



# 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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### Editorial

#### AGM

An aficionado of our group will know that usually the fourth of our quarterly newsletters appears in November. Well this year you have had to wait until December ? for a very good reason. I have been waiting to confirm dates for venue and speakers for our 2005 AGM (see details inside). I?m sure you will agree that the wait has been worth it. The venue is easily accessible ? just a ten-minute walk from the station. We will have the use of a light and airy, fully equipped lecture room, a choice of hot lunches served in a separate dining room and of course excellent speakers. The cost is still only £25. Do make a note of the date in your 2005 diaries and book to reserve a place. I can send you a map and directions or you can access these on the web at [www.queens.ac.uk/map.htm](http://www.queens.ac.uk/map.htm)

#### New Initiatives

For the New Year there will be two new initiatives starting up in the Trent Region.

#### Drop-in Information Session

To be held on the second Tuesday of every month ? beginning Tuesday 11th January at Lings Bar Hospital, Gamston, Nottingham. There will be information available on Social Services, Local Carer Support Groups, Department of Work & Pensions and of course I will be there representing the PDSG ? with booklets, leaflets etc.

#### PDSG Support Group ? Leicester

This group meeting will be held at Braunstone Civic Centre, Leicester 7.30 ? 9.30pm bimonthly on the first Thursday of the relevant months. The first three dates are: 6th January 2005 3rd March 2005 5th May 2005 Please contact me if you would like more details.

#### Work Hours

My work hours are Tuesday ? Friday 10am - 12noon & 2 ? 4pm There is a twenty-four hour answer phone and if you leave a message I will get back to you as soon as possible.

#### Phone

The 0845 number was set up to help those who can use this at a reduced (local) rate. I have been told that some calls ? eg from mobile phones may cost more. Both numbers 0116 271 1414 & 0845 458 3208 come through to the same phone so please choose the one that is

best for you. Very Happy Christmas & New Year to everyone.

*Carol Jennings*

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## **Three Years On...**

It is now three years since Val died from Pick's Disease on 21 November 2001. My memory of that day is still very vivid, at times it seems like only yesterday.

Our children Guy, now 19 and Charlotte, 15, have come to terms well with the loss of their mother. The passage of time has perhaps had a more healing effect for them than for me. I am often asked by friends how they have coped. The answer is, generally, very well. Guy is now in his second year at Exeter University and Charlotte is working for her GCSE's next summer. There seem to have been two major consequences of losing their mother, one positive and one negative.

The positive is that both Guy and Charlotte have a heightened sense of responsibility in relation to those great hazards of the teenage years, drugs, alcohol and sex. Having witnessed the disorientation of their mother's brain from the effects of Pick's disease they have no desire to experiment with drugs or indulge in binge drinking. In terms of personal responsibility they are perhaps old for their years.

The negative consequence of losing their mother is that they both suffer to some extent from what I can best describe as emotional insecurity. Their own brother/sister relationship is close and they have a concern for my wellbeing that is perhaps more characteristic of a parent for a child - this is role reversal. They are easily hurt by the insensitive behaviour or comments of their same age friends who still have two parents intact. I suppose there is a certain inevitability in this, but it does cause some heartache from time to time.

As for me, I am now 50 and of an age when I wonder whether to look forward or back. To say that my life has been changed by the loss of Val is an understatement. In one sense I have not moved on; I have not sorted out Val's clothes and her dressing table is still as it was. I have found that a busy life is a good antidote to bereavement. 50 years old widowers seem to be a relatively rare species. Indeed I have found that the word 'widower' is itself unusual and can be something of a conversation stopper. Guy, Charlotte and I continue as a closely knit little family of three and are likely to remain so. Charlotte did say that if any stepmothers start turning up she is off!! My cooking must be better than I thought; actually I rather admire her spirit!

When Dr. Lodge diagnosed Val as suffering from Pick's Disease on 19 April 1999 he did say to me that 'There is life after Pick's Disease'. Although scared and traumatised by the loss of Val, I can confirm that his words are true. Pick's Disease is survivable. If I can do it I am sure all you other carers out there can!

*John Rendell*

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## **Mum and me**

For most people the idea of dementia at a young age seems like a contradiction in terms. It did to me before I started researching the possibility of making a film about it. In my research, two things became clear to me straight away: dementia is not exclusively an old person's illness, nor is it a kind of benign forgetfulness; it's an unavoidable physical disease, which turns your and your family's life upside down. To all of you reading this in the PDSG newsletter that's perfectly obvious, but as you know that's not the case with most people. Perhaps it would help everyone involved with dementia if people understood it better.

I'm hoping that a film about dementia can be part of a series called 'Mum and Me' that we're making here at the BBC in which we aim to explore powerful issues through the relationship of a Mother and her son or daughter.

When the chance to make this series came along it seemed like the perfect vehicle for a documentary film about dementia. If we could find a Mother with early onset dementia and her grown up child who were willing to let us into their world, we could tell the powerful story of their relationship over time as the Mother's dementia inevitably progressed.

I'd been struggling with how we could approach this subject when I came across the Pick's Disease Support Group website and happened upon a story written by Dr. Bob Fay called 'Pick's from the Inside Out' in which he describes his own Frontotemporal Dementia. As I read I had shivers down my spine. Here was an articulate Doctor describing the effects of his brain's corrosion on his life and his relationships in a lucid and dispassionate way. What an extraordinary first hand account of an illness that is in general so little understood.

If we could find a Mother who still has that insight into her own disease, and her son or daughter who is able to tell the story from a different perspective, what a powerful story we could tell. But how do we really give a voice to a family to tell their own story, in their own way?

