

PCA SUPPORT GROUP

Newsletter

Welcome to the PCA Support Group Newsletter Issue 11, June 2011

Welcome to the latest edition of the PCA Support Group newsletter. At the March meeting of the PCA Support Group, around 40 members listened to Dr Natalie Ryan explain some of the more unusual symptoms of PCA. She stressed the importance of filtering out treatable concurrent health issues as opposed to assuming all symptoms are necessarily PCA related. Dr Diego Kaski went on to describe his research at Charing Cross Hospital around issues of dizziness, and how it bears particular relevance to his interest in patients with PCA. Small group discussions were the format for the afternoon session, and further details of the topics covered have been summarised in the minutes attached to this newsletter.

Inside this Issue:

Your contributions required for newsletter...please!

- * David and Pat Moon provide a beautiful insight into Pat's work as an author
- * NHS Carers Direct Service * Dementia Action Alliance and The Thomas Pocklington Trust
- * Minutes for March 18th Meeting * Change of venue for November meeting - Advance Notice

Next PCA Meeting: Friday 1st July 2011 (RSVP to Jill Walton)

11am – 2pm (half hour coffee break/snack lunch included)

Conway Hall, 25 Red Lion Square, London WC1R 4RL

This meeting will include:

Pam Turpin talking about adapting the home environment to cater to the needs of people with visual impairment

Dr Angus Kennedy talking about symptoms and diagnosis

Please confirm your attendance: [Jill Walton 07592 540555](mailto:jill.walton@pdsg.org.uk) or email jill@pdsg.org.uk

Maps and directions provided on Page 2 * PLEASE NOTE THERE WILL BE A CHANGE OF VENUE FOR NOVEMBER MEETING *



Myrtle Ellis Fund

The PCA Support Group is generously supported by the Myrtle Ellis Fund, as part of the National Hospital Development Foundation (Charity number 290173). For more information on the work of the Fund or to make your own contribution to the running costs of the PCA Support Group, please contact the Foundation on 020 3448 4724.

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Directions for meeting on July 1st

Conway Hall, 25 Red Lion Square, London, WC1R 4RL

Underground

Nearest station is Holborn (Central and Piccadilly lines) approx 3 min walk. Also within reasonable walking distance are Chancery Lane and Russell Square. London Underground Infoline: 020 7222 1234.

Buses

The following buses pass through or near Holborn stopping just a few minutes walk to the Hall:

- from Oxford Street: 8, 25, 55; 98 (terminates in Red Lion Square)
- from Euston Station: 59, 68, 91, 188
- from Waterloo Station: 1, 59, 68, 188, 521, 243
- from Victoria: 38 (Theobalds Rd, rear side of Hall)

