



# PICK'S Disease Support Group

## The Pick's Disease Support Group Newsletter

*For carers of frontotemporal dementia: Pick's Disease, Frontal Lobe Degeneration, Dementia with Lewy Bodies, Corticobasal Degeneration and Alcohol Related Dementia*

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### Pick's Disease Support Group Outings

#### *LILLE 1999*

We had a marvellous outing to Lille by Eurostar to meet the French Frontotemporal Group. Lynn Goodfellow had made the arrangements and all we had to do was turn up with our passports. There were nineteen of us, a mixture of sufferers, carers and professionals. We sat together and were able to swap seats easily to exchange experiences and information. It was particularly nice to meet members for the first time and to introduce professionals to the PDSG. Carers of sufferers of CLBD who had spoken to each other over the phone were delighted to meet at last. Simone Davies and another carer from Paris met us and we then made our way (being careful not to lose anybody) to a lovely restaurant. There Dr. Florence Lebert and other members of the Frontotemporal Group of Lille greeted us. Needless to say we had a marvellous, delicious meal, lots of courses and lots of wine (which we had to hide from one sufferer). There was a lot of cheerful talk over lunch and it was great to see how well we all managed to communicate, several of our group spoke really good French and several of their members spoke English. After lunch we had a tour of Lille which is a delightful city. A plan of our tour had been prepared by Dr. Lebert so we could recognise where we were. We had a group photograph taken; all of us facing the camera except one sufferer who wanted his back only included. Dick Lingham took a lovely lot of photos so we have a good record of our day in France. We just had time to rush round the hypermarket before catching Eurostar home.

Everybody said how much they had enjoyed themselves and how they had benefited from the day. I spoke to some members of the French Group. They said they were impressed with our carers who had brought their spouses on the trip and how beautifully they managed.

Many thanks to Lynn Goodfellow who arranged the day from this end and to Florence Lebert and her group who arranged everything so beautifully in Lille. We hope to arrange hospitality in England next year.

#### *KEW GARDENS.*

Our annual picnic at Kew was a great success - the sun shone. In fact it was a boiling hot day but we luckily found shade under a huge tree right beside the lake. We had carers, sufferers and all the Butler/Kellies, three generations worth. Jan Lock in particular enjoyed seeing the children play. More people than last year turned up which was very encouraging

although we missed Yvonne Kelly who regularly came to our picnics.

After our extensive lunch we walked round the gardens and visited a hot house and then the deliciously cool display of fish and fauna. Afterwards we went back and finished off our picnics. The picnic again offered time for carers to talk to each other, the professionals and my mother.

### *FUTURE PLANS*

We are hoping to spend a few days at Pontins the 27th September to 1st October 1999. The chalets are self-catering and cost £10.00 per head for two people in a chalet and £5.00 for four. Everybody is welcome, particularly carers, sufferers and children. The idea was suggested at Kew and quite a few of us said we would love to come. There are a lot of facilities including a restaurant and fast food. Val Bywater has contacted Pontins and they were very helpful indeed.

There are several possible venues so we haven't decided which one yet. If you would like to know more and help make the decision on where please phone Val Bywater on 01483 562233.

### **A book at last!**

During our trip to Lille I was delighted to meet Carl Cordonnier who with Dr. Lebert have written a really good book on Alzheimer's disease. Carl took the photographs and Dr. Lebert wrote the text which is in English and French. What is so important for our group is that they are now writing a book on Frontotemporal dementia and Pick's disease. It is at last a book, which will be understandable by carers and professionals. It will help enormously when trying to explain the

problems encountered in this disease to family, friends and neighbours. I would be glad if we, the English branch, would be prepared to allow sufferers to help by being photographed. The photographs would of course be anonymous. Mr. and Mrs. Hunter (of Chairman fame) have agreed to Hilary being included. She is so very young to have Pick's disease, it will show that the disease can affect people at any age. Please think about it and if I contact you with an idea,

please think about how we have longed for such a book to be written. When I approach anyone I will send them my copy of their book on Alzheimer's disease so that the carer can see the quality of such a book and how helpful it is.

