

PCA support group small group discussion A – What care and support is needed when?

Emilie Brotherhood and **Emma Harding** facilitated an activity and conversation about what sort of help and support people adjusting to a diagnosis of PCA need at what time, to inform the choice of outcome measures for the study '**The impact of multicomponent support groups for those living with rare dementias.**', funded as part of the [ESRC-NIHR Dementia Research Initiative 2018](#), and involving researchers from University College London, Bangor University, Nipissing University and Canterbury Christ Church University.

Scribe: Paul Camic

- Many felt that services/support were very London-centric
- It is difficult to find other people locally to talk to about (e.g. what's bugging you, what your fears are, tips on managing, etc.)
- Peer-peer support is important but difficult to find outside London
- Good to ask people with PCA questions about how they are finding it/experience it; not focusing on everything negative though—use of humour, strategies that work (at least sometimes), how to remain safe, how to be mindful, adaptation strategies for dressing, eating, things that take your mind off it (dance, music, etc.); talking clocks were demonstrated at the meeting.
 - For carers: need to remain vigilant, problems with disrupted sleep
- Managing changes to identity is a challenge—finding out where you fit in
 - There is a lot of stigma and even embarrassment; it's really tough a lot of the time.
“It is amazingly comfortable being with other people who are similar”
- Important not to make assumptions about PCA and the experience a PWD or carer has – we are all different
- We are given a lot of misinformation by GPs and even some consultants and charities (Dementia/Memory cafés are not helpful)
- Information about how to interact with professionals would be helpful
- Reading information is often very difficult for people with PCA
 - Suggestions included having the option with websites to hear the material rather than read it, making sure it is either said slowly or there is the option to slow down the recording (e.g. having a block of text read out to you such as on Google speech, although that does not always work well)
- Support with benefits would be helpful. There are many options people do not know about such as National Insurance options, NHS carers break, council tax refunds, supporter's allowance, etc.)
- Problems: physical exhaustion, self-isolation (“I've become a different person”)
- Physical health is neglected: help with exercise suggestions, planning routines such as going to the park
- Large groups are difficult to participate in and smaller groups, such as this one, are easier – we can hear better and there are not a lot of competing distractions
- Impact on work life, family relationships, leisure activities
- Mental health and wellbeing for people with PCA and carer
- Role of support groups should be considered
- Use of life coaches might help with strategies