PCA Support Group Meeting – Friday 19th October 2018

Video recording of the main talk and open discussion available at the Rare Dementia Support YouTube channel here: https://www.youtube.com/channel/UCuVA3iffOcwz04qBkjZgKqg

Speaker – Lori Hayden:
Arts4Dementia Trustee & former full-time carer

Notes by Millie van der Byl Williams

- Precious and surprising that arts played such a part in their lives
- John loved music, read and wrote – but did not sing dance or draw
- Started by attending singing for the brain – loved it (https://www.alzheimers.org.uk/get-support/your-support-services/singing-for-the-brain)
  - Started singing at home after attending these groups
- Other activities included
  - Sensory sessions at Hampton court palace (https://www.hrp.org.uk/hampton-court-palace/explore/sensory-palaces/#gs.bJQPLW4)
  - Ballet lessons (http://www.rambert.org.uk/join-in/adults/dance-for-dementia/)
  - Pottery lessons
  - Music for life (https://wigmore-hall.org.uk/learning/music-for-life)
  - Positive spin – cycling for PEOPLE LIVING WITH DEMENTIA
  - Concerts: Discounts for carers and people with dementia – Royal Opera house: Carers ticket is free and other ticket is half price, Albert hall: carer’s ticket free
- Learnt about these projects through sharing information with others
- Taking part in the arts was something that could be done as a couple
- Sense of community
- Gave John a sense of control, he could be himself, connect with others
- John Gregory Williamson memorial award – given to project in London borough for outstanding contribution to arts and dementia – nominations now open! (more details: https://arts4dementia.org.uk/2018/10/john-gregory-williamson-memorial-award/)
- Learning to live in the moment

Main group discussion:
Facilitated by Seb Crutch & Emma Harding

Notes by Millie van der Byl Williams
Sport

Question: Father had to give up golf when he had PCA, difficult to find a sport that he could do.

Golf in Society run dementia-friendly golfing sessions: https://golfsociety.com/

...and you can read this blog post about them: https://www.alzheimers.org.uk/blog/dementia-friendly-golf-sessions-bring-fun-fore and contact their Programme Partnerships Officer Steven McFadyen at the bottom of the page if you are interested in setting up a dementia –friendly sport or activity

Another support group member has a similar problem and uses tennis ball, throwing it in the air to recalibrate hand eye co-ordination

Rehabilitation officer for visual impairment (ROVI): signpost people to sporting organisations (metro blind sports) – there is the blind golf association, tandem riding... (https://www.metroblindsport.org/)

Seb: sports that involve balls that are still more difficult but often things that are moving are easier to see and perceive – lots of people don’t try this but counter intuitively it may work

From Kent – the Alzheimer’s Society has link up with local sport centre and there are volunteers that help – may be worth looking at local area

Regular rower – rowing clubs now geared up to take visually impaired rowers

Cycling – have a trike which is modified (three wheels)

Oxford – people go out and take you to parks, a lot of people use this for cycling

Tandem bike riding – charity in Coventry (can get envious of everything available in London!)

Centre in the Berkshire area where they do adapted activities for people with co-ordination difficulties (https://wokinghamwatersidecentre.com/), canoeing

Hertfordshire – sailing club, have a day where they take people out onto lake for an hour (have hoists etc) – check with local sailing clubs, lots may offer this

South Gloucestershire – sport centre, every Monday, Yate leisure centre: Mike Jones runs this and is interested in rolling out this programme – so get in touch if interested about badminton and table tennis (https://www.activecentres.org/centres/yate/)

Theatre

Theatre and opera – Theatre was great but access difficult – walking along row, so now need an aisle seat. Is there an organisation that can help with getting access? Baring Foundation (https://baringfoundation.org.uk/) and Alzheimer’s Society did produce suggestions of accessible arts

ATG Ambassador theatre card, can register as a carer and get concessions (https://www.atgtickets.com/access/access-scheme/)

Arts groups
YoYo – group in north London, mostly in Crouch End, set up by carers, been running for 4/5 years, info online north London dementia support, runs every week, each month different activities. Not specifically for PCA but number of people in the group have PCA. Currently looking for new people to join (http://dementiapathfinders.org/north-london-young-onset-dementia-support-group.html)

Opportunities may not be designed for people with PCA but good to share ones that do work for people with PCA.

Alzheimer’s Society groups – may be starting to hand these over to other voluntary groups

Singing and music therapy group – find that PEOPLE LIVING WITH DEMENTIA can often sing, “everybody can do something” important to go and meet people and have fun. People enjoy it! Music is the best medicine!