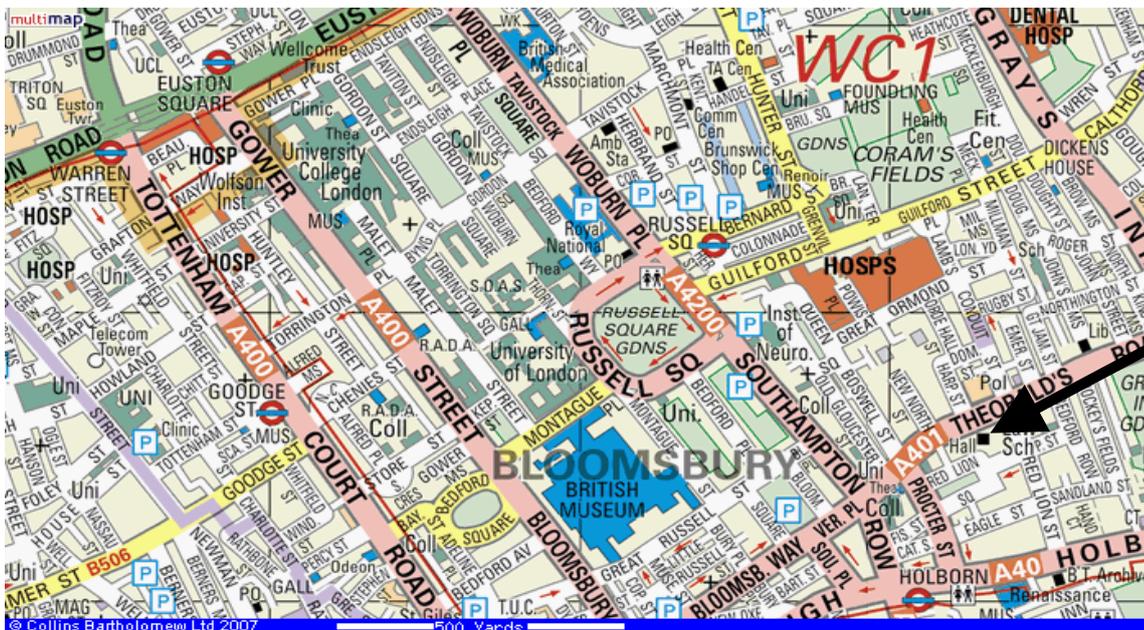
London Buses Infoline: 020 7222 1234

British Rail

Excellent connections via numerous bus routes from most central London main line stations. British Rail Infoline: 0845 748 4950.

Parking

There is metered parking available in Red Lion Square and adjacent streets, unrestricted weekdays after 6.30 p.m., Saturdays after 1.30 p.m. and Sundays all day. Please note some parking areas are for "Residents Only" and other local restrictions. For info ring LB Camden 020 7278 4444.



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Can you help?

Do you have access to a printing facility that the PCA Support Group could use at cost price? We would like to upgrade our welcome packs and publish various short fact sheets, identity cards etc. but are reluctant to use our funds unwisely.....

Can you contribute?

We wondered if members of the PCA Support Group would welcome the opportunity to contribute to the newsletter, and thereby share experiences, helpful hints, or stories which may benefit the wider group. Examples of typical contributions from within similar support groups might be: issues surrounding the journey to diagnosis, how to handle misunderstandings amongst family, friends and wider social groups, as well as practical suggestions for coping with some of the symptoms of the condition in question.

Typical examples of issues worthy of further comment, description and personal account - raised during the March meeting - were the references to visual hallucinations and the propensity of people with PCA to lean sideways, though sensing for themselves that they are upright. As Celia has noted in the minutes, there is a very real value and comfort to be gained simply in realising you are not alone in a particular symptom manifestation. It would be great to take that a step further by way of personal input to the newsletter.

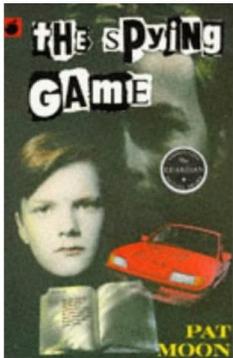
Updates on issues relating to raising awareness of PCA or other local initiatives which members are aware of could also be shared.

Published pieces could range from snippet 'one liners' to more detailed commentaries....whatever feels most appropriate!

Please send articles for inclusion in future newsletters to Jill Walton, 22 Brushwood Drive, Chorleywood, Herts, WD3 5RT or email them to jill@pdsq.org

Thankyou!

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David and Pat Moon have been members of the PCA Support Group for several years now. The article below has just appeared in 'Carousel' magazine (a guide to Children's books). It is about Pat dealing with her PCA. A correspondent visited David and Pat for the day – and they have kindly allowed us to share the sensitive report with the group.

When Pat Moon was assembling her poems for *Earth Lines: Poems for the Green Age* twenty years ago, she needed to seek the advice and guidance of the peace campaigner Bruce Kent. In the way of these things, Kent returned her telephone call at the very moment her three children, Sam, Daisy and Ben, decided to start weighing in to each other with empty plastic cola bottles. The juxtaposition – conversation with notable CND activist against a background of mock warfare – has something of the same diverting incongruity as the vignettes of family life she later included in her fiction. Family life had long been a source of inspiration, as I learnt when I visited Pat and her husband David at their home in Norwich.

