

PCA small group discussions at 7th May 2019 Carer's Meeting

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The information in this document reflects the content talked about at the two PCA small group discussions at this Rare Dementia Support meeting. Please note that any mention of or links to apps, services or products are provided here for your reference as they were mentioned in the discussion and that these do not constitute endorsements or recommendations from Rare Dementia Support. The suggestions discussed are not intended to be used as a prescriptive list as people's experiences of dementia vary hugely - people may or may not find the information helpful.

Practical actions after receiving a diagnosis

Practical steps mentioned included:

- Going to your [local adult social services](#) and getting [a carer's assessment](#) (alongside an assessment for the PLWD)
- Applying for [Personal Independence Payment](#) (PIP) or [attendance allowance](#) if the PLWD is over 65. These benefits are seen as a gateway to other benefits/support
 - If you would like help completing these forms you can contact your local [Citizens Advice](#) Bureau
 - If you are eligible for PIP or Attendance Allowance you will also be able to get a [council tax exemption](#) for the PLWD
- [Applying for a Blue Badge](#) (disabled parking)
- Registering as partially sighted with your local council; in the following tax year the PLWD will be granted the Blind Persons Allowance in addition to the Personal Allowance
- Applying for [road tax exemption](#)
- [Lasting Power of Attorney](#) (LPA) - for both Financial & Property as well Health & Welfare. People suggested doing it as soon as possible and also that the government is offering a rebate on some applications as the fees have recently been reduced
- [An Age UK assessor](#) will look at your attendance allowance application; recommend keeping a 2 week diary of 'helping' e.g. every time you get up in the night, how long for, etc., to ensure you paint an accurate picture of how much assistance you're providing

- Good information sources included: [GOV.UK website](#), solicitors/family lawyer, memory clinic, [Alzheimer's Society](#), [Dementia UK Admiral Nurses](#)

Arranging care ongoing

- People discussed ways of advertising for and finding helpers and home carers and suggestions including asking for recommendations in online forums, searching online for home care agencies, schemes that involve having a live-in helper in exchange for low rent costs and word of mouth recommendations in the local community although reliability had been an issue for some people
 - Specific examples shared were:
 - Someone asked via the [PCA Facebook group](#)
 - Someone is using [Home Instead](#) at a cost of about £25/hour

- Someone recommended [Share and Care](#) who match up households who have a spare room with someone happy to provide some hours of companionship and support in return for an affordable place to rent
- Someone had found a personal trainer at their local gym helpful for one-to-one support and to prolong meaningful activity and fitness (they explained PCA symptoms and difficulties to the instructor during the initial assessment)
- Alzheimer's Society offer the [Side by Side](#) scheme where they match people to volunteers with overlapping interests (isn't available in all areas but worth checking!)
- People had had mixed responses to their [Continuing Healthcare Funding](#) applications but most were in agreement that the process is very detailed and a lot of supporting evidence is needed and that it's a good idea to make sure you're known to social services, district nurses, palliative care teams ahead of applying (also that it can be backdated to the application date if successful)

Travelling abroad and using public transport

- It's possible with some airlines to request an extendable curtain so that a person with dementia can be accompanied to the toilet
- Some airports (e.g. Gatwick and Heathrow) offer a special service - you can use a sunflower lanyard to make staff aware you need extra help
- Consensus was to contact airline/airport in advance (at least 48 hours) to let them know of any difficulties and to see what support can be offered, also to mention to cabin staff when boarding so they are aware and can provide assistance where required
- Travel insurance:
 - [Staysure](#) were recommended, other companies recommended by other support group members include [Holidaysafe](#) and [Able2Travel](#)
 - Others arranged theirs via their bank
 - Some confusion about what condition(s) to select on the drop down 'Conditions' list - benefits of selecting 'Alzheimer's' and 'partially sighted' were discussed
- Some carers mentioned either their or their partner's loss of motivation to travel, because of extra time needed to plan and prep and potential stresses along the way

Tips included:

- getting taxis to avoid public transport (escalators and tube can be really stressful)
- If using escalators, someone standing in front of the PLWD can decrease anxiety
- allowing plenty of time
- pre-planning/thinking ahead
- finding strategies for common difficulties to reduce carer's stress when things are difficult but also plan workarounds in advance as much as possible
- Generally avoiding travel plans which involve too many transfers or changes
- Taking battery powered fairy lights away on holiday was one suggestion for guiding the way to the bathroom during the night in an unfamiliar apartment/hotel room
- A [symbol cane](#) was described as useful for making others aware of visual difficulties

Phones

- [Jointly app](#) - an app designed by carers for carers. Particularly useful for storing information (e.g. medication, photos, appointment times) in a way that's accessible to a whole group (e.g. family, care team)
- [Doro](#) make easy-to-use phones
- People mentioned designating 'In Case of Emergency' contacts in their mobile phone contact list (saving them as 'ICE [name]' and also the importance of completing your 'Medical ID')

information on your mobile phone so that emergency services can access the information in case of an emergency

