

PCA support group meeting Friday 1st March 2019 – Care and Support

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- Some were uncertain over how the condition progresses over time and were therefore uncertain how to plan out aspects of their lives eg. potentially needing to move house. There was a suggestion that a database of PCA patient stories would be helpful. There was an agreement that there are Facebook groups which are good for this.
- It was discussed how difficult it was to find activities to do and those with PCA were often bored and frustrated because of it. Members of the group shared stories of taking up new things which they have enjoyed since the diagnosis when they have not been able to continue doing the things they used to love eg. playing golf or the guitar. There is an online resource which helps for this but no-one in the group had seen this before, here's a link to it via our website: [Adapting Activities – PCA support group meeting minutes](#). Young dementia UK, local dementia action alliances and Age UK were recommended for activities.
- The group shared stories of getting NHS support declined and the frustration of this but also of when persistence with the NHS led to good support. The group also discussed the benefits of being declared visually impaired for getting additional support. There was also a discussion on benefits of the sunflower lanyard and where it is recognised. There is more information about the scheme (including where to get a lanyard) and its implementation at airports and Sainsbury's supermarkets here:
[Sunflower lanyards at airports](#)
[Sunflower lanyards at Sainsbury's](#)
- The group shared stories of positive and negative experiences of getting carers from agencies. A frequent problem was agencies sending different people every time and no meaningful relationship can be built from such care.
- The group said a UK map of people with PCA would be really helpful.