She had been writing and illustrating books for the children long before anything was published. "Little stories," David explained. "Little drawings. About family life." He showed me one called *Time To Get Up*. Landscape format, stoutly bound, with a clear, simple text, hand-drawn lettering and attractively crisp and detailed (she was unusually good at feet, I noticed) colour illustrations. "There's a whole pile of them upstairs," said David. She also had a gift for poetry, so when, in 1989 or thereabouts, an advertisement appeared in the TLS asking for a writer to help on a new project, and to please send poetry, she was ready to oblige – particularly as her horoscope told her that now was the time to use her talent. Off went a poem, and within days back came a telephone call acknowledging her skill and asking if she would like to supply some English verses to match the illustrations in a book originally published in Spanish. She "scribbled" a few lines, and being requested to fax them over agreed that she would. When David came home that evening, she asked him, "What's a fax?"

Then, a publisher called Pimlico wanted some verses on green issues, a subject in which Pat was greatly interested, so she started writing the series of poems that eventually became *Earth Lines*. Although the book is no longer in print, and Pimlico has ceased to exist, she continues to receive appreciative letters from schoolteachers who swear by it and still use the poems in their classrooms.

She went on a writing course at a retreat near Ipswich, which was under the tutelage of Jan Mark, a writer she greatly admired; and, later, won a Sunday Times story competition with an entry Pat and David are pretty sure (it's too long ago to be absolutely certain) was called *Onions Make You Cry*. The prize was to be a special guest (not a speaker) at the Hay Festival. There, she met Rosemary Sandberg, who was in the process of setting up her own literary agency. She asked Pat to write for her.

With the publication of *Double Image* and *The Spying Game* in 1993, two novels for older readers about identity and how we perceive other people, Pat Moon laid down her marker as one of that select band of novelists able to create highly entertaining narratives from the minutiae of everyday life. *Double Image* was shortlisted for the Smarties Prize and *The Spying Game* for the Guardian Award. Subsequent books for the same readership, *Nathan's Switch*, *The Ghost of Sadie Kimber*, *Four Days Till Friday* – respectively, social comment spliced with Wellsian sci-fi, a genuinely scary ghost story, and an account of bullying, and separateness – share the same common ground as the first two in their sensitive awareness of other people, at home and at school, and in their evocation of the sometimes untidy hugger-mugger of family living. ("Mum!

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Where's my snorkel?" Gav's sister demands in Nathan's Switch. "On top of the microwave," comes the reply.)

The way families behave is a recurring factor in Pat's books. She's a dab hand, for instance, at mimicking the blather and joshing between siblings. "Mature? Mature?" Laura screeches at her brother, in *The Ghost of Sadie Kimber*, before continuing in a vein that is almost Wodehousian in its disdain: "Are we talking about the person who stood in the queue in McDonald's with trails of Sarah's green Play Doh running out of his nostrils?" And in *The Spying Game*, Lucy's debunking response to Joe's new blazer is cool in the extreme.

"Has he forgotten to take out the coat hanger?" she asks, pointedly squeezing the shoulders of the over-large garment.

Then, in a different vein, but in the same book, she displays a whole range of other sorts of perception in depicting the individual sorrows undergone by Mum, Joe, Lucy and Tom in their grieving over Dad's accidental death. The writing is consistently clear-cut, dexterous and exact, with a keen humour and wholly convincing dialogue, the result of an alert ear and a vigilant eye; and the characters are distinctive and independently minded, and tend to determine the course of the plot rather than be manipulated by it. And the same is true across the range of her work, from young read-alones like the *Jungle Bunch* series, to shorter fiction – *Ben's Bean*, *The Stare*, *Barking Mad*, *Little Dad* – and the novels for older readers.

David who nowadays, with Pat's compliance, acts as a sort of spokesperson, for reasons that will soon become apparent, mentioned the 'Finch books' (in which family life is almost exclusively the subject). This series attracted an enthusiastic and loyal readership as soon as the first book, *Do Not Read This Book*, was published in 2000, and shortlisted for the Sheffield Children's Book Prize. It was followed by two further instalments – *Do Not Read Any Further* and *Do Not Read Or Else!* – of Finch Olive Penny's funny, poignant and definitely top secret diary. In view of the books' popularity it's not surprising that Pat's publishers asked for a fourth.

