



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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Health Information Survey

Caroline de Brun is a medical librarian at the Royal Free Hospital in London. Her work involves helping health professionals to find good quality health information so that they can make informed decisions with their patients. Caroline is currently undertaking a PhD which is looking at ways of improving access to good quality health information for patients and their families and carers. She would like to identify what would be useful for people, to help them get the information that they need, but obviously can only do this by obtaining with the opinions of the people who need it, e.g. patients, family members, and carers.

Having attended the Alzheimer's Show in April, Caroline learned more about the work of the support group and has asked us to circulate an online survey she has created. She is focusing in particular on the information needs of people with Alzheimer's Disease and related conditions, and their families and carers.

The survey is available here, if you would like to find out more: <http://www.patientsandcarers.blogspot.co.uk/>

Raising Awareness

During August 2013, ARUK will be mailshotting copies of their 'Alzheimer's and dementia: your questions answered' booklet to every GP surgery in the UK. These booklets are designed to be made available in the waiting rooms of GP surgeries, and we are excited at the opportunity to include our raising awareness literature and support group information within this distribution. Information about frontotemporal dementia will also be included in the covering letter accompanying this mailshot. ARUK are funding our printing costs for which we are also very appreciative. Laura Phipps, the Science Communications Officer from ARUK spoke at our 2013 Annual Seminar, and as you know, ARUK funds much research into FTD across the United Kingdom.

The service needs of younger people with dementia

The FTD carers meeting in February 2013 was one of a series of meetings attended by younger people with dementia and their carers, facilitated by UCLH. At these meetings, strategic commissioners from Camden listened to the experiences of people, and heard that younger people often have to wait a long time for a diagnosis and are not able to access services which are age-appropriate and meet their needs.

The commissioners presented a report summarising what they heard to the Council's adult social care Senior Management Team, who endorsed the report's recommendations to improve access to, and experience of, services by Camden residents with a young onset dementia. This is to be achieved through:

- Raising awareness of rarer forms of dementia among GPs, opticians and other health and care professionals
- Reviewing the pathway for those with a young onset dementia to ensure those with the illness have access to information and support

Whilst this report is a relatively local response to the unmet need we all know exists, it is a significant step forward in general and one which the support group is pleased to have contributed towards. We will use the information gathered as a result of these meetings as a platform for further and wider publication of the needs and service requirements of younger people with dementia, and in particularly FTD.

Excerpt from a support group members published letter....

It is important that health practitioners are aware of dementia symptoms and listen to family concerns. Experience has taught me that GPs and consultants are not always aware of the different types of dementia. In common with the general public they think dementia is covered by the term Alzheimer's, but there are several types of this degenerative brain disease, which can lead to violence, disinhibition, change of personality, financial ruin, driving problems, speech loss, lack of motivation and few memory problems. Initially families are the only ones to notice change. Indeed the patients themselves are, in some cases able to hide their symptoms. The comparison with cancer is appropriate, 20 years ago it was often a death sentence, but daily we learn of new treatments and sufferers having longer to live, this has been helped so much by the investment in research funded very often by charities, I hope that soon dementia will have more funds for research, there are some promising signals from the leading neurological hospitals, here and in the USA. Dementia needs enormous funds to train specialists in early diagnosis, for the technology to support diagnosis, compassion, understanding and belief for the families, and to educate the general public.

A carer's story

The middle period of looking after someone with dementia needn't be too bad, so long as the patient is on the right drugs, and so long as the carer remembers two rather difficult rules –

1] just live day by day

2] just take things as they are, and don't get cross.

My wife, who I'll call Louise, was diagnosed with FTD early in 2012. For the rest of that year there was a difficult period during her addiction to alcohol. This came to an end just before Christmas 2012 when she suffered an accident, falling over and damaging her head. After a period of hospital and convalescence, she became as she is now, with the dementia worse, and having almost completely lost her hearing.

Alcohol was a major problem last year, and I wish the doctors had imposed a total ban at the time of the diagnosis. The only solution, eventually, was to take all drink from the house, including the bottles for cooking, and any tourist liqueurs and party leftovers. This was all given away, or poured down the sink. I then checked Louise every time she returned to the house, to see if she'd bought some more, and then checked the area outside the front door too, where she would hide bottles to bring in later. When we went out, I forewarned friends and other guests, though that didn't always work as some people thought it might be amusing to see what happened when she was drunk. In public places I had to appoint someone else in advance to share the warding, for times when I wasn't close enough. This didn't always work, but it was better than the scenes of drunkenness.