### **Gossip Corner**

When you read about the events above you may feel that the Group is being positive and so it is. However Carol and I have been hearing some heartbreaking stories recently to which there seem to be no answers. It is a constant battle against ignorance, lack of facilities, complicated family relationships, money and behavioural problems to name but a few of the problems which are encountered. Problems affecting children are particularly hard to bear. We listen, give practical advice and explanations when we can but long to do more.

It is very encouraging that there have now been two meetings dedicated to Frontotemporal dementia and Pick's disease. Professor Martin Rossor who is head of our Medical Committee spoke at the recent meeting in Philadelphia. The objectives of this meeting are outlined and I spoke to one of the organisers after the meeting and she definitely thought these objectives had been met. Elaine Duncan kindly took the PDSG poster to the meeting and said that there was a lot of interest. We will all continue to help raise awareness.

Dr. Jerry Brown would like to know what questions you have asked your GP to which he hasn't an answer. Dr. Brown is a Consultant Neurologist at Cambridge with a particular interest in Frontotemporal dementia and Pick's disease. His research identified the chromosome at fault in the hereditary form of FLD. He is preparing information to give to General Practitioners. We have already thought of the sad ones of "what is Pick's disease?", "what is the life expectancy", "how does FLD differ from Alzheimer's disease?" but if you have any other rarer unanswered questions please let me know and I will pass them on to Dr. Brown (via e-mail.). Many thanks.

Annette Kelly has a boy; Joseph and Clare Breen's baby is due any minute. Jill Walton has a boy Joshua, a brother for Jasmine and Ella. I often visit Jill who lives near me although I admit that I am not a great deal of help to her. I was scared she would have Joshua in the front room - my midwifery skills are way out of date!

We were very pleased with our ultra posh newsletter and would like to thank Peter Davis, Phoenix Photo Litho, Leicester for his support and help.

### ***Penelope Roques***

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#### **Jan Greet - A Carer's Story**

My wife, Jan, was a very fit healthy woman, who did karate and could walk for miles, until after her 50th birthday in 1994 but, the following year, she seemed a bit depressed at times and, early in 1996, she went to the doctor several times as she was off-colour.

Things came to a head that March when her line-supervisor at work - she was a Training Officer with Devon Training for Skills - told her that they would have to give her a written warning if she

didn't 'buck up'. In April we went to see a consultant neurologist at the local hospital who took me on one side and told me that he thought something was seriously wrong - but no suggestion that it could be dementia. I hadn't even considered that as a possibility, as there was no family history of it. After various psychological tests we were given a preliminary diagnosis of 'possible pre-senile dementia', subsequently confirmed by the National Neurological hospital as 'Pick's Disease' in March 1997. That Spring was the last time she wrote in her diary, the last time she drove a car, the last time she took herself to appointments, the last time she went for a long walk. Her deterioration was rapid and relentless. She continued to eat well in spite of a risk of choking but, by March 1998, had said her last word. She was still reasonably well physically, but, in August, virtually gave up eating, in spite of all my efforts to offer her the right food and persuade her to eat it. She wasted away rapidly that Autumn losing nearly a stone a month and becoming very weak, so the only surprise about her death was that it happened so rapidly. She recovered once in hospital from suspected pneumonia, but, after coming home again on Christmas Eve, she faded away and died on 29th December.

### ***Richard King***

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#### **Post-Apocalypse**

When someone you love dies, it hurts. Knowing they were going to, and having in many ways lost them already doesn't make it any easier. But however final losing someone to dementia may seem, death is not just final emotionally and physically - you are brought immediately to grips with the social implications. There are things you can do in advance to help minimise the trauma - some I managed to do - others I wish I had.

Make sure there is a will. If you have to get probate, this document becomes public property. Keep it as simple as possible. Make sure it is somewhere safe - preferably with someone not emotionally involved.

Get to know a friendly funeral director before you need him. Ask at the hospital, the church, the crematorium. The right person can help.

Think about a post-mortem, if appropriate. You can sign the relevant papers some time in advance, if they are ready and everyone knows about them. If you don't want one (you may not have a choice!) be sure everyone knows.

If the deceased had a pension, tell the pension provider as soon as possible. Any overpaid pension will be reclaimed. You don't have to do this yourself - rope in a friend or colleague. Most pension companies keep paying for a few months after death. Does yours? Can you raise funds if not?

Similarly, you must tell the bank/building society. Any account in the sole name of the deceased will be frozen until things are sorted out - do you have alternative arrangements?

