



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:

- *'Ian' by Lynne Settrington
- *Teeth Grinding: your responses
- *New regional contact people
- *E-petition request
- *YoungDementiaUK
- *Setting up a regional meetings

'Ian' by Lynne Settrington

It's the little things as ever that get you, I am sitting in the airport in Richmond, Virginia thinking over the repercussions of just having had my Swiss army knife confiscated by security as I prepare for my journey home. I completely forgot it was in my bag as it made it all the way to the US last week unnoticed. It's a pretty traditional knife you can pick up anywhere but has my name inscribed on the side and was a present about twenty years ago from my brother Ian when he went on a walking holiday to Switzerland. Ian was diagnosed with FLD last year and myself, and my sister, as his only close relatives are still dealing with the fall out from that diagnosis.

Ian is twelve years older than me and spent most of his adult life living in North Wales where he taught for almost forty years. He has always been an independent person and somewhat eccentric character, but kind and thoughtful of others and good fun. He was a very active person, a member of his local rambling group in Clwyd, the folk club nearby in Frodsham and also the tennis club in Mold, North Wales. He was something of a legend in the walking group known for his long walks and sense of humour; adding on a couple of extra miles as the light faded at the end of an already grueling walk. In fact, since he became ill, I have had a few cards from his old walking companions saying he was in part responsible for some marriages, as people came together and made new friends on the weekend stays Ian often organised in Youth Hostels in the Lake District.

Tracking the start of his illness is hard to pinpoint exactly, he would come over sometimes for Sunday lunch, more frequently when he split up with his long-term girlfriend. She was, it seems aware of changes in his personality but put it down to his slight eccentricities and got out of the relationship whilst she could. When he recounted to me one weekend that he was eating the same meal every night and walking the same route daily, despite his love of exploring and adventure, I knew something was badly wrong. I discussed it with a few people including my sister who put it down to depression, Ian having taken early retirement a few months earlier at sixty and the break up of his long-term relationship. However I suspected it was more than that, and it was in fact on another work trip to the US that I realised the problem. It was in a discussion with a colleague there about his wife's memory lapses and unusual behaviour. I discovered she had recently been diagnosed with FLD and from our "matching of notes" I saw similar traits. Someone who had been methodical not longer taking care, repeating stories and actions over and over and just not being themselves. Of course Ian would not go and see the doctor and would not talk about what was happening with him. Living on his own as he did, it was difficult to find a way forward and get him to acknowledge anything was untoward. The situation eventually came to a head when I had a call from the local police asking if I had any concerns over my brother's health and well being. It turned out he was at home with the very understanding policeman who had been called by someone in the village. Ian had been acting oddly and looking through people's windows and was completely unaware that this was not acceptable.

There followed six months in a psychiatric hospital whilst a whole host of tests were carried out and then six in a local council provision whilst we struggled to find some sort of solution, in terms of a place Ian could comfortably live, and still enjoy a reasonable quality of life. Thankfully a room became available at a care home in a village close to where we grew up with understanding staff and a very supportive manager and Ian has settled in well to his new environment. He gets out twice every day for long walks and exercise and has good regular meals and visits to a variety of local places. It's not ideal in that Ian is twenty years younger than most of the other residents, but his demeanour is good and he seems content and we are able to take him out each week for a meal and favourite walk.

I can't yet explore all of my pain at what has happened and why. My son's have been deprived of an uncle; as Ian's illness means he is unaware of others and appears completely self centred, myself and my sister have lost a dear brother and the chance to share memories and our future, and Ian has not had the chance to enjoy his well earned retirement and the travelling and trekking I envisaged him doing for many years to come.

Tragically the way FLD has presented in Ian means over the last year he has lost most of his speech and as a consequence it is difficult to gauge how he is feeling or what (if anything) he is thinking. I miss him dearly. Sadly he moved away from all his long standing friends a couple of years ago, when he was becoming ill and has lost touch with all of them. They thought he wanted a fresh start and was moving on when he did not pass on his new address, in fact I am sure he was already becoming quite ill.

We don't know what the future holds for him or us. Thankfully he seems happy generally although a little more emotional of late. Sadly there is little information about FLD out there so along with dealing with all aspects of Ian wellbeing we don't really have much by way of information. The support group for FLD has been a big help in answering general queries however. Most people I know have no comprehension of what FLD is and all too quickly associate it with Alzheimer's and old age. A recent article in the Guardian was helpful in outlining the plight of a family where the dad, a man of thirty six was discovered to have the illness. It seems FLD can strike at anytime and anywhere; I would dearly love to know why Ian has been afflicted. Thankfully I hold comfort in knowing he has almost sixty healthy happy

Teeth Grinding

Changes in oral behaviour are actually one of the criteria for diagnosing FTD, and several people describe teeth grinding as one of these changes. Other changes include opportunistic food seeking whereby people eat everything in sight, holding food in the mouth rather than swallowing, changes in dietary preferences: often with fads for unusual or sweet foods, and the putting of non- food items in the mouth is also described in people with FTD.

