September 2018

Dear PCA Support Group Members,

Welcome to the September 2018 edition of the PCA Support Group newsletter which we hope you will find helpful and interesting. We are very keen that the newsletters and support group meetings meet the needs of our membership and so any feedback is really important to us. We will be continuing to look at more formalised ways of inviting this feedback, documenting it and implementing changes but for now, please continue to feel free to send any comments or suggestions to emma.harding@ucl.ac.uk. Whether it’s ideas for topics you would like to see covered in future newsletters or at meetings or suggestions for potential speakers, this is all really helpful and warmly invited. Thank you as ever to those of you who have offered feedback, steering and guidance so far and for your patience as we continue to try to incorporate this, it’s hugely appreciated.

Upcoming support group meetings –

Next PCA Support Group meeting:

Date: Friday 19th October 2018
Location: 6th Floor, Wellcome Trust, Gibbs Building, 215 Euston Road, London NW1 2BE (**please note this venue is not the same as The Hub at the Wellcome Collection; the Gibbs Building is next door to the Wellcome Collection**)  
Directions: https://wellcome.ac.uk/About-us/Contact-us/  
Time: 11:00 – 14:00 (arrival from 10:30)
RSVP: To register your place, we kindly ask you to RSVP to Laura King by Tuesday 11th October at: laura.king@ucl.ac.uk. This will help us with guest registration and catering provisions. Please also let us know if you have any special dietary requirements.

Agenda: This meeting will return to our usual format of having a large group session in the morning (with plenty of time for questions and answers), followed by lunch (and chatting) and then small discussion groups in the afternoon.

The theme of the morning session will be ‘adapting activities’, and this was decided on following several conversations with members which indicate a real need to (for want of a better phrase) find PCA-friendly things to do. We know from previous support group meetings both how frustrating it can be to suddenly need help with lots of daily tasks but also some inspired workarounds and compensatory strategies members and their families have developed. We would welcome your input and suggestions both ahead of time (to: emma.harding@ucl.ac.uk) and on the day around the following themes:

Which sorts activities have become difficult and why?

Have you developed any strategies or workarounds to overcome these?

Have you taken up any new activities since having a diagnosis of PCA?

Is there anything you’d like help to be able to continue to do?

After lunch we will break into smaller discussion groups as follows:

1) **Adapting activities** (continued) – this will be an opportunity to continue the conversation to consolidate some information that can be disseminated to the wider membership and also to hopefully help shape or inform a workshop we could offer at a future support group meeting/help us to think about other organisations we could approach to run some activities for us
2) **UCL Law dementia clinic** – colleagues in the Law department at UCL are developing plans to pilot a dementia law clinic and to advise on issues such as Power of Attorney, applying for PIP, etc. Two representatives will be joining us and leading a discussion group to establish what sorts of advice, help and support would be useful to you or others who may find themselves on the PCA journey.

3) Seb Crutch, clinical and research neuropsychologist at the Dementia Research Centre at UCL who many of you will know, will chair a discussion and **Q&A session** about what PCA is and what we know from research about symptoms, treatment and what to expect. This group might be especially helpful for those of you who have been recently diagnosed and/or are coming for the first time.

**Next Bereaved Carers’ Support Group meeting:**

**Date:** Thursday 15th November 2018  
**Location:** Seminar Room, The Hub, 5th Floor, The Wellcome Collection, 183 Euston Road, London NW1 2BE (As you come through the main entrance of the Wellcome Collection, head up the initial set of stairs. Just past the visitors’ reception desk you will see some lifts on the left. Take the lift to the 5th floor and we will then guide you to the correct room).  
**Directions:** [https://wellcomecollection.org/visit-us/getting-here](https://wellcomecollection.org/visit-us/getting-here)  
**Time:** 10.30-12:30  
**RSVP:** To register your place, we kindly ask you to RSVP to Laura King at: [laura.king@ucl.ac.uk](mailto:laura.king@ucl.ac.uk). This will help us with guest registration and catering provisions. Please also let us know if you have any special dietary requirements.
It was great to see so many PCA support group members at our last meeting which took the format of an all-day conference about dementia and sight loss and was organised in partnership with Vision UK. It was also attended by over 100 health and social care professionals working with people with dementia-related visual impairment including Occupational Therapists, Ophthalmologists, Rehabilitation Officers for Visual Impairment (ROVIs) and more. There were talks spanning the neuropsychological features of PCA, the psychological and social impacts, and various assistive technologies to support people living with cortical visual problems. For those of you who couldn’t make it, the slides from the different presentations are now available here: https://www.visionuk.org.uk/presentations-from-the-vision-uk-university-college-london-ucl-and-vision-uk-dementia-and-sight-loss-conference/

...and videos of the presentations are soon to be uploaded to our website here: http://www.raredementiasupport.org/posterior-cortical-atrophy-pca/

Two key take home messages from the day were:

(i) the need for greater recognition of PCA and dementia-related visual impairment throughout various healthcare professions.

