

PDSG *newsletter*

Welcome to this month's Pick's Disease Support Group Newsletter

This Month

January 2010

www.pdsg.org.uk

- **Annual Seminar 3rd March 2010** **BOOK NOW for your place**
 - **Nan Underhill** tells us about her husband Pete
 - **Mary Dawber** gives her observations as a PDSG Adviser/Contact
 - **Victoria Jones** gives us lots of good advice
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Annual Seminar 3rd March 2010

To be held at:

**National Hospital for Neurology & Neurosurgery,
33 Queen Square, London. WC1N 3BG**

09.30 - 09.40	Welcome	John Rendell, Chairman, PDSG
09.40 - 10.20	How research into other diseases helps understand FTD	Professor Martin Rossor, Consultant Neurologist, National Hospital for Neurology & Neurosurgery, London
10.20 - 11.00	Brain Matters	Professor John Hardy, Neuroscientist, Institute of Neurology, Queen Square, London
11.00 - 11.30	Coffee	
11.30 - 12.10	Questions neuropsychologists ask - and why	Dr. Sebastian Crutch, Neuropsychologist, Institute of Neurology, Queen Square, London
12.10 - 12.50	Question and answer session	Professor Nick Fox Consultant Neurologist, National Hospital for Neurology & Neurosurgery, London
12.50 - 2.00	Lunch	
2.00 - 2.40	How can professionals help	Riitta Kukkastenevmas CANDID National Hospital for Neurology & Neurosurgery, London
2.40 - 3.20	Young carer's project	Dr. Emma Svanberg Clinical Psychologist, UCL
3.20 - 4.00	A carer's perspective	Susan Craig
4.00	Close	

This event is a wonderful chance to hear all about the latest research. Also you will see that there is a question and answer session - so you have a great opportunity to voice your queries and get expert advice. Come prepared!

To book contact Carol Jennings tel: 02476 460 695 email: carol@pdsg.org.uk

Cost: £50 for Professionals £30 for Caregivers

Observations as a PDSG Adviser/Contact Mary Dawber

Throughout most of the contact I have with carers of FTD sufferers, both diagnosed and at the stage of displaying symptoms which could indicate FTD,

there is one theme which is distressingly and alarmingly prevalent.

All too frequently potential FTD patients and their families find the

treatment for this disease seems to be more effectively provided by the divorce court or Her Majesty's prison than the NHS.

I have several carers with spouses/loved ones ,who are clearly showing marked changes in personality, rigidity in thinking and acting with obsessive adherence to rigid routines. Uncharacteristic aggression, loss of insight into changes, irritable outbursts, belligerence and disinhibition are observed by the carer.

In some cases, even where the patient begins to display an unconcealed (out of character) interest in pornography, attempts to have extra marital affairs with inappropriate partners (40 years their junior in one case), and an out of character obsessive use and interest in prostitutes, this information is discarded by clinicians. In another case the patient was eating scraps that were being thrown to the birds, as well as displaying inappropriate gluttony by consuming kilos of apples etc, sweets, crisps, something constantly in the mouth. One carer was spending up to £200 weekly on her husband's gluttonous food bills – attempts to stop,

diffuse or distract resulted in inappropriate aggression.

These carers report that when they can manage to get their loved ones to the G.P. – then the first hurdle is to hope the G.P. is familiar with FTD not just the Mini mental State exam! Potential FTD patients can present as plausible “ my spouse is making all this up Doctor”. If these carers can obtain a referral to a local psychiatrist or neurologist, or a tertiary centre where clinicians are familiar with the diverse presentations of early FTD, then the situation becomes more hopeful, but if not the distress and frustration increases. Some clinicians are not involving the family in spite of all the research and knowledge of FTD in 2010.

I have asked one carer to present in writing a detailed account to her spouse's G.P. and neurologist – the latter even refuses to hear her account of the changes in her spouse – some of which give clear identification of the risk present. To ignore, such a high level of documented risk, without giving clear objective rationale for ignoring the views of the family the patient resides with, can only be described as negligence. Once again, a spouse has

the suggestion – ‘Why don't you divorce your spouse?’ If this patient potentially had cancer, the spouse would not be treated like this!

It is the carers that need support in dealing with this puzzling, distressing illness, through the lies, deceit ,accusations, paranoia, the personal grief of the loss of a loved one. Each stage brings its own challenges and sorrows - no one in their right mind volunteers to stand by their loved one through a disease as challenging and distressing as FTD. Carers Allowance just isn't that attractive! There are no financial gains in caring that would justify this journey!

Yet still, at the diagnostic stages, carers have difficulty in either obtaining a local referral, yet alone a specialised tertiary referral.