- Medical ID wristbands were also described as helpful and reassuring

Adapting the home

- People discussed different ways of guiding someone's way within the home when they have PCA - some ideas were using bamboo screens, or arranging furniture in a way that helps to make pathways clear and minimises confusion around having too many options
- People mentioned that familiarity is really important (e.g. visiting the same holiday home/hotel when travelling) and that having routines around regular activities like mealtimes can help (e.g. eating in the same place)
- Lighting:
 - People mentioned that an even spread of lighting and minimal shadows as far as possible is helpful (LEDs and down-lighters were recommended for this)
 - One person had had an assessment about their lighting needs via social services but noted they had to organise and fund their own electrician to implement the recommendations
 - People had also tried night lights plugged in en route to the bathroom and a motion activated light for the toilet bowl
- Highly reflective laminate tables in care homes and marble flooring were mentioned as problematic because of the glare. Difficulty with patterns was also highlighted due to how the PLWD can perceive things differently, for example black holes in checkered floors or dark colours.
- One carer mentioned having a camera set up in the living room so that she can check in and see if her husband is OK while she is out
- An [occupational therapy](#) (OT) assessment can be useful, to see what devices could be useful in the home - this can be organised via the NHS (your GP) or social services. Adaptations mentioned included high ridged plates, grab rails, raised seating areas.
- Difficulties with using a stair lift were also discussed including the sensation of going up and down alongside the transfer into the seat.
- One issue encountered by people was moving or refurbishing their house. People felt familiarity was key and to try to keep as much the same in the house as possible. For example, having the same paint colours, furniture etc. This will vary with all PLWD as some will adapt to new surroundings but this is often in the earlier stages.
- PLWD can have difficulty with seeing food on a plate, especially neglecting objects on one side of their vision. It was suggested that a coloured rim around the edge can be helpful, or using a large pasta bowl with rounded edges and keep turning the bowl to enable the person to see the food.

Safety

- Importance of protective measures where possible was discussed.
- You can contact [your local fire department](#) to ask them to fit a lock for the cooker. This was thought to increase safety in the kitchen.
- If someone felt scared of the PLWD being too close to the road, it was suggested someone else could travel with them and perhaps stand further behind them to keep them safe
- If someone is perceiving a chair they want to sit on to be in the wrong place, if possible it was recommended to move the chair towards them, rather than telling the person they are getting it wrong

- Trackers and alarms were said to be useful for PLWD, however they will not be useful for everyone. There are lots of options available... most mobile phones (iPhone and Androids) have tracking ability through GPS which some have found very useful. For alarms, one example was given of having an alarm fitted to the bottom of a door which goes off if the PLWD is walking in the night. Contact your local council or social services about setting up the alarm and if the alarm goes off giving contact details for their next of kin to call
- For falls it was recommended to place the PLWD on a risk register. There is [a risk register in Hertfordshire](#), however there did not appear to be a register in other areas. If you are concerned about the PLWD you can get an assessment and advice from a [falls risk screening](#)

Independence of the person living with dementia (PLWD)

- Several people recommended finding activities the PLWD could do and mentioned the importance of the PLWD having a sense of purpose and getting out of the house. Examples included: Zumba, anything music-related (e.g. choirs), dancing, and painting. Some people felt it doesn't matter if someone makes mistakes and that everyone can do something. It doesn't matter if they have never done it before. All communities will have something available, whether it is dementia-related or not.
- One person found the book "Contented Dementia" very helpful. They said there were three main bits of advice for carers from the book:
 - 1) Find things that are comforting for the PLWD
 - 2) Don't ask questions, it is better to state things. In particular, open-ended questions were thought to be difficult for the person to process and therefore may lead to conflict.
 - 3) Join them in their reality. Agree to what they say to reduce conflict
 - Some people felt that white lies can become the norm to manage
 - Allow the PLWD to have a go to a certain extent. As long as it is not hurting the person or others go for it!

Carer experiences

- Support for carers is especially important - people agreed it was important to look after yourself and to ask for help when you need it, this included being mindful of your own mental health.
- Other family members e.g. children mentioned worrying about the burden on their parent who is a carer
- Some people mentioned local organisations that had been helpful in providing support were: carers associations, sight loss support services and local arts organisations with outreach projects for people with dementia and carers, specific examples discussed were:
 - [Kingston Carers](#)
 - One member had received good support for adjusting to sight loss from [Middlesex Association for the Blind](#)
 - [Proactive Care teams in West Sussex](#)
 - [Turtle Key Arts Turtle Song program](#): (NEXT RUNNING IN SUFFOLK (30 APRIL - 2 JULY 2019), OXFORD (3 MAY – 28 JUNE 2019) AND GLOUCESTER (28 MAY– 30 JULY 2019))
 - [Posterior Cortical Atrophy Awareness Facebook group](#)
- Some carers described feelings of guilt and/or stress around managing social activities and balancing different needs
- People recommended taking time when given the diagnosis to prepare to start applying for benefits and support

- Some carers discussed what to do when the PLWD/carer disagree about when is the right time to start letting other people know about the diagnosis
- Also discussed trying not to take things personally and acknowledging when it's the PCA which is affecting someone's way of interacting or communicating. One example mentioned was if the PLWD looks upset or worried when they are in the community, it could be they are concentrating in that moment rather than upset/worried.
- Most people felt carers patience can be intensely tried. It was highlighted that you have not been trained to do this, do what you can. Inevitably you will stumble. If you are finding things difficult it is important to be able to walk away and have a breather
- Some people found it hard to know when to give up on a subject. It was felt it can be best to agree with the PLWD to resolve the conflict. Some people can become more upset if they are corrected
- People perceived there to be changes in family dynamics with roles changing over time
- If the person is becoming assertive or agitated this could be a sign of stress, carers thought it was best to take actions to reduce their stress e.g. going home to a familiar place and starting again
- Sometimes it is not realised that if the PWLD's behaviour has changed it could be down to something secondary, for example it could be a urinary tract infection (UTI)

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