



# RARE DEMENTIA SUPPORT

April 2018

Dear PCA Support Group Members,

Welcome to the April 2018 edition of the PCA Support Group newsletter. Thank you again for bearing with us through our recent period of readjustment and we hope you will find the content of this newsletter helpful and interesting. If you have any suggestions for topics you would like to see covered in future newsletters or at meetings, please feel free to send them to: [emma.harding@ucl.ac.uk](mailto:emma.harding@ucl.ac.uk)

## Upcoming support group meetings –

### Next PCA Support Group meeting:



The upcoming **PCA Support Group Meeting** will take place on **Friday 22<sup>nd</sup> June 2018**. This meeting will take the format of an all-day conference, jointly organised with Vision UK and UCL. It is open to PCA Support Group members and a range of professionals working with dementia-related visual impairment. There will be a series of 15 minute presentations followed by Q&A sessions on topics including:

- A discussion of the neuropsychology of dementia-related visual impairment (including PCA)

Dementia Research Centre | UCL Institute of Neurology  
8-11 Queen Square | London | WC1N 3BG

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- The social and psychological consequences of dementia-related visual impairment
- Preparing the workforce to recognise and meet the needs of people living with sight loss and dementia
- Awareness and professional focus of Occupational Therapists and Social Care Workers on dementia and sight loss
- Technology and research on dementia and visual impairment

Although the format of this meeting will be different to our usual meetings, there will be break-out space available throughout the day for those of you who would like to take some time out from the formal presentations to have conversations and discussions among yourselves.

**Date & Time:** Friday 22<sup>nd</sup> June, 10:00-16:15 (arrival from 09:30)

**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://wellcomecollection.org/visit-us/getting-here>

**RSVP:** Please note there are 60 spaces available and these will be allocated on a first come, first served basis – please RSVP as soon as possible to secure your space. We also ask you to let us know if you need to cancel your place, in case we are running a waiting list and can offer that space to someone else. To register your place, we kindly ask you to RSVP to Laura King [l.king@wellcome.ac.uk](mailto:l.king@wellcome.ac.uk). This will help us with guest registration and catering provisions. Please also let us know if you have any special dietary requirements.



Association of British Dispensing Opticians



THE COLLEGE OF OPTOMETRISTS



Supporting people with sight loss



Royal College of Nursing



Royal College of General Practitioners

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## Next Joint Carers' Support Group meeting:

**Date & time:** Wednesday 2nd May, 11:00 – 14:00, arrival from 10:30

**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\*\*)

**RSVP:** To register your place, we kindly ask you to RSVP to Laura King [l.king@wellcome.ac.uk](mailto:l.king@wellcome.ac.uk). This will help us with guest registration and catering provisions. Please also let us know if you have any special dietary requirements.

**Directions:** <https://wellcome.ac.uk/about-us/contact-us>

## Next Bereaved Carers' Support Group meeting:

**Date & time:** Thursday 7th June, 10:30 – 12:30

**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 visitor's 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).

**RSVP:** To register your place, we kindly ask you to RSVP to Laura King [l.king@wellcome.ac.uk](mailto:l.king@wellcome.ac.uk). This will help us with guest registration and catering provisions. Please also let us know if you have any special dietary requirements.

**Directions:** <https://wellcomecollection.org/visit-us/getting-here>

## Staff updates

We would also like to take this opportunity to introduce you to **Roberta McKee-Jackson**, who many of you will have met at previous PCA support group meetings – both in London and Hertfordshire. Roberta has been involved with the PCA support group for many years and we are delighted that she – with her wealth of knowledge and experience of both the support groups and the PCA journey - has formally joined our team as **Rare Dementia Support Regional Coordinator**.



Roberta will be supporting our team of Regional Facilitators in their running of support group meetings for all the types of rarer dementias that fall under the Rare Dementia Support umbrella.

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## Member contribution – Nick Fell

Late this Spring PCA support group member **Nick Fell** will be walking the Coast to Coast path to commemorate the life of his late wife Jan, who sadly passed away on the 31<sup>st</sup> January 2018 at the age of just 59 years old.

Nick is fundraising for Rare Dementia Support and has already raised an impressive £2500 towards his £5000 target. If you would like to sponsor Nick please visit:

<https://www.justgiving.com/fundraising/janice-fell>

*Here Nick tells us a bit about Jan and their journey with PCA...*

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## About Jan

Jan was born in Leicester in 1958 and was apparently a strong willed little girl, perhaps a characteristic of her fiery red hair.