Arts4Dementia’s website has a lot of information on it, do amazing activities e.g. taking people on canal boats with an opera singer! Have a look because they also try to list a lot of things (https://arts4dementia.org.uk/events/)

People enjoy being in garden and watching birds – using bird tables

General
Alzheimer’s Society connect system – can put in postcode and check what’s available in your local area (https://www.alzheimers.org.uk/find-support-near-you)

Alzheimer’s Society Dementia Advisor network, in the process of starting to work with them so they can be trained to work with people with rare dementias – improve access and awareness

Also Dementia Connect service can link you up with relevant local support and information but service is patchy as not all localities covered (at time of writing Alzheimer’s Society advise ‘This new service is being piloted in East Lancashire, Blackburn with Darwen, Birmingham and Solihull, and from October 2018, it will be available throughout Wales. You will need to live in these areas to use this service. If you live outside of these areas, you can still talk to one of our expert helpline advisers on 0300 222 1122.’): (https://www.alzheimers.org.uk/local-dementia-connect) this also includes the Side by Side service:
How to help people to understand PCA

Support group member’s wife entered nursing home recently not specifically for PEOPLE LIVING WITH DEMENTIA, initially let carers get on with it. She was just in chair very isolated. Nursing staff were ignorant of PCA, how can we get them to understand this condition? Emma sent leaflets and cards to distribute among care staff. Ran training session with Simon Ball’s film (http://www.createdoutofmind.org/stories-and-reflections/do-i-see-what-you-see). Try to promulgate the fact this condition exists

Rehabilitation officer for visual impairment (ROVI) – although not a sight problem but a rehab officer can help with educating staff and equipment in care homes. Making staff aware of issues. Most areas will have rehab officers in the area, they should be able to give advice and information or take on case and work with the home. They can help so you are not having to think of all these things yourself

Someone had a rehab officer come and help but he didn’t know what PCA was – still a lot of education needed

Another had a visit from rehab officer, gave him all the details about PCA, studied them and has been very helpful since he studied this information

Finding accessible ways to introduce professionals to this condition is very important

‘Adapting Activities’ small group discussion I:
Facilitated by Keir Yong
Notes by Millie van der Byl Williams

Activities that are more difficult:

- Walking – difficult to do hiking now on rough terrain, have to take things more slowly. But using forestry commission tracks is good – made for vehicles. These tracks are much more accessible.
  - Regular benches also make a difference
  - No steps without handrails
  - No bridges without sides
  - No boulders in the way
- Going down stairs – can be difficult, useful workarounds include:
  - Tapping step with foot
- Handrails give you a sense of security – you don’t need to see! If the steps are equal then its fine but unequal steps are much more difficult
- Just using one handrail can work
- Wearing steel toe shoes makes a huge difference to avoid stubbing toe on things

- Disorientation – difficulty going shopping on own, even in quite familiar places it can be confusing
  - Even quite simple things like lots of toilet cubicles can become confusing

- Difficulties with clothes and dressing
  - Putting clothes on the bed first can be helpful – developing systems
  - Using linings in clothes and also handbags
  - Changing from fastening items to pull on items of clothes
  - Mirrors in changing rooms can also make things confusing

- Disabled toilets were very useful
  - Can get very confusing with latches in cubicle loos
  - Can be a real fear
  - Difficulty with loos on planes with door locks and lights
  - Not being able to find the flush on the toilet
    - Some couples installed a movement sensor so they didn’t have to flush
  - RADAR key – can get these from the website and you can access disabled toilets anywhere (https://www.radarkey.org/)
  - Roommate – working on technology that will describe the layout of the disabled toilets (https://www.adiaccess.co.uk/find-a-roommate)

- Some people once diagnosed with PCA have been put in visually impaired ‘box’ but the things designed for people who are visually impaired are not very good for people with PCA
  - Especially things related to spatial awareness and short term memory
  - Perhaps there may be more opportunities by getting both sides to work together
  - How the advice is given in regards to the tools out there

- Using a cane
  - People find it really helpful
  - Sweeping technique – people get out of the way!
  - Using one with the ball on the end (https://shop.rnib.org.uk/catalogsearch/result/?q=ball+cane) – makes a noise when it rolls along and tells other people that you can’t see, makes you feel more confident
  - Cane can be useful on stairs as well
  - Takes a while to get used to
  - Short one – mixed success, sometimes people don’t notice it (https://shop.rnib.org.uk/mobility/canes/symbol-can.html)
  - Londoners can be more switched on to people with disabilities (more than at home) – training for priority seating?
Can we get a dementia friendly badge? Something to be identified by. Can buy a badge online saying ‘please be patient I have dementia’, made a difference (https://www.zazzle.co.uk/i_have_dementia_forget_me_not_support_button_badge-145754320420871269)