The death has to be registered, and this has to be done by a relative. The hospital/doctor will provide a death notification - make an appointment with the Registrar, and take this along. Take a friend as well. Get extra copies of the death certificate - one for each pension or insurance company involved, and at least one extra. This may be the first time you hear the horrible word widow(er).

Transfer as much property as possible out of the name of the person with dementia. All their property has to be declared for probate. If there is a house or savings, you need an up-to-date valuation. Do you really want to see an estate agent/financial advisor immediately after the funeral?

Get insurance policies assigned out of the estate if possible. Probate costs more the bigger the estate, so does inheritance tax (though between husband and wife none is payable). The value of the estate also becomes public knowledge at probate.

If inheritance tax is payable, it must be paid before the property is released. Be prepared to borrow money if necessary.

Accept all offers of help, especially with everyday matters. If someone else will cook dinner, look after the children, drive you around, make sandwiches for after the funeral or whatever, let them. It will make them feel useful, and it will lighten your load.

Hope this isn't too depressing. I'm told life will improve eventually, and I am slogging on in hope.

***Helen Beaumont***

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## **The Next Young Person's Day**

Last years young person's day proved to be a successful initiative (see Newsletter Vol. 4 Issue 3). Penelope and I introduced two families to each other who were able to exchange thoughts and ideas from their experiences of coping with a parent who has young onset dementia.

We have nominally fixed a similar, informal day for 26 August 1999 - venue to be arranged. If any families are interested please contact me as soon as possible for further details.

Dates - Reminder

We have been asked to reprint dates for the future.

### **Meetings in London**

The Old Boardroom, National Hospital for Neurology and Neurosurgery, Queen Square, London WC1N 3BG. From 11.30-1.30 invited speaker, 1.30-2.30 lunch in The Swan pub, 2.30-4.30 your own experiences.

September 9th Providing Day Care Facilities for FLD: Hazel Templeton.

December 9th The Experience of Dementia: Clare Morris.

## Meetings in Liverpool

The lounge of the Glaxo Neurological Centre, Norton Street, Liverpool. 2.30-4.30.

September 9th Local Support and Services: Fiona Johnson.

December 8th (NB new date) Research: TBA.

## Carol Jennings

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## Philadelphia Conference

This International, Multi-disciplinary Conference on Pick's Disease and Frontotemporal Dementia (FTD) was held in Philadelphia during the month of May. The purpose of the conference was to bring together internationally recognised scientists and care-givers for two days of discussion and exchange of new information about Pick's Disease and frontotemporal dementia.

As a result of attending this conference, it was hoped the participants would be able to:

1. Recognise the major early clinical features that distinguish the Pick's disease patient from patients with Alzheimer's Disease and other types of dementia.
2. Identify which diagnostic tests are useful in establishing the clinical diagnosis of Pick's disease.
3. Consider how differences in the mechanism of disease between Pick's Disease and Alzheimer's Disease.
4. Describe the histopathological features of Pick's disease including the major components comprising the Pick body and Pick cell.
5. List the antibodies that can be used to differentiate Pick's Disease from other tauopathies.
6. Discuss the relationship between Pick's Disease and other types of frontotemporal degeneration
7. Explain differences in caregiver issues that arise in Alzheimer's Disease compared to Pick's Disease.
8. Describe management strategies caregivers can utilise for common behavioural problems seen in patients with Pick's Disease.
9. Define the genetic aspects of frontotemporal degeneration linked to chromosome 17.
10. Recognize clinical and neuropathological features that help to distinguish patients with chromosome 17 abnormalities from other types of frontotemporal degeneration and Alzheimer's Disease.

Thanks to **Alzheimer's Association Southeastern, Pennsylvania**, for organising the conference and allowing us to reproduce this article

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## Reorganisation - Special Request

Please would those in USA and Canada wishing to register as members of the PDSG contact Doug Keck, our US secretary; Those living in Europe should continue to contact Penlope if they wish to join. See the front page of this website for more information on joining the PDSG in your area.

## Forthcoming Events

Penelope and Carol will be 'on the road' with their  
**'Unusual Dementia Roadshow'**

during the coming months.

6 October : **Preston**  
28 October : **Burnley**

If you would like to join us for either of these events, further details can be obtained from either **Carol** or **Penelope**

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