Dear PCA Support Group Members,

Welcome to the June 2019 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 you have ideas for topics you would like to see covered in future newsletters or at meetings or suggestions for potential speakers, these are 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.

Meetings

Our last PCA Support Group meeting:

At our last meeting in March, members of the PCA research team at the Dementia Research Centre (UCL) contributed to a panel discussion in the morning session on ‘Updates in PCA Research’. If you were unable to make the meeting or would like to catch the research update again, the recording of the session is available here.
Notes from the small group discussions in the afternoon session of the March meeting are available for download here:

Group A

Group B

Group C

Next PCA Support Group meeting:

Date: Friday 5th July 2019
Location: 6th Floor, Wellcome Trust, Gibbs Building, 215 Euston Road, London NW1 2BE
Directions: https://wellcome.ac.uk/About-us/Contact-us/
Time: 11:00 – 14:00 (arrival, registration and tea and coffee from 10:30)
** please note, if this is your first support group meeting, we will be running a brief introductory session from 10am if you would like to arrive a little early to be introduced to other people joining for the first time and in case you have any questions or concerns about how the session will work, and mostly so that we can say hello! Please let us know when you RSVP if you would like to attend this session.

RSVP: To help us better manage our meeting registrations we are trialling using Eventbrite, so kindly ask you to register your place by clicking here, by Monday 1st July

Live-streaming: For those of you unable to join us in person, we will be live-streaming this support group, meaning if you have internet access you can watch the meeting live, you will just need to visit our YouTube channel page at the time of the meeting. 
(If you would like to submit questions to the speaker via the Comments section on the video - bearing in mind these may be visible to others - please do and we will do our best to ensure they are read out.)

Agenda: This meeting will follow our usual format of having talks for the whole group in the morning (with plenty of time for questions and answers), followed by lunch and then small discussion groups in the afternoon. Our morning speakers will be (i) Dr Samrah Ahmed, research scientist and academic neuropsychologist from the Nuffield Department of Clinical Neurosciences at the University of Oxford, who will be telling us about her research into memory problems in PCA and (ii) PCA support group member Simon Rosser who will be talking about his personal experience of PCA in conversation with Seb Crutch.

Over lunch there will be the opportunity to talk to a number of researchers about different projects that are currently ongoing in case you might like to get involved.

Topics for afternoon discussion groups are still to be confirmed - there will be a general Q&A group as usual about what PCA is as well as groups focused on trials and medication and care and support. If there are any other particular topics you’d like to participate in discussions about we’d really like to hear from you - please send any suggestions to emma.harding@ucl.ac.uk and we will do our very best to accommodate!
Staff Updates

We are delighted to welcome three new members to the Rare Dementia Support team – Claire Waddington, Nikki Zimmerman and Siobhan Culley. Here you can read a little bit more about them and what their roles within RDS will be:

**Nikki Zimmermann**

Nikki’s background is in Public Health (BSc and Cert PPH) and she previously worked for the Alzheimer’s Society for seven years. She also has personal experience as her father had young onset dementia. Nikki held many roles in London with the Alzheimer’s Society setting up support services for people with dementia and their families and managing services in the boroughs of South London. Three years ago, Nikki established the London Neurology Project to work in a more intensive way within Cognitive Neurology departments at the National Hospital for Neurology and Neurosurgery and St George’s Hospital, London.

We are delighted that Nikki has joined the Rare Dementia Support team at UCL in her role as the RDS Support Group Advisor and Consultant and will work closely with all the Support Group teams and members. She brings a wealth of practical experience in young onset and rarer types of dementia as well as navigation through the Health, Social Care and Community services, which will be a huge asset to the service.

