

Sharing our experiences: One young carer shares her experiences by writing a regular blog which you can access at <http://www.aroundtheworldwithahighchair.com/dear-mum-with-dementia/>

Carer Support Meetings In some areas support group meetings are arranged by regional coordinators. Please see the website www.ftdsg.org or contact regional coordinators directly

London: Carers meetings take place between 11.00am-2pm at UCL Gower St site venue. Meetings currently scheduled for Mon April 27 2015, Mon July 13 2015 Contact Jill Walton 07592 540 555 or jill.walton@ucl.ac.uk for details .

Liverpool: Neuro Support Centre, Norton St, Liverpool, L3 8LR : Meetings usually take place between 1pm and 3pm .Contact Mary Dawber on 01625 879 104 or email mary1246@hotmail.co.uk for details.

Yorkshire Yates Wine Bar , Boar Lane, Leeds LS1. Contact ftld1@yahoo.co.uk for details .

South West: Lyme Regis : contact Penelope Roques –01297 445488 for details .

South West: Arundel Arms, Lifton, Devon PL16 0AA : contact Penelope Roques –01297 445488 for details.

Hertfordshire/Bedfordshire: Contact Richard Pleydell-Bouverie on richard@lawrenceend.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

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.

Surrey: Contact Karen on 07525597503 or email Karen.Tapson@alzheimers.org.uk for details.

Stockport: Contact Helen Griffiths 0161 716 4505 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—Anne Miller 01436268476
milleranne89@googlemail.com

Yorkshire – Rev. Ronald Carter 01904 610 237
Anne Squires 0113 2947139

Northern – Mrs Jillian Ramsay 0191 421 4069 m0770 885
438

Manchester/ Stockport—Helen Griffiths
helen.griffiths@nhs.net 0161 716 4505

Mersey and North West – Mrs Mary Dawber 01625 879
104
Email mary1246@hotmail.co.uk

West Midlands – Sister Ann Johnson 01743 255856

Birmingham— Pauline Ross 07815285876
polly.ross@btopenworld.com

Kirsty O'Dwyer 07887800947 kross38@hotmail.com

Kirsty is happy to take calls from anyone whose parent is affected by FTD

Central - Emeline Keown [YoungDementia UK]
01865 747698 Mob: 07909 060430
emelinekeown@youngdementiauk.org

Northamptonshire— Hilda Hayo 07920 819523
hhayo@talk21.com

London – Mrs Carole Ivey 0207 603 0550

Cambs— Val Freestone 01223 768005
valerie.freestone@addenbrookes.nhs.uk

Herts/Beds—Richard Pleydell-Bouverie 01438 833022
richard@lawrenceend.com

Kent/Sussex– Jane Smissen Bell 01323 504156
6bells.jane@gmail.com

West Sussex– Jill Butcher 01444 451 837
jillbutcher@onetel.com

Suffolk - Mrs Gillian Gubb 01502 569077

Norfolk—Gillian Litson 01263 514624

South West – Miss Penelope Roques 01297 445 488

Cornwall—Mrs Cindy Reeve 01726 71562

South Wales – Mrs Pat Coulson 01792 883 684

frontotemporal dementia



www.ftdsg.org

[FTDSG] SUPPORT GROUP

(formerly Pick's Disease Support Group)

Inside this issue:

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- *Caring for people with FTD: A Research Interest
- *Young Dementia UK Steering Committee
- *Police Contact and FTD flyer

Police Contact and FTD

The support group has recently created and published a new flyer drawing attention to the inadvertent contact with the police that people with FTD often experience. We were represented at a recent conference which brought together a panel of leading experts to speak on all aspects of mental health diversion with regard to legislation and magistrates courts. Dr Jonathan Rohrer, Consultant Neurologist, Dementia Research Centre, University College London, specialising in behavioural variant neurodegenerative conditions gave a presentation entitled 'What questions to ask, what behaviour to look for ' and the new flyers were handed out to over 150 attendees at the event. Please contact jill.walton@ucl.ac.uk for a copy of the flyer.



YoungDementiaUK
Informing Influencing Inspiring

YoungDementia UK Steering Committee

Jill is delighted to have been asked to represent the support groups on a new steering committee created by the charitable organisation YoungDementia UK.

The committee aims to create a national highly visible identity/focus for young onset dementia (YOD) , since there is currently none in place. Our purpose will be to improve the lives of people with young onset dementia and their families by harnessing passion, energy, experience and knowledge.

With this momentum, we will create effective connections and use these connections to exert a powerful influence over key areas that present a barrier to living fully and well with dementia as a younger person.

By acting with strength and determination, we intend to bring about significant changes that will have a lasting benefit for people living with young onset dementia.

Jill will keep you updated...watch this space!

Caring for people with FTD: Research Interest

Zoe Rigg is a trainee clinical psychologist at Canterbury Christ Church University with an interest in the experiences of caring for someone with a diagnosis of behavioural variant frontotemporal dementia. She is particularly interested in how carers and relatives manage difficult circumstances and whether these experiences have changed over time since receiving the diagnosis.

Zoe would like to conduct interviews with carers/ relatives who are interested. These interviews will be conducted at a location convenient for the participant. Zoe is willing to travel, ideally throughout the South East or North West regions.

If you are interested in this study and would like more information, please contact Zoe on 07846577946, or via email at z.rigg16@canterbury.ac.uk.

A personal reflection on the reality of Frontotemporal dementia

There is this woman I've known all my life. At the time of my writing this she is 59. Her name is Sue and she lives on a farm in south Devon. About 5 years ago she was diagnosed with FTD. It's a form of early onset dementia. When someone hears the word dementia they have an automatic idea of what she has.

But you're wrong, you have no idea.