In agreement with this, Prof Seb Crutch read out to us the encouraging closing paragraphs of a recent review paper about visual dysfunction by Maia da Silva and fellow clinical neurology and ophthalmology colleagues which was published in Frontiers in Neurology (2017).

The closing paragraphs read:
Despite the progress in the understanding of the neural basis of PCA in recent years, patients still frequently experience a painful delay in diagnosis, mainly because it is not appreciated that their symptoms are associated with brain dysfunction by optometrists and ophthalmologists who are consulted. The need of increasing awareness among clinicians cannot be over-estimated, and this should involve not only neurologists, but general practitioners, optometrists, and ophthalmologists.

For all who see patients with visual symptoms we would emphasize the following. First, in the anamnesis, take note of visual symptoms that have an emphasis on spatial disorientation. Second, in the basic clinical assessment, such features as unexplained difficulty with Ishihara plates, variable homonymous defects on perimetry and a tendency to omit letters on the acuity chart should raise suspicion of the disorder.


(ii) Another point of note was the attendance and enthusiastic participation of Rehabilitation Officers for Visual Impairment (ROVIs). Although several of the ROVIs in attendance had worked with people with PCA before, many PCA support group members and professionals alike hadn’t heard of the brilliant and relevant work ROVIs do or how to access or refer to their service. As a response to this we are in talks with several ROVIs to organise a contribution to our next newsletter and a presentation at one of our future London meetings so watch this space!
Staff updates

We would like to take this opportunity to introduce you to Dr Kirsten Perkins, who has joined the Rare Dementia Support team and who is also part of UCLH and based at the Dementia Research Centre. Kirsten is a chartered Clinical Psychologist with the British Psychological Society (BPS) and Associate Fellow of the BPS Division of Neuropsychology. She has experience in developing neuropsychology diagnostic and rehabilitation services in a number of different areas including in-patient, out-patient and community settings. She has worked with people with a wide range of neurological disorders including dementia, Parkinson’s disease, multiple sclerosis, stroke and epilepsy. In her role at the DRC she will be providing psychological assessment and intervention to people presenting with a range of psychological, behavioural and cognitive difficulties. She also provides psychological support to relatives and carers.

Opinion Research Services

Dementia 2020 Citizens’ Engagement Panel

Opinion Research Services (ORS) are looking for volunteers to join this panel to inform the Department of Health & Social Care in England as to whether the Government’s plans for dementia care and support are making a difference to people’s lives.
The initial report about the experiences of diagnosis (which is downloadable from the website here: https://www.ors.org.uk/surveys/dementia2020/Dementia_2020_Panel_Phase_1_Report.pdf) does mention the challenges that younger people with dementia can face in getting an accurate diagnosis, but we thought it could also be a useful forum for the voices of people with not only younger onset dementias but also rarer dementias like PCA, having heard from so many of you about the challenges of getting the right referrals. If you have time and would be interested in completing the survey you can find it here: http://www.opinionresearch.co.uk/dementia2

...and if you have any questions about the project please contact Dr Claire Thomas on: 01792 535337 or at: dementiapanel@ors.org.uk

Member fundraising – Not Only Memory!
PCA support group members Clare and Dave completed an Alzheimer’s Society Memory Walk to raise money for Alzheimer’s Society and have so far reached an impressive total of £1023!

Dave said of his reasons for taking up the challenge:

“My wife, Clare, is typing this for me.

I was diagnosed with a rare form of early-onset Alzheimer's (PCA) 3 years ago, at the age of 61. It mainly affects my vision, but also my speech. There is very little I can do at all without help...but I can walk! So I'm doing this walk as it is something useful I can actually do...and help a little bit towards getting a world without dementia!”

...and the pair were keen to raise awareness of less common, non-memory-led dementias like PCA, and they did so by wearing sashes saying ‘Not Only Memory’ which sparked a lot of conversation and interest from fellow walkers and spectators.