**Claire Waddington**

“I studied in Wellington, New Zealand. My background is in Psychology and Neuroscience (I did an MSc in Cognitive and Behavioural Neuroscience and a BSc in Biology and Psychology). I worked for the Alzheimer’s Society for 2 years, where I was a Dementia Support Worker. I worked one on one with people living with dementia and their carers to signpost and refer in regards to legal, financial and practical concerns, as well as activities for wellbeing. I also ran a peer support group, an art group, a coffee morning and a number of information sessions.”
Siobhan Culley

“My background is in Psychology. I studied my Psychology BSc at the University of Bath. I’ve worked as an Assistant Psychologist in several NHS teams, including in a Clinical Neuropsychology department, Psychological Therapies Service and Mental Health of Learning Disabilities Service. As part of my work in Clinical Neuropsychology, I met people with various neurological and psychological presentations, including people living with and caring for someone with dementia, conducting neuropsychological testing and assisted with a mindfulness course. I have carried out research into PCA in collaboration with the Nuffield Department of Clinical Neurosciences at the University of Oxford, which focused on studying the impact of PCA on activities of daily living.”

We are delighted that Claire and Siobhan have joined us here at Rare Dementia Support as Research Assistants, where they will provide assistance with the Rare Dementia Support groups, as well as being involved with the Rare Dementia Support Impact project.

UCL Integrated Legal Advice Clinic

The UCL Integrated Legal Advice Clinic (iLAC) recently launched a Dementia Advice Service Pilot Scheme and the PCA support group is one of the groups this scheme is being trialled with. They are offering FREE one-off initial advice sessions on a range of issues such as care arrangements, powers of attorney, welfare benefits and employment matters. Please contact them at: accesstojustice@ucl.ac.uk for more information about the scheme and to request an initial enquiry form.
Research Updates

Longitudinal neuroanatomical and cognitive progression of posterior cortical atrophy

We are very pleased that the journal Brain has accepted for publication the long term study of PCA that many of you have contributed to over the past decade. This is thanks to the work of many, many people, but particular thanks need to go to Keir Yong, Silvia Primativo, Nick Firth and Raz Marinescu. The official title of the article is ‘Longitudinal neuroanatomical and cognitive progression of posterior cortical atrophy’. Here is a short summary of the article.

What did we do, and what did we find out? We conducted the first major study of how the brains and thinking skills of people living with posterior cortical atrophy (PCA) change over time. We compared these patterns of progression to those of people living with memory-led (or so-called ‘typical’ Alzheimer’s disease (AD)). The results showed clear differences in the order and rate in which different parts of the brain (and associated thinking skills) were affected by PCA and typical AD. We confirmed that regions at the back of the brain are affected first in PCA. The study also showed that some regions directly in front of those first affected are subsequently affected and eventually show similar rates of change as the worst affected posterior areas. However, more distant regions such as the front of the brain never show the same extent of damage as the posterior parts.

How did we do it? Many members of the support group helped with this study. In total 117 people with PCA took part (including some from USA and Spain), together with 106 people with typical AD and 138 people without a neurological condition. People were scanned and tested between one and six times, usually once per year. To compare between the many different brain scans acquired, colleagues from the UCL Computer Science department adapted and created special mathematical models to calculate the rate and order in which volume of particular brain regions was changing. Similar mathematical models were applied for the first time to the cognitive test scores.

Why did we do it? Most people with the PCA syndrome have it as a result of underlying Alzheimer’s disease (plaques and tangles between and within the neurons of the brain, stopping them from communicating and functioning normally). These and previous results clearly indicate that this disease sometimes affects the vision circuits of the brain first (as in PCA) and sometimes the memory circuits of the brain (as in typical AD). Understanding why one disease (AD) can affect different people in such different ways may have real importance to scientists seeking to develop treatments that reverse the vulnerability or enhance the protection of those cells. We also hope understanding the order in which brain regions and cognitive skills are affected in PCA will enable us to better measure the effects of potential treatments in future clinical trials.
It’s building up a picture that’s the problem

We were really pleased to see this article ‘It’s building up a picture that’s the problem’ by Teresa Nahajski and Dr Helen Scott at University of Worcester published in the March/April 2019 edition of the Journal of Dementia Care. The journal is a multidisciplinary journal for all professional staff working with people with dementia, in hospitals, nursing and residential care homes, day units and the community, so we think it’s a really good audience to raise awareness of the particular symptoms and challenges of PCA with.