It has been suggested that there is a basic homeostatic system by which eating is regulated. The hypothalamus responds to peptides from the stomach and when you are hungry and sends chemical messengers which stimulates the system for increasing appetite and food intake. When you have eaten enough there are signals mediated by a peptide that tells the hypothalamus you have had enough.

In addition to this basic system there is also a cognitive system, which can override the basic homeostatic system by responding to a whole range of other signals: visual image of food, knowledge about the nutritional value of a food, as well as the smell and taste stimuli. It is the circuitry of the orbital frontal region of the brain that is important in maintaining this cognitive system. This is the region that is particularly damaged in people with FTD, hence the symptoms they display in respect of hyperorality, eating behaviours and, in this case teeth grinding.

Another reason by which we can override appetite controls is social - social factors might cause us to refrain from eating when we are hungry, or even to eat when not hungry! This aspect is of course particularly vulnerable in people with FTD

In the December 2012 newsletter we asked for members of the support group to respond with suggestions as to how to stop teeth grinding in a person with FTD. We don't actually know how common this symptom is in FTD, or indeed the other dementias, but here is a summary of the responses received:

- Has there been the introduction of any new medication, which could be causing the teeth grinding by way of a side effect?
- Is there any evidence of painful teeth, infection or a mouth, throat or tonsil condition which isn't being expressed as needing attention? Maybe your dentist/GP could assess, or perhaps consider a referral to the Eastman Dental Hospital explaining the dementia diagnosis within the referral?
- This behaviour has been reported by other carers and is sometimes purely a behavioural symptom, which, like most of the others, changes and passes over time.
- Very occasionally, I do believe that Botox injections have been given if there is a diagnosable issue concerning the muscles of the jaw, but obviously needs to be considered with care.
- Mouth /gum guards can be made to measure if the patient is likely to be compliant in their use. Again, your dentist might be a good place to start...unless you are happy to try an off the shelf product in the first instance. There are several internet sites which will provide these.
- A neurological as well as a speech and language therapist assessment would be advisable.
- Chewing gum might provide a distraction which helps get through this phase. Similarly, there are products known as 'chew sticks' which some of the websites for people with learning disabilities

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!

Penelope writes: Patricia Marland's husband has Frontotemporal dementia and we all know the devastating effect that this diagnosis brings and how heart-breaking the path to diagnosis is. Patricia is raising awareness with the government and there is **an opportunity to sign an e petition** as confirmation of support. Some of our members have already enlisted the support of their friends and ideally whole groups such as choirs, golf clubs or work colleagues could be asked to sign the petition too.

Patricia wants over 100,000 people to sign the petition and to date 543 have done so! We as a group need to support this cause.

You go to <http://epetitions.direct.gov.uk/> Open the web site and put in the box Pick's and sign up. I couldn't get back to Pick's page after I had read Terms and Conditions (seem straight forward) so I went back on. The site will send you an email to confirm the email address (stops me signing the petition a thousand times).

Please Support Patricia in this as you know raising awareness is very very necessary.

YoungDementiaUK Training Evening



Jill was delighted to be invited to join Sue Smith, FTDSG regional contact person for the Central region, at a YoungDementia UK team training session that she organised for their Support Services Team. Tessa Gutteridge, Director of YoungDementia UK attended the meeting, having previously met with Jill to brainstorm ways in which both groups operate, can learn from each other and are planning for the future. We look forward to an on-going relationship with the organisation, which was originally known as The Clive Project, and founded by Helen Beaumont, whose

husband had FTD and who has been part of the support group since its formation in 1994.

Setting up a regional group

The FTDSG is keen to extend its regional activity, in order that more people are able to meet others in a similar situation and benefit from the mutual exchange of experience. We are delighted to have 2 new regional groups meeting as of Spring 2013, and Penelope Roques outlines her experience of setting up regional meetings for carers of people with FTD.

When I first moved down from London to Lyme Regis it became apparent that carers would like to meet. A carer (now good friend) and I started meetings usually at her house in North Devon as she is a marvellous cook! As time passed we were asked if meetings could be held nearer Cornwall and the Arundel Arms in Lifton was suggested – it is on the Cornwall Devon border. There is a lovely bar in this superb hotel and we have thoroughly sociable meetings including wonderful sandwiches and chips.

