

# PCA SUPPORT GROUP

## Newsletter

Welcome to the PCA Support Group Newsletter

Issue 7, January 2010

A very belated Happy 2010 to everyone and welcome to another edition of the PCA Support Group newsletter.

Our last group meeting in November was mainly a social event, and provided the opportunity for group members both new and old to get to know one another and share experiences. There was also a demonstration of a range of aids and devices from the Royal National Institute for Blind People (RNIB),

details of which can be found on pages 4 and 5.

The November meeting also took place in a new venue in Conway Hall, Red Lion Square. This provided rather more space for socialising and for coffee and lunch, and will again be the venue for our next meeting on Friday 26<sup>th</sup> March. For the diary, the other meetings in 2010 are provisionally scheduled for Friday 23<sup>rd</sup> July and Thursday 18<sup>th</sup> November.

**Next PCA Meeting: Friday 26th March 2010 (RSVP to Jane or Seb)**

**11am with lunch from 1pm**

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

**(This is the same venue as the November meeting – see page 2 for directions)**

*This meeting will concentrate on issues of diagnosis and treatment, and will feature a presentation from Dementia Research Centre consultant neurologist Dr Jonathan Schott.*

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**Please confirm your attendance:**

**Jane Douglas** 08451 555 000 x 723560 or email [jdouglas@drc.ion.ucl.ac.uk](mailto:jdouglas@drc.ion.ucl.ac.uk)  
**Sebastian Crutch** 08451 555 000 x 723113 or email [s.crutch@drc.ion.ucl.ac.uk](mailto:s.crutch@drc.ion.ucl.ac.uk)