"And that," David said, "is when things started to go wrong."

Pat began to have trouble reading diaries and calendars, so much so that she bought three calendars, to make up for the others being what she called "wrong". She was making mistakes with everyday things like loading the dishwasher and opening the up and- over garage door. Traffic lights, too, were proving a problem, as was judging distances when driving. Eventually a routine eye test, during which the optician discerned all was not well, led to a visit to the GP, then to a neurological consultant, and on to Addenbrookes, where Pat was diagnosed as suffering from PCA (Posterior Cortical Atrophy), an "atypical" variant of Alzheimer's disease. (Terry Pratchett is a fellow sufferer.)

The disease affects the region of the brain responsible for visual processing, the part that "tells the eyes how to react". It means that Pat has difficulty in dealing with perceptual matters that involve sequences or the awareness of rows, layers and some shapes. Everyday activities – making a bed, loading a dishwasher, setting a table, reading a newspaper, telling the time, cooking, shopping, dealing with steps, using a keyboard – present the utmost difficulties.

She gets easily disorientated. "Sometimes I can't find my way to the kitchen. Show me where the kitchen is," she said, while still managing to chuckle at her predicament. "If I put anything down, it merges with the background. I get very anxious because I can't understand what I'm seeing. This room makes me feel ill sometimes. I can't make sense of it. The colours. I can't identify certain things. I have to get up and touch it to try to make sense." She is unable to read, "because it causes nausea". So television has proved "a blessing".

Biggest bugbear of all: she can no longer write. "I like writing too much. I grieve for it," she said, like someone marooned on a desert island. "Half of me says I could do the plotting," but only half of her. "I've tried dictating but I lose the thread of the story," which makes her anxious. "It's lovely getting letters [from readers]", which she still does. I read one from a 12 year old girl in Swanage, beginning, I LOVE your "do not read" series and before I found it I almost gave up on reading!!!

Pat and David remain positive and up-front. She, for example, willingly took part in a study of PCA that required a researcher to monitor her at home and is pleased at the thought of the research helping future sufferers. They belong to a support group at University College Hospital, in

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which the extraordinary total of four out of the 30 members happen to be authors (although “that is thought to be coincidental,” said David). And they determinedly respond to every reader’s letter, clearly explaining why the stream of Pat’s books has encountered an impassable dam.

Outwardly there was little to indicate that all is not right with Pat, apart perhaps from an occasional tendency to repeat herself. She sat at ease, her short, attractively cropped hair making her look as if she’d landed the part of Peter Pan, and told me about her early life.

Born in Bromley. Lived in Somerset. Many jobs, including working in a bank, and in a children’s home. “A huge, old-fashioned building. I used to read stories to the children.” The memory made her smile and appear slightly puzzled, simultaneously. “But I liked teaching best of all.” And she was frank and open about her bad patches, the black moments. “Oh yes, I do the stomping around,” she said. “It’s – not – fair.” It isn’t.

Although her long-term recall seemed sharp, details about the books she has written and published remain a mystery. So David reads them to her. She described her reactions. “Gosh, did I write this? It’s not bad.” She grinned broadly. “I’m surprised at the plots. It’s so strange though, to have written something I can’t recognise. Hearing them, it’s quite a revelation. Strange position to be in. I’ve written books but I can’t remember them.”

Towards the conclusion of our chat, her natural urge to create reasserted itself. She was saying how she gets into a muddle dressing – both legs into one leg – and suddenly stopped, looked up, and asserted: “That’s a book I want to write – The Knickers of Time.”

For that instant it was as though the sun had shone brightly.

Chris Stephenson

We have recently been made aware of the following service and hope to establish a link on our web page (www.pcasupport.ucl.ac.uk) directing members to it. In the meantime, we hope it will provide another means of possible support to members who wish to use the service.



Carers Direct is a national information, advice and support service for carers in England. Available online at www.nhs.uk/carersdirect and as a free, confidential helpline seven days a week on 0808 802 0202, it provides accurate, relevant information for carers and those who support them.

