosed with FTLD with just loss of memory and failure to do small tasks which had caused business problems. She was still driving and looking after the accounts etc but it became obvious that she was not coping and took less and less part in the shop. One studio was closed in 2006 and her husband and staff carried on with the other until it became obvious that she was needing more care and Graham finally gave up the struggle and closed the business down.

Elizabeth went for 4 days a week to a day centre in Leeds for "Younger people with dementia", which was wonderful, until in December 2008 she went into a care home. We had great problems in finding one to take a person as young as her. The staff in the home we found were wonderful with her and have now started taking people of a younger age, which is good. However, Elizabeth deteriorated quickly, (not their fault , the disease -) she had become mute before going into the home, and within a year was becoming increasingly immobile. Her last two years were spent mainly in bed although the staff got her up as often as they thought her capable. She could not move a muscle herself and had to be fed and given drinks etc. We had a scare 12 months ago when the doctor did not think she would last the weekend but she rallied and carried on another year, with increasing problems, and died just before Xmas at 58 years old, having had an horrific battle for a couple of months. She did not know anyone and it was very hard for her husband and children to see her. Her grandchildren miss her too.

I feel very little is published about the disease and its complications. We were given 5-7years life expectancy at the beginning and the specialists in Leeds were very good and honest with us. But so many people thought it was just "Alzheimer's" and that we were making a fuss....it was devastating to see her. There have been no signs of anything similar in the family. Elizabeth's father died at 57 from diabetes and kidney failure, my family were in their nineties without symptoms, and I am 83 and going strong (I think!!)

I hope that soon there will be medication that can help, but no-one was able to give us any enlightenment as to what would and did eventually happen as the disease took hold in the final stages, and I thought you may appreciate this information. Thank you.

Yours sincerely Vivienne Hughes.

One of our members has recently set up a Facebook site, with the aim of raising awareness of FTD, and to direct people towards our web page. Whilst we are unable to provide an official input into the site, we are grateful for all efforts which result in increasing awareness and making our material as widely accessible as possible...THANKYOU!

The site is accessible at <http://www.facebook.com/PDSGUK>

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@pds.org.uk, Tel 0845 458 3208 or post to 22 Brushwood Dr, Chorleywood, Herts, WD3 5RT. Longer articles are also welcome!

- "I had to put a sign of 'No Soliciting' in the front door because I came home after work one night and found a contractor waiting for payment after pressure washing my house. He said my husband gave him permission. My husband has FTD.
- I don't know how good they are to use, but this link may help some people:
www.Care-Home-Refunds.co.uk - Has Your Family Ever Paid For Care? If So You Could Be Owed A Refund
- I have been told that this hotel in Blackpool provides dementia friendly holiday packages...I can't vouch for them but worth a call? 01253 341218 or www.bondhotel.co.uk
- This is a good site for accessing advice on benefit entitlement: www.direct.gov.uk

Volunteers required for 2 Research Projects....

Can you help me please?

My name is Margaret Perkins and I am a researcher based in the Personal Social Services Research Unit (PSSRU) at the London School of Economics (LSE). I am doing a small piece of exploratory work about services and support for people with early-onset dementia (including FTD) and their informal carers in three areas - Surrey, Camden, London and Cambridge/ Cambridgeshire. Even if you do not live in those areas you may still be able to help me.

How you can help: I am trying to find out what experiences people diagnosed with early-onset dementia and /or their informal carers have had in getting the help they need from services (NHS and local authority) and other support organisations. As part of the work, I would like to talk to a small number of people – 3 or 4 per area - who either have EOD (including FTD), or are an unpaid carer, to hear about their particular personal stories. The meeting would last round about an hour and could take place at the person's home but can be at another venue if that would be easier. There would be a small financial thank you for agreeing to take part.

The research is funded from within LSE and has been externally reviewed and approved by the Social Care Research Ethics committee (11/ IEC08/0036).

A bit about me : I originally trained as a social worker but have also had several years experience in the voluntary sector, both in advice situations and in a medical charity, before entering academic research around twelve years ago.

Contact details : If you think you would be happy for me to come and talk to you or are interested to hear more about the research, then do please contact me, as soon as you are able, in one of the following ways:

Email: m.a.perkins@lse.ac.uk ; Tel: 020 7955 6132.

If you do not live in Surrey, Camden or Cambridge/Cambridgeshire but you would be happy for me to come to talk to you then please do contact me as I plan to extend the work in due course to other areas.

I hope to hear from you. Many thanks....Margaret.



Are you part of a family with a genetic form of frontotemporal dementia or primary progressive aphasia?

We are just starting a new study of genetic FTD and PPA. Anyone who is a first-degree relative of someone with a genetic form of FTD or PPA would be eligible to be in the study (a brother, sister, son or daughter). The genes we are specifically looking at are **progranulin** and **tau** and also people with motor neurone disease in the family. We are also studying people who are affected with genetic FTD or PPA. The study involves some psychology tests, a brain scan and a blood test over the period of a day.