The authors report on a study in which they interviewed partners of people with a diagnosis of PCA about the challenges of the condition and coping strategies and the journal editor has kindly allowed us to make the article available to our membership here.

When A’s walking he will walk diagonally across the road, he won’t see the shortest way across. And at crossings, he’ll get the green traffic lights muddled with the green man, so he’ll start to walk across when it’s green traffic lights.

A number of dementia support agencies exist, but carers do not always have the time or knowledge to research what is available locally. Study participants suggested that it would make sense to have one point of contact for a centralised support network.

If you are professional members of our support group and would like to subscribe to the journal you can do so here.
Alzheimer’s Research UK, the UK’s leading dementia research charity, has recently updated its booklet on PCA. These were first produced in 2017, in partnership with Rare Dementia Support, and Prof Sebastian Crutch has kindly provided input again this time.

The booklets provide helpful information on the symptoms, causes, diagnosis and treatment of these conditions, as well as tips to help people living with PCA deal with their symptoms. In case you would like to distribute these to your GP, consultant or family and friends, you can request a copy of these booklets, free of charge, and view the charity’s complete range of information, online at alzres.uk/resources. Alternatively, call 0300 111 5555 to order.

Sharing your story

Would you like to help increase understanding and raise the profile of PCA? We are working with Alzheimer’s Research UK to raise awareness and understanding of the challenges and demands of this disease. They would love to talk to people like you about your experiences of living with PCA, to help them get stories out into the media. This not only ensures that more of the general public are aware of PCA – vital in challenging stigma – but also helps to highlight the importance of research and making breakthroughs possible. If you would like to help, and you would feel comfortable chatting to one of their friendly communications officers about your experience, then you can either drop an email to stories@alzheimersresearchuk.org or email Emma Harding at emma.harding@ucl.ac.uk, who will be happy to talk to you about your involvement.
The Young Dementia Network have developed a checklist which – while not a diagnostic tool – is intended to help a person to become aware of the most common signs and symptoms of young onset dementia and record changes and symptoms they may be experiencing. The information can then be used to provide prompts for a conversation with a GP or other health professional, and we were encouraged to see a number of symptoms relevant to PCA covered by the checklist, including:

- Are you making repeated visits to your optician and finding nothing wrong?
- Do you mis-reach for objects or fail to find things that are right in front of you?
- Do you have difficulty judging depth and volume?
- Do words appear to float off the page? Do you sometimes get double or blurred vision?
- Do you have difficulty judging distances when driving?
- Have you developed problems with reading, managing money, figures or other mental skills?
- Are you finding it harder to keep up with work demands than you used to?
- Do you feel an increase in clumsiness; a change in how you walk or your balance, mobility, or steadiness?

They say of the resource:

Our [Personal checklist](#) is a downloadable resource that is for anyone who has concerns about signs and symptoms of young onset dementia.

It is not a diagnostic tool but is intended to be used as a checklist which individuals can use to record symptoms they, or a family member or friend, may be experiencing and then, if necessary, use it to aid a discussion with their GP.

Please email [network@youngdementiauk.org](mailto:network@youngdementiauk.org) to share your views on the resource.

You can read more about the network and how to join [here](#).
We hope many of you will have tuned in to see Vicky McClure’s two-part documentary ‘Our Dementia Choir’ in BBC One in April, featuring Prof Seb Crutch and some RDS members. The show had glowing press and we hope really helped to raise the profile of some less common forms of dementia with a national audience – we hope you enjoyed it too if you tuned in!

