

Dear Support Group members,

It was great to see you at our recent Carers support group meeting in London on the 19th November and thank you all for your input into the discussions throughout the day. We are aware that it's not possible for all of you to physically get to the London meetings and are keen to find ways we can document and disseminate the content to those of you who were not able to be there on the day. Below a brief summary of topics from the small group discussions.

[PCA small group discussion](#)

Avoidance of boredom is a real challenge!

Assistive technology

[White cane](#) very useful

[RNIB PenFriend](#) also good for labelling items but only useful for a certain amount of time because eventually finding the 'on' button and placing the device on the relevant object becomes difficult

[Amazon Echo](#) very useful for voice-calling, calendar, etc.

One starting point that was recommended for getting going with classical music was [Gareth Malone's Guide to Classical Music](#) which has suggested listening to request at the end of each chapter – so far there's only one piece that Alexa can't find!

Voice activation software [Siri](#) on Apple iPhone or [Cortana](#) for Android phones to make calls/write and read texts/emails

[Microsoft accessibility](#) features incorporate a lot of similar features to ReadClear and others, find slides from Hector Minto's talk at the 22nd June Dementia and Sight Loss conference here:

<https://www.visionuk.org.uk/presentations-from-the-vision-uk-university-college-london-ucl-and-vision-uk-dementia-and-sight-loss-conference/>

TV

Most people found following serials on TV OK, and it was mentioned that the motion can help, as opposed to looking at still images/photographs etc.

Details on how to set up Audio Description on your TV are available here:

<https://www.rnib.org.uk/information-everyday-living-home-and-leisure-television-radio-and-film/audio-description>

Simplified TV remote: [Flipper](#)

Voice-activated: can use Amazon Alexa to change channels and volume etc. if you have a Smart TV but looks as though this [Amazon Alexa voice remote + firestick combo](#) can be used with any TV with a HDMI port

Reading

[ReadClear application](#) developed by Dementia Research Centre colleagues which has numerous adjustable display settings and tackles PCA-specific difficulties including gaze stability, gaze direction and trouble seeing letters which are cluttered (available for Android devices)

Audio books - vary in popularity! Those read by actors e.g. available via [Audible](#) are much more enjoyable than programmed software that just reads text aloud very monotone. One suggestion was to

listen to radio plays on [BBC iPlayer](#) as different characters are voiced by different actors and can be more easily followed. Short stories may be more easily retained and followed than longer volumes that need to be listened to over a long period.

[Large print books](#) from the library worked for some but larger fonts make reading harder for others

Physical activity

Hampton Court offers assisted cycling as do Haringey Council (have done for North London YoYo group – see below) and [Companion Cycling](#) in Bushy Park

People had mixed experiences with Pilates – useful but all down to the instructor and their understanding of and sensitivity to PCA

Tracking apps to allow carers to view their family member's location when out walking e.g. [Find my Friends](#) and [Life 360](#)

Being able to maintain independence by continuing to go walking independently was identified as a priority by a few in the group

Difficulty of knowing when to stop someone doing something independently/when it's no longer safe

Laptop usage

[Cortana](#) voice recognition and voice assisted software for Microsoft

[Dragon speech recognition software](#) for computers – comes highly recommended by group for doing all sorts such as reading emails out, replying, coping text, etc.

Touch screen laptop may be more helpful for people struggling to operate a mouse so long as desktop is kept clean and simple

Where would you go to get advice on these products and their set up? RNIB, John Lewis were mentioned

Organisations & professionals

[Rehabilitation Officers for Visual Impairment](#) (ROVIs)

[Young Dementia UK](#) (Oxford group in particular mentioned as very helpful)

People had mixed experiences with attending support groups for people with sight loss (rather than dementia)

Isolation and loneliness can be a real issue and concern when a person with PCA lives alone – consider local organisations which offer befriending (e.g. <https://www.unforgettable.org/blog/youve-got-a-friend-dementia-befriending-schemes-and-support-groups/>)

Value of support groups like Rare Dementia Support and knowing you're not the only ones dealing with the condition

Really beneficial when these meetings spark more local regular meet ups and you can find yourself with a support network you can do regular activities with people you feel comfortable and understood by and with; the mix of medical professionals, researchers and other families affected is a real strength of the London RDS meetings

[YoYo young onset dementia group](#) – meets weekly and have tried all sorts of activities from cycling to Pilates and Otago strength and balance training – see the [patient manual](#) from the University of Birmingham and this scholarly [article](#) about health benefits.

