# Information Sheet



# What is Posterior Cortical Atrophy?

#### About the condition

Posterior Cortical Atrophy (PCA – also known as Benson's syndrome) is a progressive degenerative condition which causes damage to brain cells at the back (posterior) of the brain. This area is responsible for processing what we see.

In the vast majority of cases, the loss of brain cells is associated with the same brain changes seen in Alzheimer's disease, namely plaques and tangles. However, it can also be due to other diseases including dementia with Lewy bodies and Creutzfeldt-Jacob disease.

Whilst caused by the same disease process, the effects of PCA and Alzheimer's disease upon the behavior and thought processes of people with each condition are very different. Alzheimer's disease is most commonly associated with deterioration of memory and a progressive decline in language, perception and planning skills. People with PCA tend to have well preserved memory and language but show a decline in vision and experience difficulty with performing skilled movements and with reading and writing. This is due to the brain not being able to interpret and process information received from the eyes.

## Changes that might happen

People with PCA generally experience some of these changes associated with vision

- difficulty recognising familiar objects and faces
- increased sensitivity to bright lights or shiny surfaces
- double vision

- particular difficulty seeing in fading or low light conditions
- difficulty judging distance/speed/ perspective – this can cause difficulty with stairs, the speed of traffic, reaching out for things or putting things down on surfaces
- stationary objects may appear to move.

Some changes are hard to understand such as being able to see small print easier than large print, or objects that are right in front of the person not being seen or recognised and then suddenly being seen. This can cause frustration for the person with PCA and their supporters if the changes are not fully understood.

Other changes include:

- difficulty reading, writing, emailing, texting – this can include spelling, and remembering the shape and name of letters or numbers
- difficulty with mental arithmetic and dealing with money and change
- difficulty with coordination and making gestures e.g. waving,
- difficulty using particular tools i.e. cutlery, scissors, glasses
- difficulty with dressing / undressing (particularly zips, buttons, ties, putting arms in sleeves, legs in trousers)
- difficulty finding the chair when sitting down.

### Things to consider

Although there is no treatment specific to PCA, people with the condition may find some of the medications used to treat Alzheimer's disease helpful. These medications include donepezil (Aricept).

rivastigmine (Exelon) and galantamine (Reminyl). However, these medications are only designed to treat the changes of the condition and are not a cure.

People with PCA often have a good deal of insight and are very aware of the problems they are experiencing. Many people with PCA struggle to come to terms with the loss of the visual world around them. People often feel that they have lost their independence and that they can no longer enjoy things that they did previously like driving, reading.

There are a range of visual aids which are designed for people with visual impairment such as talking clocks, simplified mobile phones and cooking aids. There are also a range of talking books and audio recordings available. Clothing and footwear can be adjusted to enable easier dressing and promote independence. Developing coping strategies for people with PCA is essential to enabling them to live as independently as they wish.

#### **Useful information**

University College London has a PCA support group website which has a large amount of useful information. They hold regional meetings in London and the south of England. The meetings in London are recorded and can be watched live or later on their website

www.ucl.ac.uk/drc/pcasupport



Alzheimer Scotland 22 Drumsheugh Gardens Edinburgh EH3 7RN Email: info@alzscot.org Tel: 0131 243 1453 www.alzscot.org

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