If you’d like to sponsor Dave his fundraising page will be open until the end of October and you can find it here:
https://www.justgiving.com/fundraising/mw364179

Excellent effort both of you!

Created Out of Mind update I – short film festival

We are delighted to invite you along to the Created Out of Mind short film festival (details below) – unfortunately fittingly at very short notice! It’s this weekend (Sunday 23rd October 2018) at the Phoenix Cinema in East Finchley – please spread the word among friends, families and colleagues who might be in the area too. The Phoenix Cinema offers dementia-friendly screenings throughout the year with brighter lighting and reduced sound which are free for people with dementia and two guests, so if you can’t make it this time do check out their What’s On pages here when you are next in the area:
CREATED OUT OF MIND PRESENTS A PROGRAMME OF SHORT FILMS EXPLORING UNIQUE AND DIVERSE STORIES OF DEMENTIA. THE FESTIVAL AIMS TO CHALLENGE AND ENRICH CURRENT PERCEPTIONS OF DEMENTIAS AND INVITES US TO CONFRONT BIGGER QUESTIONS OF WHAT IT MEANS TO BE HUMAN.

FOLLOWING THE SCREENINGS, THERE WILL BE A PANEL DISCUSSION, REPRESENTING VOICES FROM ACROSS SCIENCE, CULTURE, ARTS AND FILM.

THIS FESTIVAL IS DEMENTIA INCLUSIVE AND PEOPLE LIVING WITH AND WITHOUT DEMENTIAS ARE WELCOME TO ATTEND. IF YOU HAVE ANY SPECIFIC ACCESS NEEDS OR QUESTIONS PLEASE CONTACT US AT INFO@CREATEDOUTOFMIND.ORG.

THE PHOENIX CINEMA
23.09.18 // 15.30 - 18.00
52 HIGH RD, EAST FINCHLEY, LONDON N2 9P
TICKETS: £5 (AVAILABLE ONLINE)
Created Out of Mind update II – Dementia and the Arts
Massive Open Online Course (MOOC)

Created Out of Mind this month celebrated the launch of the first run of a new MOOC (massive open online course), Dementia and the Arts: Sharing Practice, Developing Understanding and Enhancing Lives. This free online course has been developed by Created Out of Mind, with an interdisciplinary team of scientists, researchers, broadcasters, clinicians, musicians, care home workers, charities, visual artists and people living with dementias and carers. The course is accredited by the Royal Society for Public Health (RSPH). For more details about the course and to register please visit:

https://www.futurelearn.com/courses/dementia-arts
Why join the course?

Creating a society that supports and includes those of us who are living with a dementia is a major challenge - and opportunity. In this course you will discover how the arts can create a common ground between people, and in doing so, learn what we can all do to improve the quality of life and care for people living with different dementias.

Each of the four weeks will showcase current best practice, explain the limits of our current understanding, and set ambitious goals for enhancing the lives of anyone affected by one of these conditions.

Please also share with friends, family and colleagues who might be interested!

Research summaries

In the spirit of exploring different ideas for content in these newsletters, and taking inspiration from Dr Chris Hardy, facilitator for the Rare Dementia Support Primary Progressive Aphasias group, we wondered if summaries of PCA-specific research might be helpful and interesting to you. So we are trying this here, but as always – your feedback is warmly welcomed! Also, just to make a disclaimer, my summaries of scientific papers will be contingent on my own understanding of them, so please bear with me if things seems overly simplified or indeed, still too full of scientific jargon. As I say, feedback on the whole concept or on the details – tone/style, types of papers summarised, level of detail – and suggestions for what you would like to see take up these pages in the future are all very much encouraged (please send any thoughts to emma.harding@ucl.ac.uk).

If we continue with this on an ongoing basis, it could be a really good way to keep everyone up to date with papers at the cutting edge of PCA research, but to start off, I thought it might be handy (and not too daunting for me as a new venture) to begin with just two papers but two which are quite different – the
first one, to ease me in, is from our team and about individuals’ everyday experiences of PCA and another is from a different research centre at the University of Manitoba in Canada, about an experimental lab-based study of visuomotor function in PCA. In line with the above, feedback on if this is a useful feature and if so, what sorts of papers you might like to see summarised are warmly welcomed (n.b. don’t hold back on account of my psychologist’s background, I am more than happy to rope in my colleagues with expert knowledge on the imaging / genetic fronts if that’s where the interest lies!).