One thing we, the PDSG Support Group, must work towards is no more dismissal, or even worse, ignoring, a carer's views. This is part of the Dementia Strategy - to involve carers at all times.

Pete

Nan Underhill

I first encountered PDSG soon after a typically delayed provisional diagnosis of FTLD with MND given to my husband Pete.

The old story of a “wife failing to cope” was finally disproved when Pete had severe fits about five years ago and was in hospital for about three months. Having “recovered” from these we continued our lives as though nothing

was amiss. We travelled with our motor home (with me driving!) as we had done for some years although we now tended to travel more with friends than alone. We visited Croatia, Italy, Slovenia and other European countries.

Pete was an extremely outgoing character and this resulted in us having many friends. His character remained very placid and his social skills could be excellent right up to the end of his life.

I feel extremely fortunate that his nature and his version of this

devastating disease allowed us such freedom in these later years. He said his farewell exactly as he would have chosen, on holiday in the motor home in Spain in May 2009.

The support of friends has been exceptional and the information received from PDSG invaluable. Keep up the good work.

I write this simply to show that this disease can manifest in extremely variable ways.

Becoming a Carer

Victoria Jones

The shift from partner to carer is traumatic. You are in a position you haven't chosen and don't want to be in. There's a challenging road ahead as you learn to accept the new person you live with.

- You're not perfect and don't have to be. You will get things wrong despite your best efforts.
- Make sure you both enjoy whatever you can together – stock up good memories for you and your loved ones.

- Try very hard not to argue or to contradict your partner – it won't get you anywhere other than even more worn out and it won't help them either. (If your partner's like mine, he will insist on contradicting you and explaining away at length any obvious errors he's made).

- You'll soon learn not to make passing remarks or speak without thinking hard first – your partner can't deal with this and you'll wish you'd never said anything.

- You can't praise your partner too much – you might think you're being patronising but she won't.

- You're probably already overestimating what she can do and understand. Your partner is an expert at hiding her disability and distress from others – this doesn't mean there's no problem or that you are imagining it.

- Prioritise, prioritise, prioritise. Decide what is important for you to do and when – don't sweat the small stuff.

- Begin to develop interests that are yours and that you can pursue independently or with friends and family.

- You will begin to realise all that you took for granted as half of a couple as you have to take over all aspects of your life together.

- Support will be there but not necessarily from those you expect it from – family members and friends may have unpredictable and unhelpful reactions.

- Learn to ask for help. It may come from unlikely sources and it may need an approach from you.

- Have confidence in your own ways of dealing with what's happening – your partner and you may be feeling confused but at this stage no-one else has a clue what's happening so don't worry about what they think.

- Don't lose your sense of humour – you will be in the most absurd situations and need to laugh. We have a running joke when we attend the 'memory clinic'. Patients arrive with a card identifying themselves, name, address etc. The receptionist takes the card then asks patients their name and address. Hilarious. Don't they know why the patients are there?

Stick this on your fridge so that you never forget rule number one above!

Practicalities

The web is a lifeline for:

- getting information
- communicating with others in similar situations
- finding sources of support and advice
- demonstrating by pictures/video how to complete tasks and identify useful objects

Finances :

It is hard to look ahead but you need to do this as soon as possible. From a management point of view, the more that is in the name of the carer, the easier it will be. Don't feel guilty about this. Before I did this, I was frequently in the position of having to put my husband on the phone and telling him his name, address and other information as he repeated it, before a bank or other institution would speak to me

- Bills – it will help to put them early on in the name of the partner who is well.
- Tax – you can ask for a form which will allow you to manage your partner's tax affairs on his/her behalf.
- Income - sort out whose name is on the accounts; again at this stage, this is for ease of management. If you have joint accounts you may also wish to consider separating your income and savings. Any assessment you have from social services is based on the income and savings of the person who is ill, not the carer's if it is in separate accounts.
- Will and Lasting Power of Attorney – these need to be sorted out whilst the ill person remains capable of making meaningful and legal decisions.
- Benefits you are entitled to are not all means-tested. These include:
 - i. Disability Living Allowance
 - ii. Reduced Council Tax if there are only two of you at home
 - iii. Preferential utility rates

Home management:

Eventually the partner-carer will have to manage everything. You may previously have had separate areas – cooking, shopping, paying bills, decorating, arranging holidays – but you are going to have to know where everything is and what it's for. You may have to do this in the face of opposition from your partner. Some things I did are:

- Take charge of a filing cabinet and filing system.

- Use endless labels

- The Age Concern Lifebook can be a great help – it's free and online or by request 08456851061

Medical:

There are decisions which should be taken while your partner still can. You will need to face issues such as:

- Would s/he want to be resuscitated or kept alive after a major illness or accident?
- What kind of treatment would s/he want if diagnosed with, for example, cancer?

