January 2018

Dear PCA Support Group Members,

Welcome to the January 2018 edition of the PCA Support Group newsletter. Please accept our apologies that this edition is not quite as glossy as previous versions. We are really sorry about this – as many of you will know we have been going through a period of readjustment over the last few months with lots of changes to our core staff team here. For this edition of the newsletter, we have taken the decision that we should still send some information out to you, even if this is not as much or in the same format as usual – we think there are still some really worthwhile contributions to share with you.

Indeed, some of you will also be aware that we have been having considerable problems with our phone and email systems over the past few months. We are really sorry if you have been affected by this – we strive to offer the highest possible level of support, and we are the first to admit that certain issues with our communications infrastructure have not made this possible recently. Thank you for your patience with all of these frustrating issues. Fortunately, our phones and emails are now working again.

Upcoming support group meetings

Firstly we wanted to let you know the details of the upcoming PCA Support Group Meeting, which will take place on Friday 23rd February 2018. At this meeting, we will hear from clinical and research neuropsychologist Professor Seb Crutch, who will give a clinical overview of PCA including some recent findings from the longitudinal study of PCA carried out at the UCL Dementia Research Centre. Seb will be joined by ophthalmologist Dr Harry Petrushkin who will offer an overview of his work and a short Q & A session.
After lunch there will be the opportunity to break out into smaller groups for more focused discussions and activities. As part of this we will be inviting your further feedback on the Stages of PCA document (which can be found here: http://www.raredementiasupport.org/pca/what-is-pca/stages-of-pca/), welcoming your suggestions for future meeting topics and Seb will lead an open Q & A session.

**Date & Time:** Friday 23rd February 2018, 11:00-14:00 (arrival from 10:30)

**Location:** The Hub, 5th floor, 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)

**RSVP:** To register your place, we kindly ask you to RSVP to Laura King l.king@wellcome.ac.uk by Monday 19th February 2018. This will help us with guest registration and catering provisions for the light sandwich lunch. Please also let us know if you have any special dietary requirements.

For those of you interested in attending our **Joint Carers Support Group Meeting**, which brings together carers/ relatives/ friends of people affected by all five of the rare dementias for which we offer support, this will be held on **Wednesday 2nd May 2018**.

**Date & Time:** Wednesday 2nd May 2018, 11:00-14:00 (arrival from 10:30)

**Location:** 6th Floor, Wellcome Trust, Gibbs Building, 215 Euston Road, London NW1 2BE.

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**Staff updates**

We would also like to take this opportunity to introduce you to Laura King, who some of you will have met at our last PCA support group meeting. Laura
has joined our team as the **Rare Dementia Support Administrator**. Her responsibilities include arranging meetings for all of the support groups that fall under the Rare Dementia Support umbrella. If you would like information about organisation or timings of specific meetings, then please contact Laura at: l.king@wellcome.ac.uk.

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**Member contributions**

Many of you will have read about **Clare and Dave Ashcroft’s** driving and cycling adventures in our last newsletter, and here they share their tales and tips for travelling:

**In general...**

I allow plenty of time (especially in London!), and only aim to do one or two things in a day. We have plenty of stops in quiet coffee shops/gardens etc. Staff in Costa seem to be particularly well trained in being helpful. We try to get a bite to eat every 3 hours, go out-of-season where possible so it's quieter, travel light and try not to go out at night, unless it’s unavoidable.

I make sure Dave has his simple phone ([Doro Easy Phone](https://www.doro.com/uk/en/easyphone/), and that it works in whatever country we are in and that he practises calling me with it.

It works for us to visit tall landmarks, so Dave can recognise them on TV, in films etc. It gives him a sense of achievement. And the views are wonderful!

A [RADAR toilet key](https://www.radar.org.uk/) is very useful.

**Transport:**

We use buses, trains, planes, boats as much as possible – Dave can sit still but watch the sights/scenery go past. Also it’s a rest for me from driving. On holidays we get taxis to meet us at airports/ports to take us to our hotel.
We use a Disabled Rail Card a lot, and book as far ahead as possible. The discount means we can use more conveniently timed trains, get reserved seats and make sure there are no changes if possible.

Using 2 contactless payment cards (1 each) on the underground avoids having to battle with ticket machines.

**Attending Support Group Meetings:**

For PCA meetings (we have been to many and made lots of new friends!) we stay overnight near Euston station (either the President or the Premier Inn) so there is no rush in the morning. When we check out, we leave our bag at the hotel, and collect it on the way to the station.