What did we want to know? As there was no published research on the day-to-day subjective experiences of people living with PCA we wanted to know what the impact(s) of PCA were in participants’ own words.

What did we do? We did in-depth semi-structured interviews with people living with PCA and a family carer. We interviewed pairs in their homes (usually spouses by sometimes a parent and child and once an aunt and niece) together and then each person separately. Interviews lasted about 3 hours in total. The audio files were transcribed verbatim and the written transcripts then coded for patterns which were then organised into themes that told a complete coherent story of the whole data set. We interviewed 20 individuals in the mild to moderate stages of PCA and their 20 family carers.
What did we find? We found that the impacts of PCA on individuals and their family members could be broadly summarised into three major themes and these were:

(1) the diagnostic journey: mostly this was an unsettling and convoluted process, owing to the early age of onset, rarity and atypical symptom profile of PCA.

(2) difficulties in interactions with the physical environment: people described having profound difficulties with both functional and leisure activities because of their complex visual symptoms but they did make efforts to compensate for these and where possible, this was with adaptations (home-made or off-the-shelf) which maximised familiarity (e.g. keeping things in the same place) or simplicity (e.g. covering up unnecessary buttons on the TV remote).

(3) The symptoms also had wide-reaching implications within the psychosocial environment (i.e. people’s thoughts, feelings and behaviours and relationships with others): symptoms impacted individuals’ sense of independence and identity and required reallocations of roles and responsibilities within the household or wider family. Ongoing uncertainties and the progressive nature of PCA meant most pairs felt they had to take a ‘one day at a time’ approach to coping and to continually adjust over time. Relatively well-preserved insight and memory were both a benefit and burden for people, as it meant individuals were able to share the illness experience with family members and tackle things as a team, but this insight also meant people were very aware of their continuing difficulties and made lots of comparisons with the ways they used to be able to do things so comparatively effortlessly.

- The experience and how people responded was very much shaped lots of pre-existing factors like career history, previous interests, personality type and the longstanding quality of existing relationships.
**What does this tell us?** The impact of PCA is characterised by uncertainty and unpredictability from diagnosis through to the ongoing management of the symptoms and their associated challenges. Things which we recommended would be useful were:

- The provision of tailored information about cortical visual problems and the associated functional difficulties
- Time-sensitive environmental adaptations to help those with PCA to identify what and where things are
- Psychosocial interventions for the marital/family unit as a whole

...to improve both how able people are to do things but also their psychological well-being as they adjust to the ongoing changes. We also suggested that future research exploring (1) stress and coping in the later stages of PCA and (2) the nature and impact of visual impairment(s) in typical Alzheimer’s disease would also be worthwhile.

**What did they want to know?** PCA is characterised by progressive degeneration of the occipito-parietal and occipito-temporal cortices which are responsible for our higher order visual functions. These are more complex cognitive actions than, say, perceiving lines, shapes or colours, and include things like recognising faces and locating objects in space. These authors looked empirically at the reaching and grasping abilities of 4 people with PCA.
What did they do?

Experiment 1: Participants had to reach out and grasp a rectangular block right in front of them in clear view

Experiment 2: Participants had to look at the object for 3 seconds and then grasp the block with their vision occluded

Experiment 3: Participants had to look at the object for 3 seconds, their vision was occluded and then they had to wait for another 3 seconds before trying to grasp it

Experiment 4: Participants had to look straight ahead while trying to grasp a rectangular block placed in their periphery

Accuracy and speed was measured using sensors fitted to the thumb, index finger and wrist of participants’ dominant hands and shutter goggles were worn to allow the researchers to occlude participants’ vision when needed.

What did they find? All 4 participants showed some visuomotor dysfunction in their performance compared to the control group, such as:

- reduced speed of their reaching action
- inaccurate ‘grip-scaling’, i.e. not opening their hand the right amount to pick up the block
- taking excessively curved reaching trajectories
- ‘magnetic misreaching’ (biased reaching towards where they were looking rather than toward the object, when it was in their periphery)

These sorts of difficulties existed when people could see the block but were made worse when the block was either in their periphery or when their vision was occluded.

What does this tell us? There are a few interesting things to note about these findings –

- Firstly they should be interpreted with caution as the sample was very small and not every participant showed every difficulty
described. But these can certainly serve as examples of the different ways reaching and grasping might be affected and also as a reminder that things will be different for different people at different stages of PCA.