She made wonderful life-long friends at both school and university – a group of whom recently got together to plant a tree in Jan’s memory at a Leicestershire Country Park.

Jan was a successful competitive swimmer – becoming Midlands junior champion and ranking 6th in the country at her event – and other sporting interests throughout her life included hockey, netball, running and sub-aqua diving (to name a few!).



Jan initially studied Ecology at Loughborough University before studying for her Master’s degree at Duke’s University in North Carolina, USA. She had an eventful couple of years in the States – she worked a summer in Lake Tahoe and was also arrested for over-taking a school bus...

Jan’s professional life was also rich and varied – she studied, qualified, practiced and also taught in areas including yoga, reflexology and other complimentary therapies.

She met Nick when they were both working for Leicestershire County council and they were married in 1983. Jan took time out of her career to have their two sons, who describe Jan as ‘a dreamer, an adventurer, a believer in people’ who inspired them to ‘get the most out of life, to be kind to people, to study and to listen’.

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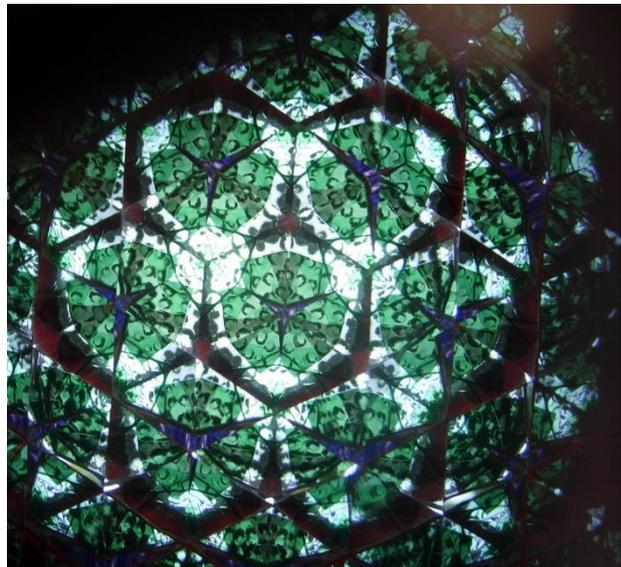
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## Our journey with PCA

### What sorts of things did you first notice?

I think from her early forties Jan felt that something wasn't quite right. Part of her professional career was as a reflexologist and she was very interested in complementary healthcare and spent a lot of her life studying biology and the body. She felt she knew how to live a healthy life and the upsetting thing was that there was something going on in her own body that she didn't understand or couldn't control or do anything about. She'd often say to me that something didn't feel quite right but that she couldn't identify it or describe it or define it to herself or to other people.

She started talking about having difficulty seeing things, especially in harsh sunlight and when there was a lot of moisture on the ground after a rain shower which would reflect the light. We were once canoeing on a canal on what we all thought was a perfect spring day and Jan was at the front and said 'this is really difficult because it's a bright spring day and there's a lot of moisture about – it's like looking down a kaleidoscope'.



Another time she was driving home from work and arrived really upset because it was a wet day at twilight and as she came down the main road and to the traffic junction there were so many neon lights and headlights and wet on the road surface and windscreen that she didn't have a clue what to do or where to go and it totally confused her.

We'd also noticed if we were in the car with Jan if there were cars parked down the side of the road and oncoming traffic she couldn't gauge the

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distance and would put her brakes on to stop the car. She felt there was too much going on in front of her for her to negotiate it.

Another time our son had been helping her with the supermarket shopping because she was having trouble using her cash card and once he'd seen her through the checkout went out to wait in his silver hatchback for her. But Jan came out and got in another silver hatchback because she couldn't recognise the car or tell the difference. It turned out that Jan had taught yoga to the woman whose car she got into so they actually ended up having a twenty-minute chat!

At the time we passed all these things off as absent mindedness – Jan did too – but in hindsight they were very clear examples of the early stages of PCA.

### **Can you tell us about the journey to diagnosis?**

Jan was initially misdiagnosed with encephalitis and was treated for that with steroids. It was only when the steroids didn't improve things that the neurologist went back to the drawing board. Jan had also seen an ophthalmologist because of her visual problems, although nothing was immediately suggested we did see later that PCA had been mentioned as a possibility on the letter from the ophthalmologist back to Jan's neurologist. Jan eventually got a referral to the Cognitive Disorders Clinic on Queen Square and from there the process was very quick, but being met with such uncertainty from different professionals at the beginning was very difficult and unsettling.