We use First Class (often no more expensive) when coming back from London to Wigan – the First Class Lounge at Euston is very useful: seats, free drinks & snacks, and relatively quiet and peaceful. We book a table at Prezzo opposite Euston station about 4 hours before our train – we have a slow relaxed meal, then cross over to the First Class lounge to wait for our train – all very relaxed.

**Hotels:**

Wherever we stay, the important things to look for are en suite bathroom, buffet breakfast, twin beds. We leave the bathroom light on all night, if it’s not connected to a fan. We also take a rechargeable, dimmable LED travel lamp everywhere to light bathroom or the way back to bed.
In the last 2 years, some highlights have been:

**Europe**

Going up the Eiffel Tower, and up to the roof of Notre Dame, Paris: 3 night break just after the Bataclan attack, so everywhere was quieter than usual. Was very cold at the top of the Eiffel Tower. Free entry for carer and cared-for to go up to roof of Notre Dame. Went slowly up steps and allowed people to pass. Great to see the gargoyles, and hear the bells.

Climbing the Belfry in Bruges: Challenging, but worth it. Went early in year (March) so not busy. Very narrow uneven spiral stairs, with people going both ways. Could have been disastrous, but lots of small landings so people could pass.

Had a week in the Italian Lakes (with my sister & a friend). Having my sister & friend with us helped a lot – different company for Dave, and a bit of a break for me.

**USA**

Going to the top of the One World Tower in New York: long queue, but then a lift to top, so easy from there. Awful coffee at the top though!

Going on the Queen Mary 2 to New York: brilliant! Excellent buffet food, no time limits for eating, no need to dress up, bracing walks round the deck, talks.
and films if you want them. Buffet has great views of the sea. Formal dining room has very limited views. Arriving in New York at sunrise was amazing. So good we’re doing it again. New York is a lovely city, away from the main busy parts. Walking along Hudson River Bank Park and in Central Park is great – very green, clean, masses of birds & flowers.

UK

Trips to Chester & Edinburgh zoos have been very successful: big animals (elephants, giraffes etc.) were easiest to see. Snakes, frogs etc. in glass tanks were too hard to see.

Going up the Shard and to the top of St. Paul’s Cathedral in London Shard were easy. St. Pauls was a bit tricky – especially the wire mesh spiral steps just before the top. Fantastic view and still worth going up if you don’t do the last bit (the rest is solid stone or wooden steps).

Going to the Farne Islands and seeing lots of puffins. No proper footpaths on Staple Island though and climbing over low rocks was a bit tricky.

Concerts & Cinema

At concerts we make sure we have reserved seat, preferably by a wall so Dave doesn’t have to get up & down to let people pass. I usually get a free carers ticket, so we can afford better seats. His vision is better to the right, so we try to sit at the left side, so he looks right towards the stage.

At cinemas we sit at the back as he doesn’t see the edges of a big screen if it is too close.
Some highlights have been Dave Gilmour in the Albert Hall – we try to sit in the same area of the Albert Hall each time, so it is familiar, and we know where the toilets are. Also meeting Mike Rutherford (ex-Genesis) after a Mike & the Mechanics concert – unplanned, he was next to me at breakfast and came over and introduced himself to Dave – a lovely gentleman, and Dave’s hero! 😊

Some problems have been:

Museums/galleries – labels, glass cases with reflections, and me pointing at things all simply cause frustration. The Pink Floyd exhibition at the V&A was particularly bad with a shiny black floor and swirling psychedelic light effects at the beginning.

Darkness is usually a problem, but the Bat House at Chester Zoo was good – no crowds or rush and Dave enjoyed the feeling of bats flying around us – not for everyone though!
Gardening – Dave has no patience with waiting for things to grow, can’t see well enough to cut the correct stems, and unintentionally stands on plants. He is good at picking up dead leaves though!

*Thanks once again to Clare and Dave for their generosity in sharing their experiences and helpful tips!*

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**Reflecting on 10 years**

Our meeting last November marked the PCA support groups’ 10th anniversary. We asked Di Garfield, one of our Advisory Committee members and co-founder of the Hertfordshire PCA support group, to share the history of how the Rare Dementia Support fund came about.

**The origins of Rare Dementia Support**

In the late 1990s, Prof Nick Fox started a support group for those people living with Frontotemporal Dementia (FTD) - also known as Pick’s Disease. Run from the Dementia Research Centre (DRC) in Queen Square by staff member Penelope Roques (who continued to do so even after her retirement), with donations looked after by the National Brain Appeal. She had assistance one day a week from nurse, Jill Walton.