Driving was another problem. Louise passed a difficult driving test, but this test did not check her one problem area, which was the danger of becoming distracted while driving, for instance by looking at people on the pavement, or adjusting the car temperature controls. I did not want to ask for her driving to cease since it was so important for her, but no one else seemed able to take this decision. This was resolved only by her falling.

Living in K&C is a great advantage. We are visited by all these specialists listed below, sometimes in different persons as the personnel changes, and all have been useful, often for areas outside their speciality. To care for someone is to be lonely, and these visitors gave re-assurance as well as practical help –

Social worker Occupational therapist Physical therapist Speech therapist Neurologist GPs,
her and my doctors Citizens Advice Bureau London Fire Brigade (who came around to check smoke alarms)
Audiologist ENT doctor Community psychiatric nurse Community mental health team
Admiral nurse (for me) Age Concern Dietician Day Centre staff Community Alarm Services
Dementia UK Arts 4 Dementia.

Louise now has to have routines, so we do things at the same time every day. She is also very particular about sticking to schedules and being everywhere in time, so I often pretend that things are to start later than is the case. But we usually arrive far too early for everything.

She is unable to concentrate, and spends most of the day in bed, either asleep or daydreaming. Sometimes she has the telly on, but changes programmes repeatedly, and doesn't usually bother to try to hear the sound through her headphones, provided by Medequip, and the subtitles are too quick for her to read. She reads magazines and papers, and underlines in biro things she has heard of.

Louise is almost always happy. She has few thoughts for the future, and is never cross with me even after my lapses of temper. She manages herself dressing, in the bathroom, walking about the house, and finding things. She thinks, on the surface at least, that there is nothing wrong, and tries to do things she no longer can, like cooking, but we can share this to an extent. I keep the front door locked, with both keys in my pockets, and an alarm set for times when I may have forgotten the keys, one of which at night I keep near the door.

Activities are scarce, as being deaf she doesn't enjoy being in groups of people, and so will not stay at day centres. We shop together, L holding onto the supermarket trolley while I gather from the shelves, with an eye open in case she runs away, as happened once. We go on short local walks, arm in arm as she's a bit unsteady, and we often call at the corner shops. We go by car or tube or bus or taxi to museums and art galleries, where L rushes around in a very quick time. As soon as she arrives somewhere, having been anxious to arrive there on time, she wants to leave again, so visits to friends are short, but enjoyable. On public transport she speaks to everybody, breaking the silence rule in the tube, mostly to the pleasure of the other travellers. In art galleries she shouts and sings, to my amusement. We drive to see friends, though not too often as she doesn't stay very long, and can't talk. We can't go anywhere where she'd have to listen.

Being in public is a slight hazard, as L makes personal comments on passers-by, almost too loud, especially saying 'fatty!' whenever there is a chance. She sings often, childish songs, quite loud, and cheerful.

Earlier this year she was eating very little. This has changed with the medication, and she now eats sweet things readily. We keep a constant supply of ice cream, real cream, chocolate biscuits, and supermarket puddings of the pannacotta type.

Current medication includes sodium valproate, memantine and mirtazapine.

Waking in the mornings can be a problem, as Louise can get muddled, and think that 5.30 am is getting up time. As she then is not wearing her hearing aid, I have to clamber around and write something down, and she has to find her glasses to read it. But she is calmer than she was, and this doesn't happen often.

Visitors are my major nuisance, whether friends or relations. They wish of course to see Louise, but stay with her only for about ten minutes, the longest she can manage, and then come down to me, or she returns upstairs, and they then stay for about an hour and a half. This is fine, but it is the only time I have to do anything, and whatever I say they will not go away. Often they bring useless presents. To make it worse they sometimes give the impression they are doing me a favour.

Louise needs someone with her the whole time, so I employ Crossroads Care to stay at our house, by the hour, so that I can go out alone. At present they come twice a week, one day from 9 – 6, and another day 2 – 5, but they would come at any time I asked, given notice. The day is for me to see people and things, the half day is for shopping and any local appointments, such as with my own doctor. On occasions when I want to go out in the evening, they will cover that too. But this is expensive, and not worth a trip to the cinema or anything less than really vital.

I have Power of Attorney, arranged as soon as we had the diagnosis, so I deal with all her letters. She no longer looks at e mails.