## 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 7829 8724.

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## Directions

**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)

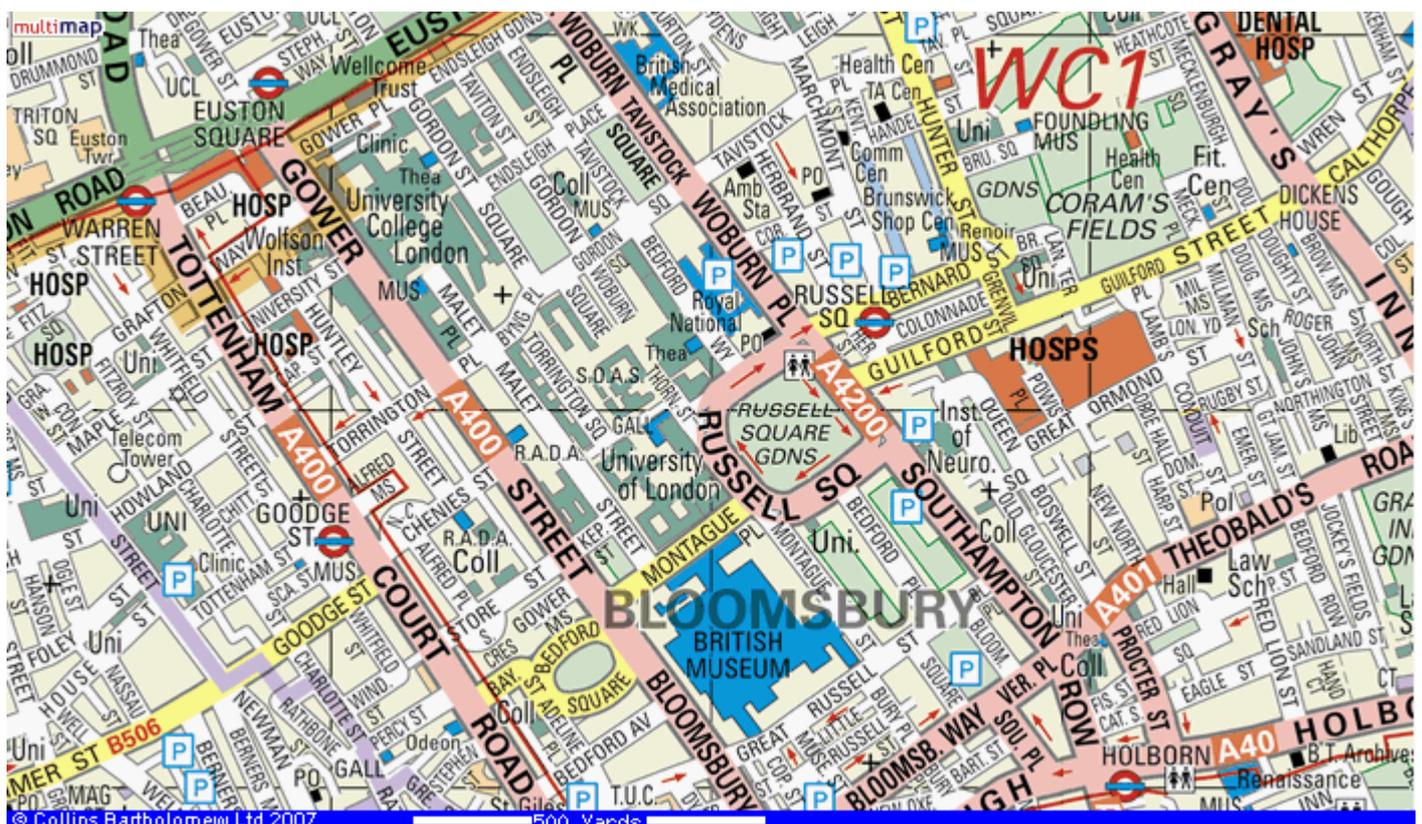
London Buses Infoline: 020 7222 1234

### *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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## Contact list

This Newsletter is accompanied by the first edition of the PCA Support Group contact list. This list provides the names and contact details for support group members who may wish to stay in touch with one another between meetings. If you have not received a copy of the list with this newsletter this is either because we have not received a signed consent form granting us permission to include your details on the list (consent forms available on request) or because of an administrative error on our part! In either case, do contact Jane or Seb if you wish to be a part of this new support scheme. Following an excellent suggestion from one of our group members, we will be offering to take photos of any willing contact list members so that future editions of the contact list can offer you the opportunity to match a face to a name.

## Contact cards

A new emergency contact card designed specifically for people with PCA has also been designed. This credit card-sized ID badge provides brief information about the nature of PCA, and has spaces for you to enter personal details such as your name, phone number and emergency

contact details. If you did not collect a card at the November meeting, they will be on offer again at the March meeting or can be obtained from Jane or Seb.

Posterior cortical atrophy (PCA) is a progressive degenerative condition involving the loss and dysfunction of brain cells particularly at the back (posterior) of the brain. It is most commonly caused by Alzheimer's disease. PCA is associated with problems with perception (seeing what and where things are) and frequently affects reading, writing, counting and other skills.

**I have PCA:  
Posterior Cortical Atrophy**

This affects my vision  
I would appreciate your help  
Please see inside for more information on how to help  
Thank you

My name is	
I have an illness and I need help with	
Other medical conditions	
Allergies	
Someone who might help me	
Name	
Daytime phone	
Evening phone	
Doctor	

## Research into PCA

Many members of the support group have given and continue to give generously of their time to help clinicians and investigators with their research. You may have read in the last newsletter about some of the brain imaging research conducted at the Dementia Research Centre by PhD student Manja Lehmann, published recently in the journal *Neurobiology of Aging*.

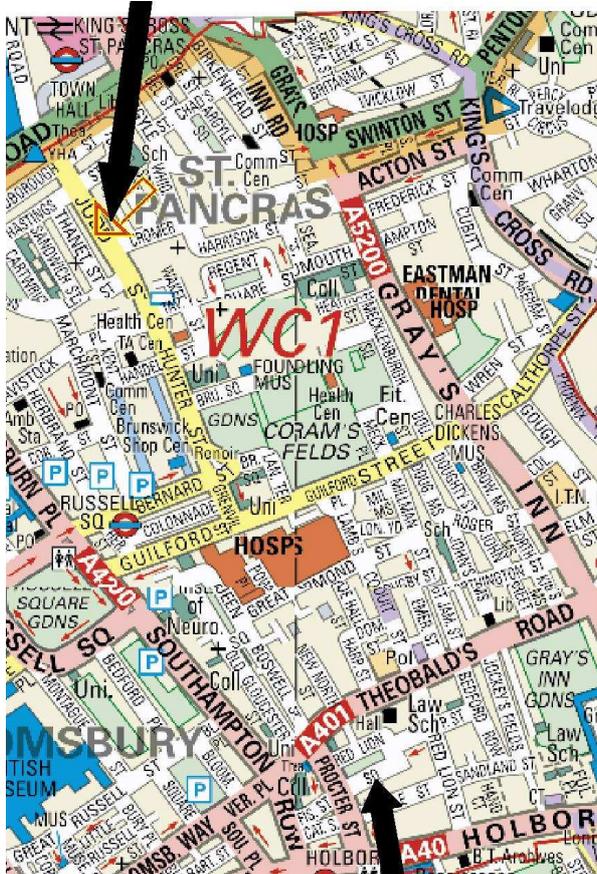
Other significant recent contributions to our knowledge about PCA include work by Migliaccio and colleagues in the journal *Neurology*, who have suggested that PCA may share many common anatomical characteristics with other memory- or language-focussed variants of early onset Alzheimer's disease (AD).