- Also interestingly, only one of these participants had reported noticing these sorts of higher order visuomotor difficulties in their day-to-day lives, the other three had reported only noticing problems with simpler perceptual processing like ‘fuzzy’ vision, difficulties reading and recognising objects. This tells us perhaps to be cautious that very sensitive lab-based measures of function don’t always exactly capture or fit with our own experiences of how symptoms and difficulties manifest or how we are managing at home.

- Another thing to take from the findings is that we (and our brains!) can be resourceful and creative – one of the suggested reasons for the ‘inefficient’ curved reaching paths was that these simplified the input from the visual scene as it meant the participant’s hand didn’t obstruct the view of their target object for too long.

- This in turn potentially tells us something about the brain regions involved in these tasks and/or which are impacted for these participants. In this case it’s thought the curved reaching and ‘magnetic misreaching’ happened because of damage to parietal regions which usually house the on-line control centres which plan movements based on incoming visual information. In addition, the fact that participants’ performance was worse when their vision was occluded and with a delay implies that the temporal cortical areas which would ordinarily be able to provide the visuomotor systems with lasting perceptual representations of the environment are impacted for these 4 participants.

- Finally, it’s hoped that increased understanding of the sometimes subtle manifestations of PCA symptoms like this could help clinicians to more quickly and accurately diagnose PCA and also that professionals (e.g. occupational therapists) and families living with
the condition can be better equipped and informed to develop tailored coping and support strategies for these sorts of difficulties.

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**National Brain Appeal update – fundraising**

**Update on Nick Fell’s Coast to Coast Walk**

Rare Dementia Support would like to thank and congratulate Nick Fell for his extraordinary effort and commitment to raising funds for the Dementia Research Fund held by The National Brain Appeal. Nick succeeded in completing the Coast to Coast Walk from St. Bees to Robin Hood’s Bay, and is pictured here with his sons at the end of the walk. He took on this challenge in memory of his late wife Jan Fell who sadly passed away in January 2018 after 12 years living with Posterior Cortical Atrophy. Thank you to all you those who donated towards Nick’s challenge, his fundraising currently stands at an
incredible £6,479 including Gift Aid. To see pictures and updates on Nick’s wonderful (and arduous!) journey please go to: justgiving.com/fundraising/janice-fell

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**Keep in touch! – social media**

As well as signing up to our email/postal mailing lists we’d love you to follow us on Twitter and add us on Facebook (details below) where you can find lots of interesting articles and information being shared as well as meeting details – it would be great to hear from you and to spread the word so please like, comment and share!

Rare Dementia Support

@raredementia

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Facebook

Tweets by @RareDementia

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Dementia Research Centre | UCL Institute of Neurology
8-11 Queen Square | London | WC1N 3BG
Enquiries: contact@raredementiasupport.org | www.raredementiasupport.org
Travel costs

We are aware that some people travel long distances to attend our meetings, and that perhaps this isn’t always viable from a financial point of view. We have had a small donation from the National Brain Appeal to help with travel costs for meeting attendance for those who need it. Please let Emma know if a contribution towards travel expenses would help to make it possible for someone to attend the meeting.

We look forward to bringing you more of what we hope is useful and interesting PCA-specific information in our next newsletter and thank you again for all your input and thoughts as we continue to try to make the service as helpful and supportive as we can. We remain completely committed to supporting people with a diagnosis of PCA wherever possible, and hope to see as many of you as can make it at our meeting on October 19th. If you need or want to get in touch before then, please do so and we will be glad to help.

Yours faithfully,

The PCA Support Group Team

DISCLAIMER: Please note that you assume full responsibility and risk in the use of information contained on our website, in our newsletters, at support group meetings and in subsequent correspondence. Our support group based correspondence is generic in nature and we are limited in our ability to offer specific advice via this means. We aim to ensure that all information is as accurate as possible but we accept no responsibility for any errors, omissions or inaccuracies, or for any adverse consequences of any kind arising from the use of support group based content. Our regional group facilitators are volunteers. They may refer to regional facilitator guidelines from RDS but are not governed by RDS. They operate independently and with best intention and you assume full responsibility for your contact and engagement with them and in the regional groups they facilitate. Please see the clinician responsible for your care, a social services representative, or your GP if you have specific needs which require attention. Any medical decisions should be taken in discussion with an appropriate health care professional.