What I need is time in the house with Louise out. This is difficult to arrange, but a few friends have taken her out for a time. Two people are needed to be with her.

An overall problem for me is tiredness. Louise goes to bed at about 8.30 pm, but wanders around for about an hour after that. In theory we get up at 6.30 am when I make us coffee and return to bed, but L is often up earlier than that. Between these times I am on duty, unless a friend or a sitter from Crossroads is here. I often sit at my computer, as I am now while writing this, or go into the garden, but always I have to pay attention. I do not listen to the radio or music. This is ok, but only if I am able to sleep in the mornings, and often I have several days in a row of waking at 4ish and staying awake. Sleeping pills work for the day, but cause difficulties later, and I don't take them if at all possible.

The two rules above are difficult, as it is so easy to look ahead with despair, or to listen to stories from sitters or others that are depressing. To keep them in mind I keep notices on my desk written in fake Latin to make them sound more important and to remain private –

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TauRx drug study now recruiting in Southampton

The TauRx drug study for people with behavioural variant FTD was referred to in the December 2012 newsletter. A 12 month study involving 10 clinic visits and several telephone contact visits in between these, it is open to people who are under 70 years of age, live at home with a caregiver who is also willing to participate and fulfil the necessary entry criteria. In addition to the Charing Cross study centre which we previously referred to, [tel 07903 242429 for details] the study is now also taking place at the **University Hospital Southampton NHS Foundation Trust** with Dr Christopher Kipps as principal investigator. Anyone interested in receiving more information should email lesley.mackinnon@nhs.net or telephone her on 01962 825568 . For more information about the trial visit <http://clinicaltrials.gov/ct2/show/NCT01626378>

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!

Toni Battison writes: please tell any other carers and members of your team who might be interested to have a browse at the blog I now have up & running . I am slowly uploading readable-sized parts of the story that I wrote earlier, interleaved with new information about our daily lives. I have called it Mr's Story as I feel a strong need to protect my husband's identity. It can be found at www.myhusbandhasftd.wordpress.com

It has been good emotionally for me to get our story on paper but my prime aim is to share information with other carers .

The Doctor thinks it's FTD: What Now?

AFTD has a new publication called "The Doctor Thinks it's FTD. Now What? A Guide for Managing A New Diagnosis." This booklet helps individuals and families take a strategic approach to a diagnosis of FTD. It reflects the cumulative experience of thousands of individuals and families who have faced FTD and the professionals who work with them. It can be downloaded from the website or hardcopies ordered via info@theaftd.org.

UNIVERSITY OF BIRMINGHAM STAFF PEDAL TO PARIS FOR FTDSG

Michelle Khan Prices mother was diagnosed with FTD 8 years ago. In July 2013, Michelle and her colleague Cheryl Shepherd cycled to Paris, to raise funds for the support group. Michelle says "My mum is in the final stages of this cruel disease and we want to raise awareness of its rarity and to help to meet the needs of those who care for people with Picks."

People can support Michelle and Cheryl's cause by donating via www.justgiving.com/Cheryl-Shepherd1
On behalf of the support group... 'THANK YOU!'

Forthcoming Carer Support Meetings

London: The Old Boardroom of the National Hospital for Neurology and Neurosurgery, Queen Square, WC1N 3BG: 9th Sept, 4th Nov, 2013. These carers meetings take place between 11.00-am-2.30pm and conclude with a visit to local Italian restaurant for lunch. **Feb 13 2014 ; 11am—2pm : Wilkins Haldane Room, UCL, Gower St, WC1E 6BT** Joint FTDSG and PPA support group carers meeting . Contact Jill Walton 0845 458 3208/jill.walton@ftdsg.org for details.

Liverpool: Neuro Support Centre, Norton St, Liverpool, L3 8LR : 19 Sept 2013, 21 Nov 2013 [for details 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 : Sat 23 Nov 2013(for details contact Penelope Roques –0845 458 3208)

South West: Arundel Arms, Lifton, Devon PL16 0AA ; 28 Nov 2013 (contact Penelope Roques –0845 458 3208)

Herts/Beds: Sept 18th 2013, 10am -12 noon. Contact Richard Pleydell-Bouverie on ropb@easykey.com or tel 01438 833022 for more information

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

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

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

One more thing...

I have been asked to find both a French and Spanish speaking carer contact for 2 families affected by FTD. If you can provide a relevant contact please let me know at jill.walton@ftdsg.org

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

Tel: 0208 467 1462 Mob. 07760 224 396