If you would like any further information please contact:

Dr Jonathan Rohrer (University College London) - j.rohrer@ucl.ac.uk, Dementia Research Centre, UCL Institute of Neurology, Box 16, National Hospital for Neurology and Neurosurgery, Queen Square, London, WC1N 3BG

or

Dr James Rowe (University of Cambridge) - james.rowe@mrc-cbu.cam.ac.uk, MRC Cognition and Brain Sciences Unit, 15 Chaucer Road, Cambridge, CB2 7EF.

*****Dementia Priority Setting Partnership*****

The Alzheimer's Society has invited the FTDSG to become a partner in this project. More information to follow, but in the meantime could I please encourage you to take part in the survey by downloading at www.alzheimers.org.uk/dementiapsp or telephoning 0207 2645998 for a hard copy version. No limit has been set on the number of responses that will be included in this survey, so please distribute widely!

Speaking to the GP....

We are often asked if a carer has the right to speak to the GP about a friend or relative, in confidence. Below is the position the Alzheimer's Society advocates in view of this issue, and we would add that you may benefit by explaining to the GP that you are not requesting information be **disclosed ABOUT the person** in concern, but that your **concerns for them** be noted;

Sometimes people with dementia prefer to see their GP alone, or it may not be possible for anyone to accompany them. If this is the case, the person's carer or a family member may wish to talk to the GP afterwards. However, sometimes when a carer or relative contacts a GP with concerns about a person, the GP refuses to talk to them on the grounds that they will break patient confidentiality.

The General Medical Council has issued guidance (Confidentiality, 2009) that says that doctors should listen to the concerns of carers, relatives, and friends or neighbours because they could contain valuable information that may help their patient. The GP should make it clear that they may tell the patient about the conversation. If the patient has capacity, the doctor should only disclose information about them in exceptional circumstances where the benefit to the public or an individual outweighs the public and patient's interest in keeping the information confidential.

The guidance states that if the person does not have the mental capacity to consent to the disclosure of their information, the doctor should assume that the person would want those closest to them to know about their condition, unless they have indicated otherwise.

If the person who lacks capacity objects to the disclosure of their information, the guidance states that the doctor can still share relevant information with carers, relatives or friends if they think it is important for the person's best interests. The GP may need to share some information with relatives, friends or carers in order to determine what is in the person's best interests.

If a GP refuses to share information about someone who lacks the capacity to consent to the disclosure and you believe that this is not in their best interests, talk to the GP about the General Medical Council's guidance. If the situation is not resolved, ask the surgery for a copy of the complaints procedure and information about how you can access an Independent Complaints Advocacy Service (ICAS) to support you in making a complaint.

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

Scotland– Mrs Elaine Anderson 01292 442 273

Yorkshire– Rev. Ron Carter 01904 610 237

Northern– Mrs Jillian Ramsay 01914 214 069
mob. 07708 857438

Trent– Mrs Janet Carpenter 01162 392913 [Also the contact person for Carers of Alcohol Related Dementia]

Mersey and North West– Mrs Mary Dawber 01625 879 104

West Midlands– Sister Ann Johnson 01743 492 175

Oxfordshire– Mrs Sue Smith [Young Dementia UK Mon-Thurs]
01235 522 382

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

South West– Miss Penelope Roques 01297 445 488

Kent– Mrs Mary Silverton 01233 205738 [work]
01580 213607 [evenings and weekends]

North Wales– Mr Roy Jones 01248 351 537

South Wales– Mrs Pat Coulson 01792 883 684

Northern Ireland– Mr Martin McCrory 02887 753 812

Lynne Ramsay: Adviser re. the medical profession and obtaining funding and services 0208 467 1462

Mob. 07760 224 396

Forthcoming Carer Support Meetings :

London: The Old Boardroom of the National Hospital for Neurology and Neurosurgery, Queen Square, London:
dates: 14 May 2012, 10 Sept, 10 Dec. Joint FTDSG/PPA Carers Meeting 4 Feb 2013

Meetings take place between 11.00-am-2.30pm and usually include visit to local Italian Restaurant for lunch.

Liverpool: Neuro Support Centre, Norton St, Liverpool, L3 8LR
dates: March 15, May 17, July 19, Sept 20, Nov 22 [for details contact Mary Dawber on 01625 879 104. Meetings usually take place between 1pm and 3pm.]

South-West : 28 April 2012: Phone Penelope Roques for details
Arundel Arms ,Lifton ,Devon PL16 0AA June 8th 2012. We can meet in Exeter and car share if you are in this neck of the woods. Phone Penelope Roques for details.

Bristol : Phone Penelope Roques for details.

Bristol – venue to be arranged Friday 10th February.
[for details contact Penelope Roques 0845 458 3208