### Your Turn with the Camera

What we'd like to do is to make this an empowering experience for the Mother, son or daughter by giving them a camera and some training, so enabling them to film part of their own film, any way they like. We'll be around for guidance and at times we'll be there with another camera too. The idea is that in the end this film will have been a truly collaborative effort between you and us. We'll work together to make a really great film that we should all be proud of.

Even if you have no interest in being filmed, if you'd like to tell me about your own family's experience of dementia, I'd love to hear from you. There's absolutely no commitment to anything further from anyone who calls me and all calls will be treated with confidence.

Thank you

**Caroline Jones**

'ONE Life'

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### AGM March 18, 2005

The Queen's Foundation, Birmingham

For more information and to book a place please contact Carol. Price £25 including lunch.

#### **PICK'S DISEASE SUPPORT GROUP ANNUAL GENERAL MEETING - 18th March 2005.**

09.30-10.30	<b>Annual General Meeting</b>
10.30-11.00	Coffee
11.00-12.00	<b>Searching for Genetic Patterns in Neurodegeneration</b> Dr Kevin Morgan. Reader in Human Molecular Genetics at Nottingham University Medical School
12.00-13.00	<b>Care Pathways ? Pillars and Posts</b> Dr Karim Saad. Consultant in Old Age Psychiatry Lead Clinician for Young Onset Dementia Service, Coventry
13.00-14.00	Lunch
14.00-15.00	<b>Working with People who have Frontotemporal Dementia</b> Jo Scarle Occupational Therapist* Tracy Smith Team Manager* *Birmingham Working Age Dementia Service

15.00-15.30

**Dementia and Ethnic Culture**

Moni Grizell Research Sister, Memory Clinic, Penn Hospital  
Wolverhampton

15.30-16.00

**The Carer's Perspective**

Win Harris. Former Carer

## **Anglo-French Link - Spring date to be confirmed.**

The FTLD group from Lille will once again be joining us for a day in Spring and look forward to meeting our friends when they arrive on Eurostar. This time we plan to take a boat trip from Waterloo Millennium Pier (in front of the London Eye) to Greenwich.

The boat trip lasts about an hour each way and costs £8.00 return. City Cruises ([www.citycruises.com](http://www.citycruises.com)) 500-seater boats are wheelchair friendly and have a commentary in English. On arrival at Greenwich ( [www.greenwichguide.org.uk](http://www.greenwichguide.org.uk) ) provisional plans include a choice of joining a group to

- a) walk up the hill through the Park to the Old Royal Observatory and Meridian Line - admission free ( [www.rog.nmm.ac.uk](http://www.rog.nmm.ac.uk) ) with a late lunch (cost under £10.00) in a local hostellery
- b) visit the National Maritime Museum and/or the Queen's House - admission free ( [www.nmm.ac.uk](http://www.nmm.ac.uk) ) with a late lunch (cost under £10.00) in a local hostellery
- c) visit the indoor Arts and Craft market ( [www.greenwich-market.co.uk](http://www.greenwich-market.co.uk)) with a late lunch (cost under £10.00) in a local hostellery
- d) Spend longer visiting the above attractions with time for a quick snack. Some active members of the group may prefer this, since there is so much to see.

We will all return together by boat from Greenwich to Waterloo. Everyone is welcome; relatives and friends and especially people with Picks Disease - whatever their behaviour. You may decide to join us by Greenwich Pier, if this is more appropriate for you.

To register your interest in joining us - please contact Val by E-Mail ([valbywater@tiscali.co.uk](mailto:valbywater@tiscali.co.uk)) or telephone on 01483 562233 and leave your name and address. Final details will be sent or E-mailed to you about 4 weeks before the date of the trip. Please also let me know if you would be prepared to act as interpreter for one of the small groups!

***Val Bywater***

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## Regional Contacts

- | **Scotland:** Mrs. Ina Chalmers 01505 813844
- | **Cleveland, Cumbria, County Durham, Northumberland and Tyne and Wear:** Ms Judith Watters 01670 367241
- | **Humberside, North Yorkshire and West Yorkshire:** Rev. Ronald Carter 01904 610237
- | **Derbyshire, Leicestershire, Lincolnshire, Nottinghamshire and South Yorkshire:** Ms Janet Carpenter 0116 2392913
- | **Cheshire, Isle of Man, Lancashire, Manchester and Liverpool:** Mrs. Mary Dawber 01625 879104
- | **Hereford & Worcester, West Midlands, Shropshire, Staffordshire and Warwickshire:** Sister Ann Johnson 01743 492010
- | **Cambridgeshire, Essex, Norfolk and Suffolk:** Mrs. Lyn Lingham 01954 201609
- | **Bedfordshire, Berkshire, Buckinghamshire, Hertfordshire, Northampton and Oxfordshire:** Mrs. Helen Beaumont 01235 200360
- | **London and Middlesex:** Mrs. Carole Ivey 020 76030550
- | **Dorset, Hampshire, Isle of Wight, Kent, Surrey, EastSussex, West Sussex and Wiltshire:** Mrs. Jenny Mackie 01722 336352
- | **Cornwall, Devon, Gloucestershire and Somerset:** Mr. Richard King 01392 669238 (often away from home) can also be contacted on Mobile 0772 0049487
- | **North Wales:** Mr. Roy Jones 01248 351537
- | **South Wales:** Pat Coulson 01792 883684

**The articles in the PDSG newsletter do not necessarily express the views of editors**