Gatwick airport have a hidden disability help desk – very helpful (https://www.gatwickairport.com/at-the-airport/passenger-services/special-assistance/hidden-disabilities/)

Can use the dial a ride service if you have a visual impairment (https://tfl.gov.uk/modes/dial-a-ride/)
  - Can also ask for assistance at train stations – Tubes and trains

Difficulties in getting certificate on visual impairment – hopefully should be improving

Arts activities
  - Using adapted brushes or sponges
  - Using pastels (larger and more contact with paper) on big sheets of paper

Couldn’t cycle anymore so bought a really good indoor bike so can still ride - good to be able to do something independently
  - British cycling have disabled cycling club (https://www.britishcycling.org.uk/disabilityhubs?c=EN)

Continuing playing music
  - Piano and organ
  - Tremor medication for parkinsonian symptoms has helped co-ordination to be able to play more

Age UK COGs Clubs (cognitive stimulation): https://www.ageuk.org.uk/dacorum/our-services/cogs-club/
• Singing for the brain groups – really stimulating, the music making was really engaging and there were lots of tactile objects to work with
• Seated yoga – offered by care homes
• Swimming classes for people with dementia offered by some local pools
• Quiet shopping hours – are these useful?
  o Good idea – crowds can be overwhelming
  o Difficulties with promotions, moving everything around in the supermarket
• Fear of escalators quite common
  o Ask for assistance they may be able to stop it so you can walk up it
  o Amount of visual movement on escalators can be confusing
• Mobile phones
  o Doro can be good
  o Alexa is also useful
  o Apple earphones can also be good

‘Adapting Activities’ small group discussion II:
Facilitated by Lori Hayden & Emma Harding
Notes by Emma Harding

Recommendations for aids and adaptations
The following online shops were recommended as sources of some useful aids and adaptations:

• Unforgettable: https://www.unforgettable.org/ or 0203 322 9070

• Complete Care Shop: https://www.completecareshop.co.uk/ or 03330 160 000

• Co-op Mobility online shop: https://www.co-opmobility.co.uk/ or 0800 622 6001
In response to comment about microwave buttons being difficult to manage, one suggestion was the **RNIB PenFriend audio labeller**:

![Image of RNIB PenFriend audio labeller](https://shop.rnib.org.uk/new-rnib-penfriend2-voice-recorder-labeller.html)


...and you can see a video of it in action here: [https://youtu.be/VXqBZvLfiLY](https://youtu.be/VXqBZvLfiLY)

It was also recommended for labelling CDs.

A **talking watch** was mentioned as helpful. Lots priced around £30 on Google Shopping pages, link here: [https://www.google.co.uk/search?rlz=1C1CHBF_en-GBGB806GB806&biw=1707&bih=838&tbm=shop&ei=TFfMW532AsnOgAaD94PlDQ&q=talking+watch&oq=talking+watch&gs_l=psy-ab.3..0j7.972.1584.0.1893.2.2.0.0.0.0.163.246.1j1.2.0....0...1c.1.64.psy-ab..0.2.243....0.jmtEIKETYWg](https://www.google.co.uk/search?rlz=1C1CHBF_en-GBGB806GB806&biw=1707&bih=838&tbm=shop&ei=TFfMW532AsnOgAaD94PlDQ&q=talking+watch&oq=talking+watch&gs_l=psy-ab.3..0j7.972.1584.0.1893.2.2.0.0.0.0.163.246.1j1.2.0....0...1c.1.64.psy-ab..0.2.243....0.jmtEIKETYWg)


...and there are some cheaper available on Amazon and not just watches but also clocks, touch buttons etc., available here: [https://www.amazon.co.uk/s?ie=UTF8&me=A39FNVZGDMJPMW&page=1](https://www.amazon.co.uk/s?ie=UTF8&me=A39FNVZGDMJPMW&page=1)
Sensor lights were mentioned to guide the way down a hallway/to the bathroom/etc., and in particular these strips of sensor lights which can be easily packed when going on holiday:

...these ones are battery powered and approx. £12 [https://www.amazon.co.uk/Auraglow-Wireless-Battery-Powered-Wardrobe/dp/B01N0DSDSR](https://www.amazon.co.uk/Auraglow-Wireless-Battery-Powered-Wardrobe/dp/B01N0DSDSR)