Keir mentioned Janet Carter's development of a psychiatrist-led care pathway for younger onset and rarer dementias and there are more details here: <https://www.rcpsych.ac.uk/pdf/Janet%20Carter.pdf>

Raising awareness among different professional groups so important – prevent misdiagnosis (e.g. of anxiety), opticians are a key group to raise awareness among
How RDS can reach different audiences and those being missed (either with regards to diagnosis and assessment or support)

[Facebook group](#) very helpful for most but can be difficult to read posts from others further along in their journey with PCA especially when posts aren't marked as 'SENSITIVE' – some smaller breakout groups now such as just for carers/children of those with PCA

Dementia-friendly cinema screenings are offered in some cinemas (e.g.

https://arts4dementia.org.uk/?post_type=event&p=2683) – check your local area/cinema

[U3A \(University of the Third Age\)](#) singing and current affairs groups were mentioned (but they offer a whole host of other things and you can search by local area

The condition

First symptoms can be so variable – for some literacy and numeracy rather than visual

Knowing the underlying pathology causing the PCA can be very helpful in terms of understanding symptoms and progression (e.g. hallucinations more common earlier on in people whose PCA is caused by dementia with Lewy bodies rather than Alzheimer's disease) and for medication purposes

Legal and financial

People with PCA often have difficulty managing cash and coins and working out financial sums

Ask your bank – varies considerably in how and what they can do to help

Think about a pre-paid card or placing a limit on what can be withdrawn per day

With a [Monzo](#) card you can top it up and freeze it remotely using an app

Spam phone calls were a worry

Important to have Lasting Power of Attorney (LPA) set up as soon as possible even if it isn't registered for some time

The [Office of the Public Guardianship's](#) (OPG) helpline is really helpful for a range of queries:

Office of the Public Guardianship

Archway Tower

2 Junction Road

London

N19 5SZ

Tel: 0300 4560300

Text phone: 0207 664 7755

E-mail: customerservices@publicguardian.gsi.gov.uk

Website: www.publicguardian.gov.uk

Online and phone support for LPA completion is really helpful

Deciding whether to make it take immediate effect or in the event of a loss of capacity (latter can be complicated because of determining when this is – legally it's black and white but people's experiences aren't that clear-cut and there can be disagreements between family members and professional bodies).

Is also worth bearing in mind that there can be a 6-8 week wait to hear from the OPG sometimes which can cause difficulties if there is a time-critical decision to be made

Important to think about who to register for it – some people had registered only younger generations (sons/daughters) but this had sometimes been problematic when their parents had a joint account, and

others had only registered their spouses which had occasionally proven tricky because they may be more likely to also fall ill.

Becoming a deputy for someone was also discussed – this can be done once someone lacks capacity i.e. if an LPA wasn't in place before they lost capacity. In this case you as deputy remain answerable to the Court of Protection and there were opinions shared that the application for this can be quite intrusive and the ongoing filing of accounts required is very detailed and time-consuming.

PPA small group discussion

- **Progression of the disease** -- stages document mentioned and those who have lapsed from the mailing list will sign up again so they receive future mailings and can provide input to stages document.
- **Genetic testing** -- this topic launched a big discussion on why PPA is separate from FTD and why we do not just refer to the FTD group as bvFTD or combine them into one group.
- **Coping in social situations** -- relevant to how to advise others of PLWD's condition and what to expect; as difficulties progress and memory may be impaired, it is OK to go along with their questions/moods/concern by telling little white lies if necessary. Also discussed reverse progression of the PLWD -- becoming more child-like and requiring total care.
- **Understanding of PPA** -- this was mostly directed at the individual with the diagnosis of PPA; what to tell them if anything, what is their level of understanding. Discussion also includes benefits and services available and the inconsistency around those benefits, e.g. attendance allowance, Council tax reduction, Carer's allowance, CHC.
- **Communication**-- how to communicate more effectively or methods to use as PLWD has less and less communication skills -- included use of flash cards; speech therapy, particularly Rosemary Townsend Dyscover communications course (<https://dyscover.org.uk/>); learning how to read facial expressions -- eyes, smiles -- or grasping hands, leading you to the object they are trying to discuss, etc.

FAD small group discussion

- **Coping with situations** --it is important to find time for yourself. Different strategies might work for different people, trying to focus/deviate the attention of person you are caring for to other things can help sometimes. If possible, ask other members of the family to help. Sharing responsibility and taking some time to yourself can help.
- **Progression of the disease**-- Consider planning for the future. Even if it might seem early, some members have mentioned the advantages of planning things in advance.

- **Carers course** – a few members mentioned the use of some carer courses. For example, the Individual Support Plans (ISP's) offered by Dementia Carers Count:

<https://dementiacarers.org.uk/our-courses/>

An ISP is an individualised plan that aims to make life easier for you and the person you are supporting. The ISP is not a medical plan and we are unable to review or give advice about medication or other medical matters, or to predict what is likely to happen in the future in terms of changing behaviour or health.

The ISP is designed by our team of health care professionals following an assessment session during which you and (ideally) the person you are supporting spend time with us to formulate the plan which may include one or more of the following strategies for:

- coping with stress, anxiety or other difficult feelings
- communicating more meaningfully with the person who has dementia
- making the environment at home safer
- responding to changing behaviour
- assisting with daily activities such as washing, dressing, eating
- staying active