This rare neurodegenerative disease is vicious and horrible to watch and deal with. Every person with it will experience different symptoms. The worst thing is the diagnosis. The doctors were terrible, they just said she had repressed memory and that's all. We had to travel up to London to speak with a specialist, and then finally we got the horrible news.

Her two children, aged 12 and 14 at the time had no choice but to accept the fact their mother would only get worse. Someone once said that the person with the FTD had the disease but their family has to suffer with it. If you haven't heard of FTD then what I say in this might shock you, but please don't judge me. FTD is the most mentally draining and challenging thing to deal with.

In later stages of the disease, the person becomes completely dependent on care. They cannot do anything for themselves, and show no appreciation for anything. In this particular case Sue could often become violent and often verbally abused family members and friends. Normally things like 'I hate you', which was particularly hard to hear, especially when you're trying to help them. Take it from me it's hard to accept that is not the person saying and doing what they are doing.

Sue's husband Mike became her main carer, along with managing a farm and trying to raise children. Their daughter became the mother of the house and was responsible for most of the duties. Their son felt it hard to be around her and often resorted to retreating to his room and going out with friends. The thing with FTD is that you don't know when it started, and when it's going to go to the next stage- looking back there were many strange signs which were overlooked at the time. I'm writing this to try to raise awareness of this horrible disease. When speaking to other people dealing with FTD they all say the same. Many go so long without diagnosis, resulting in divorce and loss of jobs. I honestly don't know what would happen if Mike wasn't there. It takes a real special person to give up your life to care for someone with FTD- not many people could deal with it 24/7.

Trying to explain her behaviour is easier said than done. She had her good and bad momentsnot good or bad days because she can change so quickly. One minute she can be laughing and happy and the next in tears and trying to hit you. There is no logic in her behaviour and it is very frustrating and draining. She cannot comprehend simple instructions, for example 'can you pass the milk' would cause utter confusion. She has no sense of hygiene, without going into detail, you can imagine what I mean in regards to going to the toilet or having a shower. Such tasks can only be done with the help of Mike, her husband. She won't let anyone else do it.

Luckily she qualified for NHS funding which pays for her carers. They come in Monday to Friday, mostly to give Mike a much needed break, but soon she will need 24 hour assistance. Unfortunately this is easier said than done, as she is completely dependent on Mike and when he leaves the house she is deeply upset and cannot be calmed, even by other family members. She can easily reject people. At the moment her current problem comes in sleeping; she wakes up every hour and has to be held in bed to fall asleep again. As you can imagine this illness is physically draining and not sleeping properly only adds to the problem for her carers.

She is now on new medication which has made all the difference, she is happier, unfortunately that is the only change it's made. At one stage she went through a need for walking, she would walk from one side of the farm to the other up to 18 times a day. Each time they would pick her up (often with huge difficulty and violence especially to her daughter) then, when she got home she would not go into the house but walk off again and nothing you said would stop her. They tried everything from physically restraining her to trying to talk her in, nothing worked.

She didn't understand the cold and would go off without a coat and wouldn't let you assist her to put one on. The only thing stopping her from doing it all day would be to lock the doors. On many occasions she would have lost control of her bladder and would continue to keep walking without noticing. Trying to clean her is especially hard; she still has a sense of dignity.

This 'wandering' (and I use the term lightly because she is driven to walk) also happened when she was taken out for the day by the carers. Amazingly she still has an amazing sense of direction. Her favourite carer (a trained mental health nurse) even had difficulty getting her back into the car, resulting in abandoning the car and walking with her and calling Mike to rescue them.

Entertaining her is another problem. She loses focus and gets agitated easily, and this is when problems occur.

Unlike normally dementia, her facial recognition is brilliant, -she cannot name people but she remembers their face. So if she gets a bad idea about someone then it's game over. Her speech gets worse; her current vocabulary consists of few words and cannot be composed into a sentence. She loves music and will constantly hum different tunes aloud.

I hope by reading this I have given you some idea of how it's like. Please be aware every story is different.

Sue is my mother. I'm currently 16. I have accepted the fact my mother is not the same person who raised me and that she will not be with us for long. I hope you can help my campaign to spread awareness of this truly horrible disease. Dementia shouldn't happen to someone so young; it has completely broken my family and affected us all in different ways.

I can't remember her when she was 'normal' and all I have is this woman who looks like my mother and but isn't her. I don't know if she actually knows whether I'm her daughter, or if she just recognizes my face. I don't really know what it's like to have a mother, someone to talk to and laugh with. Instead I have to care for her. Because of this disease my mother won't be in my future, at my wedding or be there if I have children. Cancer is not the only thing that needs a cure.

Thank you for reading and please share this.

Information resources for younger people

Unlike many other dementias, FTD often affects people in middle age, or even younger, meaning that it is likely that there will still be children at home. When any parent faces a serious illness, their children need support and understanding. It is important to help young people manage and understand the disease they are witnessing in their parent.

Children are very perceptive. They are likely to be confused by the symptoms of this disease in a parent or family member, and without being given factual information they may fill the gaps in their knowledge with their imagination or with incorrect facts. It is therefore very important to facilitate conversation, provide information and allow for emotions and feelings to be discussed.

There are several links which provide helpful information in respect of providing young people with the information and opportunities for discussion that they need. The links are not all FTD specific, but provide information that is transferrable and relevant:

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[Understanding dementia: a guide for young people](#) (PDF download). Also available through Dementia Helpline Alzheimer's Scotland Action on Dementia:
Tel 0808 808 3000
[What about the Kids? AFTD](#)

Carers Trust: [Young Carers](#)

[Information for Young Carers from the NHS](#)

[When Dementia is in the House - for parents and teens](#)