Website information

- All information on Carers Direct is Information Standard accredited and was developed in conjunction with carers and national carers organisations.
- Since its launch in Jan 2009, Carers Direct has grown to become a substantial online resource for carers and those who support them. It now has more than 1,000 articles, 12 videos and web tools available on the site.
- Visitors to the website are regularly surveyed to ensure Carers Direct offers the information they need.

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- Carers Direct provides online blogs and forums for carers. It also has an active Facebook fan page with over 7,000 carers available at www.facebook.com/carersdirect, and a twitter account with nearly 3,000 followers at www.twitter.com/carersdirect

Helpline information

- All calls to Carers Direct are free and confidential.
- Over 20 specially trained advisors are available to give information and advice to carers, allowing them to take decisions about their personal support needs and the needs of the person they are looking after.
- The Carers Direct helpline advisors can put callers in touch with specialist national or local sources of help, including social care departments, respite centres, specialist charities and other carers support groups.
- Enquires can be made by phone, email, post, Type talk, Text Relay and language line*.

***Additional information on helpline contact methods**

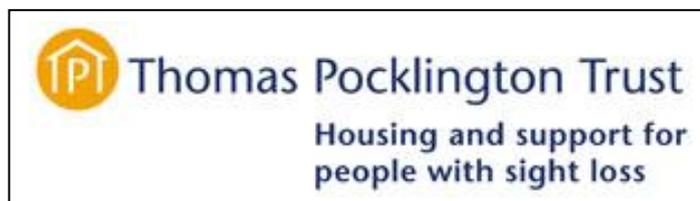
Telephone enquiries -The Carers Direct helpline number is 0808 802 0202. Lines are open seven days a week, from 8am to 9pm on weekdays and 11am until 4pm on weekends and Bank Holidays. All calls, including mobiles, are free.

Language Line - If you need help in a language other than English, you can request a call back in the language of your choice [LINK: <http://www.carersdirectenquiry.nhs.uk/callback>]. We use Language Line, a telephone translation and interpreting service that allows a conversation in one of more than 170 languages.

Email and online enquiries - If you have a question about caring you can ask it using the Carers Direct online enquiry form at <http://www.carersdirectenquiry.nhs.uk> . A Carers Direct advisor will normally respond within 24 hours of you submitting your enquiry. Carers Direct web address is www.nhs.uk/carersdirect

Text Relay and Typetalk - Deaf, deafblind, hard of hearing and speech-impaired people who use a textphone can contact Carers Direct by textphone/minicom, on 0800 988 8657.

Postal enquiries -You can send a written enquiry by post to Carers Direct, PO Box 4338, Manchester M61 0BY.



Dementia Action Alliance is made up of over 40 organisations committed to transforming the quality of life of people living with dementia in the UK and the millions of people who care for them.

Members of Dementia Action Alliance have signed up to a [National Dementia Declaration](#). Created in partnership with people with dementia and their carers, the Declaration explains the huge challenges presented to our society by dementia and some of the outcomes we are seeking to achieve for people with dementia and their carers.

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Outcomes range from ensuring people with dementia have choice and control over decisions about their lives, to feeling a valued part of family, community and civic life.

Signatories to the Declaration have published their own [Action Plans](#) setting out what they each will do to secure these outcomes and improve the quality of life of people with dementia by 2014. Organisations commitments include work to promoting information on dementia to councils and delivery of a national project on the care of people with dementia in hospitals.

The **Thomas Pocklington Trust** has signed up to the alliance, and we thought you may be interested to read of the directions it envisages taking with regard to people suffering from dementia and sight loss. They are set out in response to a series of questions:

1. The National Dementia Declaration lists a number of outcomes that we are seeking to achieve for people with dementia and their carers. How would you describe your organisation's role in delivering better outcomes for people with dementia and their carers?

Thomas Pocklington Trust provides specialist services for people with sight loss, some of whom may also have dementia, and we commission research and development about sight loss, including concurrent sight loss and dementia.

We will seek to deliver better outcomes for people with dementia and their carers by improving operational practices and by commissioning research and development projects that can inform good practice across housing, care and support.