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## Royal National Institute of Blind People (RNIB)

At the last meeting, a number of aids, gadgets and gizmos sold by the RNIB to assist people with visual impairment were displayed. Whilst not all of these items are appropriate for people with PCA, a number of group members have found it of use to visit the RNIB shop, located just a short walk from our meeting venue, to view the available products in more detail. Below are the directions from Conway Hall to the RNIB, in case you would like to visit after the next PCA Support Group meeting, together with details of a few selected items which caught some people's eyes.

Resource Centre  
Royal National Institute of Blind People  
105 Judd Street  
London  
WC1H 9NE  
Tel: 020 7388 1266



Conway Hall, Red Lion Square

## UV shields and colour filters

UV eyeshields act to reduce the amount of ultra violet light that enters the eyes. They are designed to improve visual comfort by reducing glare and increasing contrast while maximising protection and remaining vision. There has been no formal research to establish the utility of colour filters in PCA, but some individuals have reported improved comfort when viewing under different (particularly bright) lighting conditions.



## Simple mobile phones

The RNIB Resource Centre offers a range of mobile with simplified visual designs aimed at making contacting friends and family and receiving calls as easy as possible. The devices vary in expense and complexity, but include features such as pre-programmed speed dial buttons, backlit display screens and distinguishable ring tones.



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## Talking watches

A range of talking, tactile and high visibility watches are also available. Some models provide a spoken reminder of the time in hours and minutes, as well as the day, month and year and the touch of a button.



## Computer software

The Resource Centre can also offer advice on computer packages designed to ease the burden of reading books, letters and articles. Used in conjunction with a standard computer and scanner, programmes such as the Cicero text reader software Cicero convert printed material into speech. Products like the DAISY EasyProducer also allow the conversion of onscreen written material (e.g. online newspapers, reports) into synthesised spoken voices. Speech recognition systems such as Dragon Naturally Speaking which convert spoken words into text are also available, but often require significant amounts of training in order to accurately recognise a person's voice.



*Apart from the RNIB, a number of PCA group members have discovered products from other stores which they have found of use. These include:*

## Touch sensitive lights

Touch activated lights eliminate the need to search around for concealed switch. Various retailers including John Lewis sell a range of designs.



## Plate guards

A couple of group members have also found plate guards useful, to prevent food slipping from the edge of the plate. These can be particularly for those people who have difficulty seeing or attending to the whole plate whilst eating.



IF YOU HAVE IDEAS OR SUGGESTIONS FOR DEVICES WHICH OTHERS MAY FIND USEFUL, DO TELL JANE OR SEB IN PERSON, BY PHONE OR BY EMAIL SO THAT WE CAN INCLUDE THESE IDEAS IN FUTURE NEWSLETTERS.

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## How is it for you? - Living with PCA

*In this regular section of the newsletter, PCA Support Group members Pat and David Moon describe some of their experiences leading up to and following a diagnosis of PCA. Their story, which will be familiar to many, describes their gradual discovery of what it means to live with PCA. If you or your relatives would like to share of your own experiences, thoughts or opinions, please do contact Jane or Seb so that other group members can benefit from hearing your story.*

About 3 years ago, Pat found that she was unable to wrap her usual 'Pass the Parcel' for a Christmas game. It was bizarre at the time – she seemed to have forgotten what to do. Later we noticed that she was having trouble doing certain everyday things like loading the dishwasher and even closing the (up and over) garage door. In every other respect she seemed quite normal so we just didn't recognise a problem.

