

PCA support group small group discussion B

Strategies for Supporting Reaching

Dr Keir Yong facilitated a discussion about how activities which require reaching and coordination (e.g. dressing, meal times) are challenged and supported for people with PCA. Keir was recently awarded an Alzheimer's Society 3 year fellowship to investigate this further.

(Scribe: Hannah Carr)

K = Keir

G = group

K: PCA is thought to be a visual condition but people's experiences suggest there is much more to it. For example, with regards to spatial awareness; the ability to find a light switch in the dark or putting a jacket on – finding your arm behind your back. Do these examples align with your experience?

G: Yes – difficulties with dressing, understanding terms 'left' and 'right' and putting cups down. Not sure of any practical solutions other than just being patient and trying hard with them.

K: The core of our work is to understand the nature/mechanism of these symptoms that you have described and finding strategies and approaches to manage them by applying a more neuropsychological approach.

G: With regards to the 'left' and 'right' issue, it is something that we noticed first. It appears to be about the terminology rather than a lack of understanding of actual left and right. For example, the term 'behind' is not comprehended but 'rotate 180 degrees' seems to be intact. Another strategy we have used is to label the left and right arm. For example, he has his emergency bracelet on his right arm so this is now called the 'bracelet arm' instead of 'right arm'.

K: An example strategy we have heard of with regards to putting on a jacket is to utilise a combination of senses and strategies to help. For example, stitching a bright coloured piece of fabric with a different texture to facilitate finding one of the sleeves of a jacket based on both visual and touch information. After the difficulty of putting this first sleeve on, the rest of the process seems to be slightly easier.



Colours

G: Are colours affected in PCA?

K: Previous studies suggest colour perception tends to be somewhat intact but may be altered. The major element to colour that people often consider is colour contrast. If everything is of a similar colour it will be harder to distinguish between the two.

G: I have a problem with stairs so I put a piece of pink tape on the bottom step to indicate that I have come to the end.

G: Does it have to be a specific colour such as pink? I seem to struggle with hazard tape, marble steps and also white. Is there something difficult about bathrooms?

K: Based on reports from support group members, it's not often a particular colour but more so to do with contrast. For example, there is often a lack of contrast with white objects which may make them harder to distinguish from the surroundings.

G: Rather than relying on colour, I tend to feel for the step with the back of my leg to help me down. My stairs have a certain texture to them that I can identify and help me to know I am on the step.

Freezing

G: Another thing I find with stairs though is that they will get half way up and then change their mind but are unable to come back down so will freeze. We can spend ages trying to get them down but they just freeze.

G: We also have this problem with getting into the car and also turning to sit.

G: There appears to be a stress and psychological element - a sense of panic. When frustrated it makes it harder and others trying to help is useless. Is there a way of looking at how to calm the mind to get physical movement to come back?

G: Distraction seems to help me. For example, if I can't find something I'll go away to make a cup of tea and come back to the problem after. For some difficulties such as tip of tongue moments, being left alone is helpful rather than people trying to help and causing further frustration.

Meal Times

G: Another issue is meal times such as putting down and picking up a glass or putting food onto cutlery. Can be frustrating when eating in public – may spill food down self and can make one refrain from eating to not show struggle and feel embarrassed.

G: Strategies that help me are using a spoon rather than a fork, picking easier foods such as rice. I also use a pasta dish with a curved edge rather than plate so the food doesn't spill off. Softer meats are also better and using a steak knife to cut all foods is easier.



G: Also, if out we take our own travel mug for drinks so that a suitable cup is used (e.g. bigger cup, colourful) rather than glass or cups with a "quirky" shape.

G: Is it because a certain visual field is more impaired that this occurs?

K: It seems that people often find that keeping items in the central visual field is easier– this is something that could also benefit from further research.

Trail of thought

G: We find that trail of thought is often lost mid-sentence.

Leisure activities

G: Can hobbies be adapted? Writing, for example, cannot use a keyboard anymore so use a dictation services called Dragon so can speak and words come up on screen. But do struggle with this.

K: Have you thought about using a scribe?

G: I used a scribe when I was part of a workshop writing a play. We were all designated a scribe so that we could express our ideas and they would put them to paper for us.

Painting: I use sponges to paint – I like the texture and it is OK to be messy when using sponges.

Weaving: exercises brain and is good for concentration. Takes me a while to complete but worth it.

Rug ragging: done by feel so is a good art based hobby to take up. It is easier than weaving and not as precise. Relaxing and doesn't matter if make a mistake as can put right quite easily.

Reading: audiobooks can be helpful

Photography: needs a lot of hand eye co-ordination and ideally to be done along with someone supporting. Tried to use iPad as an alternative but did not like the quality.

K: Adapted activities may also be available to some such as recumbent cycling and kata-canoeing

G: We find that for some activities, working 1:1 with someone can be helpful. For example, Pilates groups are too difficult but working 1:1 with instructor so they can focus on his needs and struggles with left and right etc.



Professionals

K: What professionals should I speak to such as OT's who advise on activities?

- Activity co-ordinators employed by charities
- [Admiral nurses](#)
- Social workers
- [Resonate Arts](#) – Wigmore Hall & Royal Academy of Music