We are committed to increasing awareness and supporting action to address the needs and aspirations of the growing number of people who have concurrent dementia and sight loss. In 2010 we estimate that at least 100,000 people in the UK have dementia and sight loss and we know that this creates particular challenges for them and their carers and that this dual burden is often the trigger for increased care services, including a move to a care home.

With the Alzheimer's Society and RNIB we actively support the development of the Dementia and Sight Loss Interest Group of VISION2020UK and work to increase mutual understanding and partnership working among practitioners in dementia services and sight loss services.

2. What are the challenges to delivering these outcomes from the perspective of your organisation?

Pocklington faces challenges in developing better outcomes for people with dementia and their carers through its operational services and its research and development programme. Across our work we face challenges in raising awareness of the impact of sight loss on people with dementia, and vice versa, and of the value of interventions that maximise vision and support independence, activity and occupation which improve quality of life and make care and support services more effective.

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Our operational services for people with sight loss face the challenge of limited resources that temper our ability to deliver specialist services; we need well trained and knowledgeable staff. That requires an adequate training and qualifications system and resources to recognise skills.

Our research and development programme faces the challenge of limited resources to fund the high quality research that is needed to identify and demonstrate positive outcomes from practice and to challenge poor practices.

3. What are your plans as an organisation to respond to these challenges between now and 2014?

- We will work with dementia and sight loss organisations with the aim of increasing mutual awareness and understanding and encouraging collaboration that can result in better outcomes for people with concurrent dementia and sight loss and those who care for them: this is ongoing work and includes an active role in the dementia and sight loss interest group of VISION2020UK
- Year on year we will seek to secure funds to support and / or commission research and development projects that address the needs and aspirations of people with concurrent dementia and sight loss and those who care for them; this is ongoing
- We will work with other organisations that are seeking to undertake research and development projects around dementia and sight loss so that our research findings and experiences in practice may inform their work and that findings from other research informs our research and practice; this is ongoing
- We will seek to ensure that staff in our operational services understand dementia and its effects and, as appropriate and possible, we will draw on specialist resources to ensure that; this is ongoing.



Out of interest.....



We will be looking more closely at at the Vision 2020 initiatives, particularly with a view to investigating whether any of their technological adaptations might be of use to our members! Visit their site: www.vision2020uk.org.uk

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Minutes of the PCA Support Group Meeting March 18th 2011

The Venue: Conway Hall, Red Lion Square, WC1R 4RL. This venue is easy to reach with rooms on the ground floor and is situated close to The National Hospital, the Central and Piccadilly Lines and bus services.

Attendees: 40 people attended from across the UK.

Welcome: Seb Crutch welcomed members and outlined the programme for the session.

1. An update on the more unusual symptoms of PCA, lead by Natalie Ryan and Diego Kaski, both of whom are Clinical Research Fellows in Cognitive Neurology. This was to be followed by a discussion of how these symptoms are experienced by individual sufferers and their families. Approximately 45 Minutes.
2. A Buffet Lunch. 25 Minutes.
3. A choice of activities:
Either a) A discussion in small groups lead by members of the Neurology Team at the National: Theme "The impact of PCA on the personal lives of sufferers, their friends and family"
Or b) The chance for carers and patients to socialise quietly over coffee and soft drinks.

Seb also welcomed two groups who were visiting our meeting:

Pam, Sue and Angela who were visiting as observers from the Alzheimer Society, and Valentina and Thomas who are members of the "Dancing Brick" Theatre Group. Valentina and Thomas were visiting to observe our work, as they are planning to develop a theatrical piece on the theme of living with Alzheimer's disease. We wish them every success; it will be interesting to hear how the play works out.

He introduced Jill Walton, the newly appointed Nurse Advisor to the various support groups at the National. Her role will be to co-ordinate these groups and set up further support groups across the country. We are very happy to have Jill on board and wish her well in her work.