We do not have speakers– it would be awkward in a bar but we all exchange experiences and I am there with my knowledge of ftd gained over the last 25 years (My knowledge is a luxury but not necessity). The diagnosis is not important, if we can help with advice and support over managing challenging behaviour that is important. We have all become good friends and treat the event as a day out. We are very aware that groups can become close-knit and we are careful and happy to welcome new members. We had 19 at the last meeting and the hotel has kindly agreed to give us more space which is extremely kind of them as they could easily have suggested we use their (expensive) events room. We divide the bill so there are no overheads. Cindy Reeve has agreed to become the Contact Person for Cornwall and she hopes to run meetings locally – also in a pub which shows what a good example I set – in between the 3 monthly meetings in Lifton.

I also run a group from my home in Lyme Regis which is easier for people in Dorset and Somerset. First we just had chats over tea but as some carers had to come quite a way we decided to include a fish and chips lunch (or something similar) at a local restaurant and to come back at my house after lunch to meet the people who couldn't spare the time for lunch. Quite often a person with ftd will come to the restaurant and then look round Lyme whilst we have afternoon tea. Getting care organised for the person with ftd who is vulnerable is often difficult and we understand that it is often not possible for carers to attend regularly.

Setting up a group is not easy and sometimes in the early days you can wait patiently (with a book) and nobody turns up. You have to soldier on and eventually it all happens. You might also have to try a variety of venues. I put the dates and details on the calendar on the web site and I send an e-mail round to remind people about a week before the event; we decide on the next date when we are together. I have been down here 13 years now and I have only just got my brain really organised for these meetings. If you are setting up a group I would be very happy to talk if it would be any help.

Penelope Roques.

....'they love his humour!'

Mary Dawber has offered this example of the difficulties of behavioural FTD, and the inherent problems around making medical staff aware of them...

I was called yet again by the Nursing Home as Ken, my husband, was having a profuse nose bleed ...again ...and in spite of 3 cauterisations in the last month and 10 trips by blue light to Casualty. I arrived at the Casualty Department as usual, giving all the history.

Ken once again had his nose cauterised and the doctor said to him "do not poke or pick your nose."

Well, I'm sure you can imagine what came next!

"Well doctor, my wife picks her nose as we are driving along!"

Continued from page 1...years, more than some people enjoy, and did all the things he wanted to in that time. I can't think too much about what he and we have missed but I am grateful for all the memories I hold. Our walking in the Peak District together, his old Opal Kadett car he gave me when I passed my driving test and all the little things he fixed for me over the years. More awareness of this devastating illness and research into its causes can only help those affected and the family and carers that support and deal with its consequences on a daily basis. Lynne Settrington

Cornwall and Herts/Beds Regional Contact People

We are pleased to announce that the FTDSG has 2 new regional contact people . Richard Pleydell-Bouverie is a longstanding member of the group and has offered to act as a point of contact for the Hertfordshire /Bedfordshire region. Carer meetings will take place near Luton so please feel free to get in touch if this is within reach for you. Cindy Reeve has also been involved with the group for some time ,since her husband was diagnosed with FTD . She will coordinate carer meetings in the Charleston area of Cornwall. We are very grateful to Richard and Cindy, both of whose contact details are listed below.

Forthcoming Carer Support Meetings

London: The Old Boardroom of the National Hospital for Neurology and Neurosurgery, Queen Square, WC1N 3BG: 10 Dec 2012. **Joint FTDSG/PPA Carers Meeting:** 10th June 2013. 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. Contact Jill Walton 0845 458 3208/jill.walton@ftdsg.org for details.

Liverpool: Neuro Support Centre, Norton St, Liverpool, L3 8LR : 23 May 2013, 8 July 2013, 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: May 10th 2013, 11am –2pm. It's fine to just turn up on the day, or you can e-mail ftld1@yahoo.co.uk for details of forthcoming meetings

South West: :Lyme Regis : 18 May 2013 (for details contact Penelope Roques –0845 458 3208)

South West: Arundel Arms, Lifton, Devon PL16 0AA 16 May 2013(contact Penelope Roques –0845 458 3208)

Herts/Beds: The first Herts/Beds carers meeting will take place near Luton on May 21, between 10am and 12 noon. Contact Richard Pleydell-Bouverie on ropb@easykey.com for more information, or contact Jill Walton.

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 492 175

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

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

Tel: 0208 467 1462 Mob. 07760 224 396