Once we had the diagnosis we felt on the one hand thank goodness we now know what it is and a sense of relief about that but then of course you also start thinking about the overall prognosis which isn't good, so we had very mixed feelings at that point.

For me, getting a diagnosis as early as possible would be really important because it means you can make the most of capabilities earlier and do even more and really maximise the time you have. That of course relies in part on greater professional awareness and knowledge of these rarer dementias.

## Is there any advice that you'd give to others based on your own experience of PCA?

For me it was really important as Jan's main carer to have access to information and to read up on PCA to understand what's going on. I think especially early on when vision is mainly being affected it's a really good strategy for a partner to talk to the person with PCA about what they perceive and what they see. Asking them to describe what they are seeing gives you a much better idea of how things seem to them and you can then take that into consideration and adapt your care around it.

Sometimes we'd go for walks and Jan would make comments about the beautiful scenery and I'd say 'describe to me what you can see', or 'there's a windmill on the horizon can you see that?'

And sometimes she could but other times with slightly different light she wouldn't. Once she described what she saw as 'like looking through a broken mirror' and that helped me to understand that the sections of what Jan was seeing were fragmented or distorted.



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## What are some of the most useful pieces of advice you've been given by others?

One really good piece of advice which I think would be helpful for lots of people with different neurological conditions was that we'd need to slow down, a chap said to us 'travel life on the B roads...slow down and take your time and work to your own speed' and that was very useful.

Another was from a consultant nurse who said 'you need to understand that time is limited so you need to make the best of everyday and what you can do in every day' and that was great advice for us and that's the advice I would give to anybody living with PCA. Of course everyone's different, but Jan was quite an emotional person and found it very difficult at first when she contemplated the prognosis. So I sat down with Jan and said 'let's make the best of the time that is available to us and let's do what you can do and what you can enjoy. We need to minimise the sad time and maximise the happy time in our lives' and from that point onwards that's how we dealt with it. We didn't talk much about the illness, we focused on the things which brought joy to our lives and Jan loved walking and the dog and so we did that every day.

There are some lovely places around where we live to walk, places with nice flat stone paths with no obstacles which is really important. Places with uneven ground and lots of stairs would exhaust Jan very quickly but if it was a place that she knew had a flat path and no obstacles she could walk confidently and enjoy it much more. Also, Jan's granddaughter was born nearly 2 years before she passed away so she got a lot of joy out of that and we still went on holiday to places we loved when we could and my sister would come with us and housekeep and give me a little bit of a break too. There was lots of music too, Jan loved music and I always tried to create little milestones of things to look forward to, whether that was a new album of a favourite artist coming out, friends coming over for food and a glass of wine or visits from family members. It's really just about as much as you can, filling your life with the things that bring you joy.

## Alzheimer's Society update – Sharing your story

Would you like to share your experiences?



By talking about what you've been going through, you can help Alzheimer's Society tell powerful stories that engage hearts and minds and ensure all types of dementia are a public and political health priority. Whether you are living with posterior cortical atrophy or caring for someone with the condition we'd love to hear from you. By raising awareness, experiences like yours can change attitudes, challenge stigma and help fund vital research.

If you'd like to find out more please contact us at: [stories@alzheimers.org.uk](mailto:stories@alzheimers.org.uk)

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## Created Out of Mind update – short film