It is really difficult to keep a sense of proportion when a partner who finds communication hard is in obvious pain or distress. S/he has no way of knowing what a headache is or that s/he's had it before or how to take a painkiller. You may have no idea whether it's a headache or something catastrophic to do with their condition and the doctor may not know either.

Eating

There are so many issues with this, which makes it a huge area of concern: many of them are social – eating is or should be an occasion for enjoying food and drink, company and conversation as well as meeting our nutritional needs. It is also the area where 'manners' are considered all-important. For the FTD person it is only the eating that counts and this can create many a fraught situation for the carer.

Nick has failed to recognise foodstuffs for several years now. Even if he has eaten the same food yesterday he won't remember what it is today or whether he likes it or not. At home this is relatively easy to control as I do all the food shopping, meal planning and cooking; however, Nick is currently still able to be involved in preparation by chopping or mixing under supervision and so cooking is one of the things we can still do 'together'. If I want to make him especially happy, we make brownies. He doesn't understand why he is stirring the ingredients or pouring the mix into the tin to help me, but when he licks the bowl out for him it is the

first time he has experienced such sheer bliss!

We are still able to go away at present and for me to have someone else give me food is a great treat so Nick's ways have to be accommodated. I always order for him but if he sees a buffet e.g. at a social occasion or in a hotel, he will pile everything onto his plate – hot and cold, sweet and savoury. I show him which section of the buffet to choose from at any one time (- this avoids a repeat of a public ketchup on cornflakes incident we had!!) It allows him some independence and usually avoids embarrassment.

Special note: I used to feel really embarrassed that we weren't engaged in meaningful conversation when in a restaurant but then I noticed that so many people don't talk to each other at mealtimes – often don't even look at each other, so I stopped worrying – except you want to shake them!

Obviously romantic dinners are in the very distant past, but we eat out occasionally at lunchtime and Nick can really enjoy this. He will take out of his mouth anything which is difficult to chew and he doesn't even attempt the right cutlery, so it's easier to pick a table where you are not under scrutiny or just stop worrying about it.

As he forgets to eat and drink, hasn't much of an appetite, and suffers from the sudden stone-coldness and glassy eyed look, we now have a variety of soft drinks, squashes, hot chocolate, sweet biscuits – all of these restore energy and warmth quickly and easily.

Nick does not connect what he eats (lots of sweet things) with how his digestive system works and we often have problems related to this, but I find the GP very patient and helpful in sending off for tests or examining Nick whenever we're concerned.

Travelling

There are all sorts of issues around this, whether everyday travelling by car or public transport, or holiday travel.

The car:

- Get an automatic and a satnav – both will help.
- Inform the DVLA and your insurance company of the diagnosis.
- Make sure you pack picnic stuff for journeys – you don't want to be left without drinks/snacks by any unforeseen stoppages.

After a test the person with dementia may still be allowed to drive. Although they may be able to control the car, it is

inevitable that reactions to circumstances or instructions will deteriorate over time. The granting of the short-term licence still leaves the partner-carer with the responsibility of taking these decisions day by day.

Weekending/Visiting/Holidaying:

Often the person with dementia may retain a very good visual memory still for places s/he used to know. They can then still visit familiar places and can enjoy walking about well known streets, otherwise cities and large towns aren't a good option – too much going on.

- Countryside, seaside, peaceful places are easier than exciting cosmopolitan ones.
- It takes a lot of confidence to manage on your own in a non-English speaking country with a partner with dementia.
- It may be increasingly difficult for the person to relax in strange places or to have anything to do on their own in a room –it helps to take familiar activities so s/he can be occupied e.g. jigsaws, sudokus – even if you're only away for a night.
- Taking familiar drinks and snacks may also be necessary.

Your partner may have to sleep at unpredictable points so make sure there is somewhere for him/her to rest if necessary.

Future Meetings

London

Annual Seminar 3rd March (see front page)

South West The next meeting is planned for Tuesday 2nd February at the Arundel Arms at Lifton. For details contact Nan email: underhin@aol.com or Penelope 01297 445 488

Liverpool Neurosupport Centre, Liverpool, 13.00-15.00

11th March, 13th May For details contact Mary Dawber

Tel: 01625 879 104

Regional Contacts

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Yorkshire - Rev. Ron Carter 01904 610 237
Northern - Mrs Jillian Ramsay 0191 421 4069
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(Also contact for Carers of Alcohol Related Dementia)

Mersey & North West - Mrs Mary Dawber _ 01625 879 104
West Midlands - Sister Ann Johnson 01743 492 175
Central - Mrs Helen Beaumont 01235 200 360
London - Mrs Carole Ivey 0207 603 0550
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