‘What Dementia Teaches Us about Love’ by Nicci Gerard

During the course of our residency at Wellcome Collection, a number of us met author and campaigner Nicci Gerrard, whose book ‘What Dementia Teaches Us about Love’ has just been published by Penguin Books (UK) to wide acclaim:

Essential reading about love, life and care (Kate Mosse author of Labyrinth)

Nobody has written on dementia as well as Nicci Gerrard in this new book. Kind, knowing and infinitely useful (Andrew Marr)

Gerrard writes beautifully, encyclopaedically and with humanity (Nicholas Timmins senior fellow at the Institute for Government and the King’s Fund, honorary fellow of Royal College of Physicians, author of Five Giants)

Nicci Gerrard exudes understanding of the breadth, scale and complexity of the dementias and the challenges they pose for society. Yet she communicates simply, personally and practically as if speaking individually to each of us (Sebastian Crutch Professor of Neuropsychology, Dementia Research Centre, University College London)
Nicci Gerrard is also co-founder of John’s Campaign, named after her father, which is a campaign for extended visiting rights for family carers of patients with dementia in hospitals in the United Kingdom. Recognised by NHS policy makers, by charities, by nurses and doctors and carers, almost every hospital across the UK has now signed up.

‘Testing Situations’ events with artist Charlie Harrison

Many of you will know Charlie Harrison from his time as resident artist at Created Out of Mind, and we are pleased to let you know that he now has an exciting schedule of events and workshops related to his ‘Testing Situations’ project, touring all over the UK. Here are the details of a few events coming up over the next couple of months:

**JUNE**

**SYL @ #BrainPower: UCL Neuroscience Festival**

**Date:** 22nd June, 11am-5pm  
**Description:** Brain Power will be a whole day of public events showcasing the best of neuroscience at UCL, including interactive stalls, talks, short films, artworks, live demonstrations, storytelling, and workshops. At this event we will be presenting research and artworks looking at artistic gestures in relation to balance and movement produced as part of trials at UCL Whole Body Sensorimotor Laboratory. Single Yellow Lines will also be trialling a new interactive activity for public engagement, inviting visitors to paint single yellow lines in virtual reality.  
**Location:** The Cloisters, University College London, Gower Street, London. WC1E 6BT  
*This event is open to the public, please drop in.*  
(Suitable for 100+ participants)

**JULY**

**Alexandra Palace – Transmitter Hall**

**Date:** 16th July, Time 2pm-4:30pm  
**Description:** Alexandra Palace Charitable Trust is a Grade II listed entertainment and sports venue in London. Thanks to Heritage Lottery Funding, the palace has established a programme of activities that supports people who are living with dementia and their carers. We will be working alongside established dementia groups and networks at Alexandra Palace and in the first session we will be screening the ‘Neva’, a film made in collaboration with members of rare dementia support groups. The screening will be followed by conversation about people’s experiences of cognitive testing and object handling inspired by objects seen in the film (approx. 1hour). Following refreshments, we will invite participants to reflect on testing roles and new research through a series of drawing exercises (approx. 1hour). Drawings produced will form part of an exhibition at Alexandra palace taking place in November.  
**Location:** Transmitter Hall, Alexandra Palace, Alexandra Palace Way, London N22 7AY (Map)  
(Suitable for 20-50 participants)  
*Places are limited, for more information and to register for the event please contact or phone 07824778390. All are welcome to participate or observe but please be aware that some aspects of these sessions may not be suitable for everyone.*
**Unique Cottage Studios, Spalding**

**Date:** 9th & 10th August, 10am-4pm  
**Description:** This will be a two-day drop-in exhibition and event, where visitors to this beautiful rural arts facility will be able to watch and talk about the ‘Neva’, a film made in collaboration with members of rare dementia support groups. Visitors will also be invited to take part in our drawing activities, reflecting on testing roles and new research themes, whilst contributing to conversations about cognitive testing and art.  
**Location:** Unique Cottage Studios, Fulney Ln, Spalding, Lincolnshire PE12 6FA  
*This event is open to the public, please drop in.*  
(Suitable for 100+ participants)

...and there will be many other stops on Charlie’s tour later in the year including Glasgow, Newcastle and Brighton. You can keep up to date with Charlie’s upcoming events [here](#).