**'Do I see what you see?' A film about dementia, disconnection and seeing the world differently**

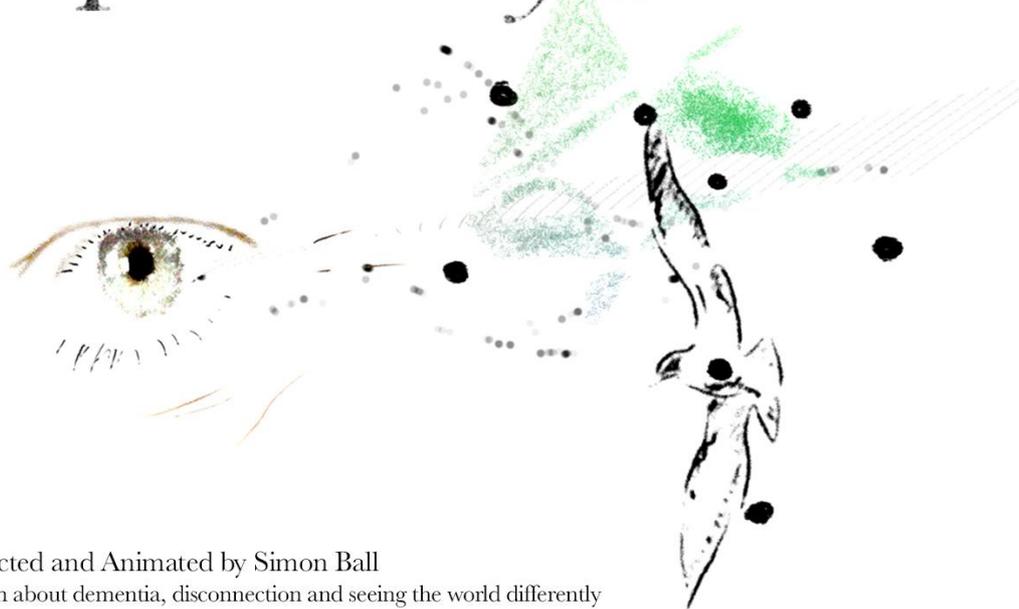
'Do I see what you see?' is a short, animated film directed by Simon Ball for Created Out of Mind, developed in partnership with Alzheimer's Society and supported by Wellcome.

The film asks 'How do changes in the brain cause us to see differently?' and offers viewers the opportunity to experience the world through the eyes of people living with PCA.

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# Do I See What you See ?



Directed and Animated by Simon Ball  
A film about dementia, disconnection and seeing the world differently

"It's very hard to describe what somebody sees to somebody else. We might all see this differently, but we would assume we all see it the same. But I can't say "What do you see" because you're going to look at me and say "Well I see what you see" aren't you? It's such an amazing thing"

The film features 6 personal stories from people living with PCA and their family members and recreates what it feels like to live with the knowledge that your brain might be playing tricks on you and that you are seeing differently from everyone else. Everyday tasks such as making a cup of tea, reading, driving and walking down stairs are beset with obstacles, but their stories also force those watching to question their own perceptions and whether we are all truly seeing the world around us the way others do.

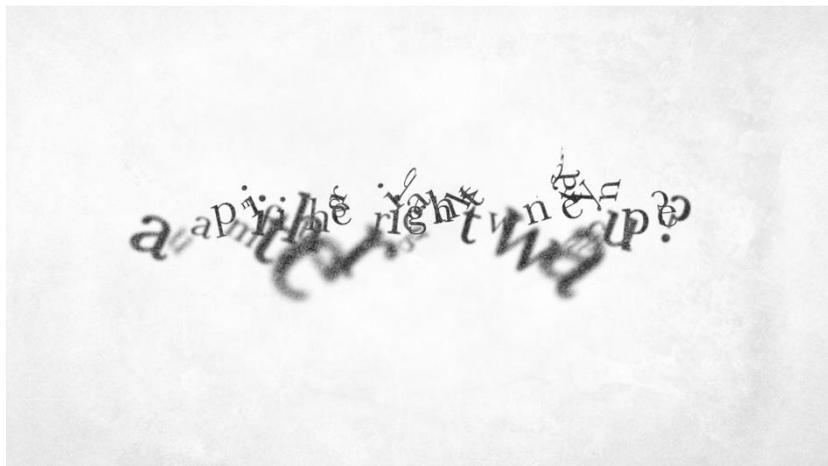
It all started when filmmaker and animator Simon Ball met with Created Out of Mind Director and UCL neuropsychologist Sebastian Crutch. Seb talked about some of the experiences of people with PCA and Simon realised he could use his skills to give these unheard voices a platform. He worked with Seb to construct multiple stories, bringing to life these lesser-known experiences of dementia.

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On his inspiration for the film, Simon said: "When I met Seb and he began describing the various symptoms of PCA to me, I felt that the specific experiences described related strongly to my interests in everyday spaces, such as the home or the high street; how when we look at these places differently, they can in a sense become new worlds and offer new experiences. The whole process exposed me to new subjects, such as medical and scientific research, affected individuals and families and of the uncertainty of the brain. It was of great satisfaction to me that all of the participants felt that it helped them and others to understand the condition better".



You can watch the film here: <http://www.createdoutofmind.org/stories-and-reflections/do-i-see-what-you-see>

...and please feel free to share the link among your networks!

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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 June 22<sup>nd</sup>. 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.

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