The Meeting

- 1.1 Each of our meetings contains an innovation based on the desire to interact well with sufferers, as well as with their carers, and to use the experiences gained from previous meetings. This time, the lighting was brighter and the circular seating arrangement made it much easier for people to see each other and also to have direct eye contact with the persons speaking. The interchange between the two main speakers gave added stimuli and visual cues for those who find it hard to concentrate. The input from PCA sufferers was most welcome and lead to a relaxed atmosphere, where carers and sufferers felt enabled to speak.

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1.2 Natalie Ryan began by asking where the boundaries of the disease were and what unusual symptoms presented themselves. Sufferers generally experience difficulties in calculation, reading and spelling. They may also experience unusual difficulties with complicated motor skills such as sewing and using tools. Some people find that one hand may twitch or work independently of the other. Others experience a sensation of dizziness, of the room spinning. Medication can help with such symptoms, but it is important to check that there is no other physical cause first. The inner ear monitors balance and the eyes monitor movements of the feet – both need to be healthy.

1.3 Diego, the “Dizzy Doctor”, spoke further about the effects of dizziness and the need to eliminate the possibility of an underlying physical condition. Clive described his PCA experience. He felt he had had to hold onto walls, as if he were on a boat in rough seas. He felt very disorientated. Headaches, continued Diego, are associated with these symptoms. Sufferers feel unsure of where they are in space, since multi signals from the environment are poorly integrated as PCA progresses. The sense of vertigo gets stronger and can be experienced everywhere - even in bed.

1.4 Diego asked for further experiences from the floor and members shared the following symptoms:

An obsession e.g. with crumbs on the table.

Disorders of balance:

One side of the body seems to disappear.

Sufferers lean to the left but believe they are standing or sitting upright.

The sense of imbalance can feel as if one side of the body is damaged.

There is a sense of falling over when walking.

People feel they are doing things with one hand or do a mirror action with the other hand.

Sufferers forget what one arm is holding.

Problems of speech

Hallucinations:

E.g. of seeing snakes: one sufferer had damaged the wall with her stick to chase them away, so real was the experience.

Or of seeing people in their familiar chairs when they were not present – another sufferer reported this did not happen on holiday, when he was in a different environment.

Many other attendees recognised similar experiences in their own lives. It was very helpful to be able simply to talk about what was happening and to feel that one was not alone. Diego explained that symptoms can fluctuate, but his advice was to always mention symptoms and push them with the GP – it all adds to the body of experience – knowledge about PCA is still relatively new and not always widespread.

1.5 The meeting felt strongly that there is a continuing need to target PCA information to professionals in all fields.

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1.6 The failure to adequately meet the needs of PCA patients in hospitals is a source of great concern. The normal brain uses 70% of body glucose: in illness involving other parts of the body, this can lead to greater tiredness and poorer function of normal tasks by patients.

1.7 In physiotherapy, many practitioners dealing with loss of balance do not realise they need to break down tasks into much smaller units for PCA patients, or to give instructions facing the patient using mirror movements. Nevertheless, movement is good for the brain.

1.8 It is important to log experiences and write them down.

1.9 The National Hospital is building a Brain Bank. Donor Cards are available, so that brains can be donated and studied after death.

The Small group discussions.

Riitta's group raised the issue of the impact of diagnosis on sufferers and their families, and hence on their social life. It discussed whether or not one should tell people and what one should tell them. Of further concern were the effects on parenting and the relationships with children and grand-children.

Jane's group talked about sufferers and their families on holiday and on cruises.

Seb's group discussed the effects on friendships, the differing reactions of friends and young children to the disease.

The remaining group talked about practical issues. The use of a bird-song clock by one sufferer, when normal time telling had become a visual problem. The need for more than one carer, the need to pass the baton, e.g. for someone else to help with single sex WC visits on outings.

How sufferers might cope with the family coming only intermittently. How to effectively access Alzheimer's and Dementia Support Services, including those of Community Psychiatric Nurses. The Samuel Paul Foundation monitors problems across boroughs.

The Social Group. Some members find this a welcome relaxation after concentrating on the new ideas of the first session. As many members have very long journeys, a chance to relax before starting for home is really appreciated.

Celia Heath

Our grateful thanks to Celia for producing these minutes!!