In 2005, Prof Wise at the Royal Free Hospital diagnosed our mother Myrtle Ellis with Posterior Cortical Atrophy (PCA). In the first cohort of people identified with this rare form of dementia, Mum was advised to join the drug study being run by the DRC as it was the best way to have her condition closely monitored.

In 2007, having raised over £11,000, we set up the Myrtle Ellis Fund (MEF). Designed to support people with PCA and their carers, it was initially run by the staff at the DRC with the first meeting in the National Hospital’s boardroom. As Dad recalls: “There were just six families back then so seeing the numbers of people turning up to meetings now, it’s good to know we helped provide the infrastructure for support work that’s making a difference.”
The money also paid for other support groups, specifically Primary Progressive Aphasia (PPA), familial Frontotemporal Dementia (fFTD) and Familial Alzheimer’s (FAD). However by 2011, it became clear that the task was too big for the staff themselves to handle so, with about two years' of funding in hand, Jill added these groups to her workload.

**The merger**

In 2014, although the FTD fund was doing well, the MEF was struggling financially. Through the PCA support group’s connections, we made a grant application to Sir Terry Pratchett’s Discworld Foundation and £24,000 was generously donated. At the end of the same year and after a successful dementia awareness event where both Funds were represented at the House of Lords, it was decided that the most sensible way forward was to put the two Funds into one - they had almost identical goals and donations for both were looked after by the same charity.

In 2016 the merger was complete with an advisory committee overseeing our governance, communications and how we interact with external organisations and policy makers. The National Brain Appeal continues to provide financial administrative services and now, a fundraising manager.

**Activities**

So here we are celebrating 10 years of support for those living with and affected by PCA - and PPA, fFTD, FTD and FAD! What a long way we’ve come from sitting round a boardroom table to theatre-style seating in large halls with the capability to live-stream over the internet to our global audiences!

It’s no longer just three meetings a year in London; our activities have broadened to include full telephone and email services, a buddying system and support for bereaved families. The database comprises more than 450 people who receive three newsletters a year and various other notifications eg about new research and creative programmes.

Regional meetings are also gaining strength with a co-ordinator appointed to play a vital role for those who would otherwise feel isolated simply on the basis of their geography.
And for our international colleagues, we do our best to assist them in the work they do - both academics studying PCA within their own populations and those who are setting up support services. Where possible, a few of us travel to meet our far-flung friends; there have been gatherings in Australia, Canada, the United States and Europe.

**What next?**

Fundraising is of course the first item on the to-do list. All contributions are deeply appreciated and money can be donated via JustGiving, either directly into our campaign ([https://www.justgiving.com/campaigns/charity/tnba/rare-dementia-support](https://www.justgiving.com/campaigns/charity/tnba/rare-dementia-support)) or by setting up your own page so you can tell your story. Please contact Eva Tait (eva.tait@nhs.net) at the National Brain Appeal for more information.

The regional network is a key focus for 2018 and if you’re interesting in finding out more, please contact Roberta McKee Jackson at: rmckeejackson.rds@gmail.com. She and I run the Hertfordshire group that’s celebrating its third anniversary this spring. We meet once a month for lunch and once a quarter for a more substantial event: speakers, a Christmas tea or park outings. It’s nice to know we can offer something that is relatively straightforward to engage with as we try to choose venues with easy parking and decent food! We both make sure we are reachable by phone and email for anyone to chat through worries or simply to vent frustrations.

So in conclusion, I’m looking forward to a future where early diagnosis results in a better quality of life for longer and of course ultimately a cure. In the meantime, we have each other - a strong network of support based on the needs of the individual. However we can only do what we can with the resources available so watch this space for new support ideas and ways in which you could help!

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**Alzheimer’s Society update**

The Alzheimer’s Society are currently raising awareness of their Fix Dementia Care campaign, here is some further information:
Demand the Government fixes dementia care

Successive Governments have promised to fix our broken social care system, but up and down the country people with dementia are stranded in hospital with nowhere to go. Many more are losing their life savings to pay for basic care.

The Government has promised to lay out their plans to reform the social care system next Summer. As the largest users of social care, we must make sure the needs of people with dementia are included. Without us, they will be forgotten.

It’s time to end this national disgrace.

Will you call on the Government to put in extra funding to fix the social care system once and for all?

You can add your name to the campaign by following this link:

www.alzheimers.org.uk/fixdementiacare
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 bearing with us as we adjust to our new set up. 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 February 23rd. 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.