A 'problem' came to light when Pat went for a routine eye test at Spec-Savers. Instead of the usual recommendation, the optician said that he wanted Pat to take a note of his findings to discuss with her GP. In turn the doctor said that, as the optician had noted something odd about her vision, he wanted Pat to see a neurological consultant.

The consultant did a lot of checks – and told us quite bluntly that Pat might have a 'nasty' brain tumour! Bit of a shock! The consultant arranged for an immediate brain scan. A week later the consultant showed us the results of the scan. To our great relief it was not a tumour. However, the consultant pointed out an unusual pattern in the 'folds' of Pat's brain – at the rear. He recommended a visit to another consultant colleague at Addenbrookes' 'memory' clinic.

After about four visits to Addenbrookes, for further more advanced scans and tests, PCA was diagnosed. It has taken a very long time for clarity about the condition to emerge – particularly over potential treatment through drugs or lifestyle adjustments. Pat takes medication in the form of a daily 'patch' but we really don't know what it is supposed to do. Pat agreed to take part in a study. We have been visited at home by a researcher in order to gather data. Pat's part in the study leads us to conclude that the specialists are learning as much about the brain as we are about the nature of PCA.

Together we have started to list the outward effects of PCA and we think we can see something of a pattern. We would be very interested to know how closely others share the same experiences.

The pattern: Pat has difficulty in dealing with perceptual matters that involve sequences or the awareness of rows, layers and some shapes. All of her main difficulties seem to fall into those categories.

- Pat finds it hard to make a bed (changing a duvet cover is impossible)
- She cannot load a dishwasher or use similar household appliances
- She cannot set a table (in the usual 'knife – fork – spoon' logic)
- When Pat tries to read a newspaper she disrupts the pages and cannot re-assemble them.
- She has big problems in reading because of her difficulties in following the

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rows and columns – many newspapers which use fonts which are inaccessible to her.

- She cannot read from a calendar, reading a watch is very challenging, and she finds it hard to read or write telephone numbers.
- Pat is a good cook, but cannot follow a recipe that requires sequences.
- In a supermarket Pat can get lost because of the rows and shelves.
- Descending a series of steps is quite tricky.
- Using shelves at home (such as in the fridge) is very difficult and she will rarely put things back in the same place.
- Pat finds it hard to judge whether objects will fit spaces. She cannot judge volumes.
- Number sequences are impossible – such as a telephone or calculator. This includes the ‘hole in the wall’ machines used for banking.
- Any sequence of directions is difficult. Pat will easily get lost in what was once a familiar place – such as the shopping mall.
- Folding anything – for example towels or sheets – is particularly difficult.
- Sorting anything into categories, even clothing, is a challenge.

We could go on but we think the pattern is clear...

Fortunately, apart from writing and reading, (which is a big blow, as Pat made her living as an author), none of these things actually matter much. Pat’s intellectual capacity, her speech, and her personality are much the same. So, for example, if we do a crossword – Pat is just as likely to provide the answers although she can make no sense of the rows and columns.

Pat sometimes says the world ‘looks like a jigsaw’ or ‘like being underwater’. Sometimes she cannot make sense of what she sees – says it ‘looks like coloured shapes floating about’. Other problems include lack of confidence, feeling insecure (understandable) and sleeping a lot - up to 12 hours daily.

Just a thought: From rudimentary knowledge of child-development, we know that babies ‘learn to see’ in their first few months. At birth, a baby’s eyes work – but it can take up to a year for the baby to make sense of the visual messages. Perception of place, depth and perspective, for example, are not fully formed at birth, even though the eyes function well. Precisely the opposite seems to happen with PCA – instead of learning to see, the brain is ‘unlearning’. A baby needs a lot of sleep which gives the brain ‘down time’ (dreaming?) whilst it organises its waking experience’. The PCA brain also has to work hard, could this explain why PCA seems to go with plenty of sleep?. We wonder if knowledge of perception and development of the brain in the early years might possibly inform what happens to the brain in the senior years.

We would be interested to know how other members of the support group feel about these observations. Particularly how widely the symptoms are shared – and are there others that should be added?

*Pat and David Moon*

*13<sup>th</sup> December 2009*