**Testing Situations is a research project working with the mechanisms of neurological assessment.** A series of artworks have been created in response to testing materials and archival videos of people undertaking assessments, and the project has initially focused on tests of language, object, spatial and semantic perception developed at UCL Institute of Neurology.

**Rare Dementia Support sign-up postcards**

As some of you will have seen at recent support group meetings, we have had a series of postcards produced which enable people to sign-up to our mailing list and to receive information about our support groups. If you would like to request some of these to give to your GP or consultant so that they can signpost others receiving a rare dementia diagnosis towards us just let Emma know at [emma.harding@ucl.ac.uk](mailto:emma.harding@ucl.ac.uk):
Financial safeguarding app

Knowing that managing finances can become difficult for some people with PCA, we wanted to mention an innovative new mobile and web application which helps to protect the finances of vulnerable adults at risk of online fraud and scamming. **Dr Dexter Penn**, Clinical Research Fellow at the UCL Dementia Research Centre developed the application after observing this problem daily through his clinical practice. Dexter devised a solution which applies neuroscience research and machine learning to detect subtle changes in financial behaviour associated with vulnerability to fraud.

Kalgera – meaning ‘good old-age’ in Ancient Greek – is a mobile and web app that analyses past and present financial behaviour to identify risks and trigger personalised alerts. Users can also nominate trusted family and friends to manage shared financial decision-making without compromising their account details or their ability to move money.

After shaping his idea at a UCL enterprise boot camp, Dexter won the UCL Bright Ideas Award and obtained financial support, mentorship and guidance from UCL Innovation & Enterprise. Dexter has also contributed to discussions around public policy at a round-table meeting at 10 Downing Street and the Cabinet Office and has subsequently been appointed to the NHS England Clinical Entrepreneur Programme, and secured more than £300,000 of additional investment in 2018. Kalgera has formally launched as a subscription service in 2019, and you can find out more here: [https://kalgera.com/](https://kalgera.com/) and Dexter will be joining us at a future support group meeting to demo and answer any questions about the app.
Alex Hudson Crauford ran the Edinburgh Half marathon over the Bank Holiday weekend to support RDS raising over £420 as he would like to raise awareness for PCA.

Joseph Costello-Bromwich has raised a wonderful £2366 for Rare Dementia Support after completing the London Marathon, Joe was running the marathon to support his mother Cecilia who received a diagnosis of PCA at aged 55. Our team of Rare Dementia Support runners raised over £20,000 in total! Huge thank you and congratulations to all of them.

Michelle and Callie Burnley are chopping off their much loved hair on 30th May for RDS – and have raised an amazing £330 so far!

They will also be donating their lovely locks to the Princess Trust who make wigs for cancer patients. Michelle is the carer for her Mum who is living with a diagnosis of PCA. Good Luck to both Michelle and Callie and their new hairstyles!
The Rare Dementia Support Fund at The National Brain Appeal

This fund, held by the charity The National Brain Appeal, raises money to support people with rare, early onset and devastating forms of dementia, and their families, friends and healthcare professionals. The Rare Dementia Support service is organised by the Dementia Research Centre at The National Hospital, and runs specialist support group services for individuals living with, or affected by, a rare dementia diagnosis.

Over the past three years The National Brain Appeal has committed to raise £150,000 per annum for Rare Dementia Support to provide current levels of support for six rare dementias – this includes meetings in London and other regions, support and admin staff and all other associated expenses.

This year we are increasing our fundraising target to £250,000 to develop and extend the service, with the ultimate aim that everyone affected by a form of rare dementia will have access to specialist information and support, as well as contact with other people with a similar condition. For more information, download Rare Dementia Support or find our latest fundraising e-newsletter here.

To make a donation:

- Set up a direct debit
- Make a donation by cheque or bank transfer – call 020 3448 4724 for details
- Go to Justgiving
- You may also wish to consider leaving a gift in your Will – for further information, please see our legacy page.

Keep in touch with us on 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

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.
Until next time...

We look forward to bringing you more of what we hope is useful and interesting content 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 5th July. 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.