...and these rechargeable, also approx. £12: [https://www.amazon.co.uk/Rechargeable-Wardrobe-LUXJET-Flexible-Warmwhite/dp/B07B4VZWKM/ref=sr_1_4?ie=UTF8&qid=1540060080&sr=8-4&keywords=rechargeable+motion+sensor+led+strip+light](https://www.amazon.co.uk/Rechargeable-Wardrobe-LUXJET-Flexible-Warmwhite/dp/B07B4VZWKM/ref=sr_1_4?ie=UTF8&qid=1540060080&sr=8-4&keywords=rechargeable+motion+sensor+led+strip+light)

Glow in the dark stickers to help with finding light switches at night were also mentioned, these are under £3:
These brightly coloured self-adhesive **tactile markers** were recommended for highlighted important or most used buttons on appliances and are also very affordable (approx. £2 for a pack of 10):

![Tactile markers](https://www.amazon.co.uk/LIGHT-SWITCH-STICKERS-Luminescent-Labels/dp/B00TCKPCES)

An easy to use **photo-phone** with photos of faces of saved speed-dial numbers on the buttons was recommended and is available from the Complete Care Shop website here:

![Photo phone](https://www.amazon.co.uk/Tactile-Markers-Coloured-Adhesive-Partially/dp/B00EY6JHT6/ref=sr_1_1?crid=1540118653&ie=UTF8&qid=1540118653&sr=1-1&keywords=tactile+markers)

![Photo phone](https://www.completecareshop.co.uk/household-aids/cordless-phones/photodect-big-button-cordless-photophone-view-large?gclid=CjwKCAjwpKveBRAwEiwAo4Pqm0MVDIRkicpL5A9BmwS3sQmaPafpeGp1N56N68PJsj9l07SQjKqZ-ARoCTWgQAvD_BwE)
iPhone’s Siri was mentioned for voice-calling:

https://support.apple.com/en-gb/HT204389

...as was the Amazon Echo (providing the person you’re calling also has one). The Amazon Echo was also recommended for: asking about the weather, time and date, adding items to a shopping list, quizzes. Different items in the range cost from £49.99 - £139.99 and they are available here:

https://www.amazon.co.uk/s/ref=nb_sb_noss?url=search-alias%3Damazon-devices&field-keywords=echo
Doro was mentioned as a manufacturer of simple phones (prices ranging from £28-£130), and they now also have a range of smart phones (e.g. for syncing up with the Amazon Echo app above) and prices for those are closer to £200: https://www.doro.co.uk/mobile-devices/smart-phones.html

**Travelling and using public transport**

People spoke about how helpful a Blue Badge is, and there’s more information about applying for one here: https://www.gov.uk/apply-blue-badge

We also have some specific guidance on applying for a Blue Badge with a diagnosis of PCA – please contact emma.harding@ucl.ac.uk if you would like more information on this, although this may now hopefully be less difficult following the recent update to the eligibility criteria which has now been extended to people with hidden disabilities (like dementia), and there is more information about that change here: https://www.alzheimers.org.uk/news/2018-07-29/people-hidden-disabilities-benefit-blue-badges

We heard about mixed experiences of having requested passenger assistance when travelling. This needs to be booked in advance (at least 48 hours) and there is some more information about how to organize this from the UK Civil Aviation Authority here: https://www.caa.co.uk/Passengers/PRM/Arranging-special-assistance/

Customs was mentioned as an especially difficult part of airport journeys and one couple were directed to a quiet route once they asked for assistance. Another group member mentioned that he tells airport staff at customs about his wife’s visual impairment at the electronic passport gates so they can be taken to a manual gate.
There was consensus in the group that it can be difficult to get assistance because often it is not immediately obvious there is a need, as it might be with a severe physical disability for example. If you would like to request a PCA ID card to quickly explain your diagnosis and possible needs to others, just let Emma know at emma.harding@ucl.ac.uk, they look like this:

![PCA ID card image]

Members also mentioned some difficulties in navigating public transport, particularly escalators. There is more information about how to get assistance when travelling using public transport in London on the TfL website here: https://tfl.gov.uk/transport-accessibility/help-from-staff
The **Taxicard** scheme was mentioned, which allows people with severe visual impairments to book Com Cabs in London at subsidised rates, there is more information here:

[https://www.londoncouncils.gov.uk/services/taxicard](https://www.londoncouncils.gov.uk/services/taxicard)

...including information about people accompanying you, the way the subsidised rate is calculated and more.

Another member mentioned **Mobility Exemption Pass** for the M6 toll which they use regularly and suggested there might be similar exemption arrangements for other toll roads and the Blue Badge Company has details on a number of major toll road exemptions here:

[https://www.bluebadgecompany.co.uk/bridges-and-tolls](https://www.bluebadgecompany.co.uk/bridges-and-tolls)
Reaching and/or coordination difficulties in different parts of the home and strategies

At home:
- High shelves can be difficult to reach for some, as can certain areas in space e.g. the left hand side.

Glass
- Glasses were quite difficult for many members, people described pouring into a glass that’s up the wrong way and not realising, reaching for other’s glasses instead of one’s own. This was mentioned with food too – reaching too far into space as if seeing the food on a further away plate more clearly than the food on one’s own plate.

Mealtimes
- Placing a cup back on a saucer was mentioned as tricky, and someone described using the spoon as a guide.

- Cutting food was mentioned as a potential problem, with someone mentioning cutting a steak until it moved off of the plate. Some people preferred to use only a spoon, and a clip on lipped edge for a plate was mentioned by a couple of group members like this one:

![Image of a plate with a lip]

Which is about £2 from the Co-op Mobility shop here: [https://www.co-opmobility.co.uk/in-the-home/dining/plate-surrounds/p/incurve-plate-surround?gclid=CjwKCAjwx7DeBRBJEiwA9MeX_LrxmyvX9IS74CpV2j07dfuuz9qKpob-PdnaVsazLmTxNUfrxnn-SBoCpuMQAvD_BwE](https://www.co-opmobility.co.uk/in-the-home/dining/plate-surrounds/p/incurve-plate-surround?gclid=CjwKCAjwx7DeBRBJEiwA9MeX_LrxmyvX9IS74CpV2j07dfuuz9qKpob-PdnaVsazLmTxNUfrxnn-SBoCpuMQAvD_BwE)
- Someone mentioned looking for a **bowl** which curves inwards at the top to help with spillages when eating soup etc., and there is this available for £4.95 on the Complete Care shop, but it is only lipped on one side:

![Image of a bowl](image)

...and it can be found here on the website: [https://www.completecareshop.co.uk/eating-aids/bowls/large-scoop-bowl](https://www.completecareshop.co.uk/eating-aids/bowls/large-scoop-bowl)

**Mobility**
- Someone had found a **lever for helping with getting in and out of bed** helpful and the Complete Care shop has a few here to suit a range of budgets:
  
  [https://www.completecareshop.co.uk/beds-and-bedding/bed-grab-rails/](https://www.completecareshop.co.uk/beds-and-bedding/bed-grab-rails/)
Out and about in public places:

- People described not feeling sure that their feet were in the right place on the ground when walking, especially when in the dark, or when floor surfaces colours changed quickly (e.g. with a mat or shadows), and on reflective floors. People described seeing puddles or shadows as holes in the ground.

- Going downstairs or escalators was described as being more difficult that going up.

- Glass doors/windows such as those in the doors on tube carriages had also caused some problems for some members.

- Several people had found value in using a white symbol cane to let others know of their visual problems when out and about, particularly foldable ones which can be used at a number of lengths. The RNIB shop has a selection for about £12: https://shop.rnib.org.uk/mobility/canes/symbol-can.html

- The locks on public toilets could also be challenging and a number of members had purchased RADAR keys which allow independent access to accessible toilets all over the UK, here’s an example, it’s £4.50 including deliver: https://www.disabilityrightsuk.org/shop/official-and-only-genuine-radark-e.html
The Life360 app is available for iPhone and Android phones and uses GPS to allow family members to locate and communicate with each other, and you can read more about it and watch a demo here: https://www.life360.com/

**Finding out about different activities**

- Not always having the time to look these up (often easier if you are approached about things than having to search for them independently)
- Attending groups like the PCA support group and others can be a useful place for swapping details of recommended activities
- Endorsement by other group members/word of mouth recommendations from others with PCA is really valued

**The purpose of taking up different activities**

- For some it was most important to find things to do that are enjoyable and allowed them to meet and connect with others in a similar situation
- For some this is about distraction and being occupied; arts activities like singing and music groups were mentioned as especially helpful for this
- Others expressed a want to do something useful/practical/productive/hands on rather than just filling time
- We discussed the fact that often by attending groups/activities (arts or otherwise) you can be really useful/helpful for other members of that group by providing support and reassurance and an understanding ear
- Taking part in research was another activity people described as feeling purposeful and meaningful

**Organisations:**

One member mentioned finding the community charity Jewish Care very helpful for connecting her up with a social worker and occupational therapist: https://www.jewishcare.org/
Thank you everyone for your input!

Please send any additional comments, questions or suggestions to emma.harding@ucl.ac.uk

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.