DementiaUK
Helping families face dementia

Posterior cortical atrophy (PCA)

Posterior cortical atrophy (PCA) is a rare form of dementia that mostly affects the parts of the brain that process visual and spatial information. It is also known as Benson's syndrome.

Most people with PCA have changes in the brain associated with Alzheimer's disease – please see Sources of support on p10 for more information. However, it may be caused by other conditions such as Lewy body dementia, corticobasal syndrome (a condition that causes damage and shrinkage in the brain) and some rare brain disorders such as Creutzfeldt-Jakob disease (CJD).

PCA can affect people of any age but most commonly develops between the ages of 50 and 65. Dementia that develops in people under 65 is known as young onset dementia – please see Sources of support on p11 for more information.

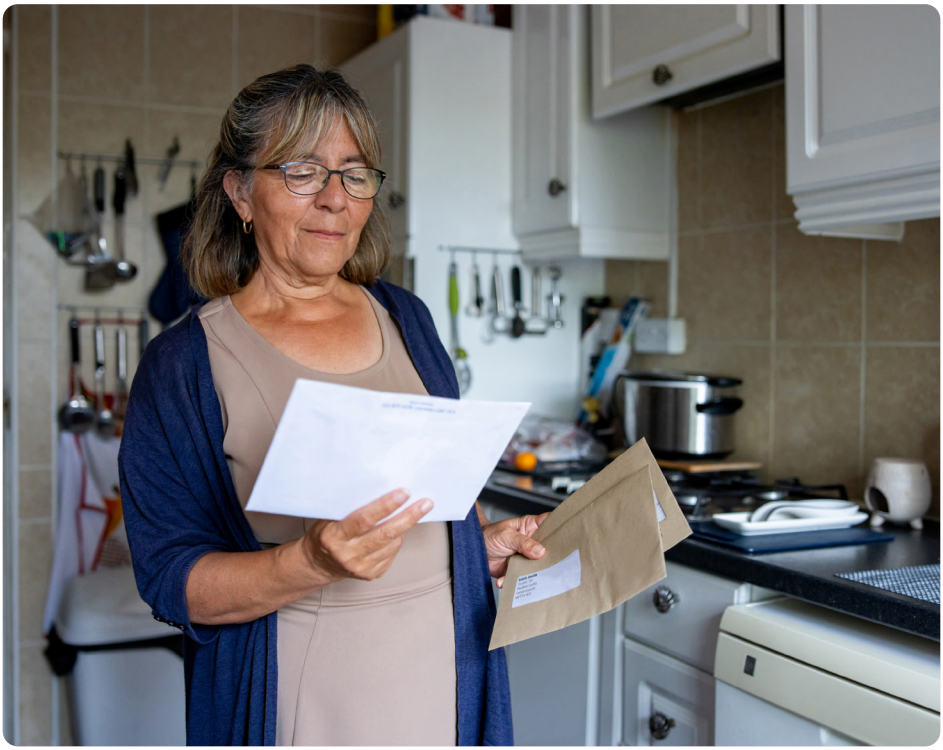
Symptoms of PCA

Although PCA is usually caused by Alzheimer's disease, the symptoms are very different. Alzheimer's disease typically affects memory first, but in the early stages of PCA, people are more likely to notice problems with vision and spatial awareness.

A person with PCA might have difficulty recognising objects, especially out of the corner of their eye. Objects that are close together might seem to merge into one. The person might struggle to interpret surfaces and depth – for example, a dark coloured rug might appear like a hole in the ground. They might have difficulty judging where things are – they might bump into things or try to pick up an object like a cup and miss. Objects might appear to be an unusual colour, distorted or moving around.

These visual disturbances could cause difficulties with:

- judging motion, distance and speed, which could affect things like driving and crossing roads



- moving around, especially in shadows, bright light or around patterns such as patterned wallpaper or carpet
- reading: the person might lose their place on a page, miss out lines or find words jump around on the page
- spatial awareness, which could affect navigating, sense of direction and being able to tell left from right
- coordination, such as doing up buttons and zips, typing, or using a mobile phone or remote control
- literacy and numeracy
- face recognition

Other possible symptoms of PCA include:

- language difficulties, such as trouble finding words or understanding written or spoken language
- problems with coordination and balance
- changes in behaviour or personality, such as increased apathy or irritability
- changes in mood, for example low mood or anxiety
- problems with multitasking or planning tasks

As PCA progresses, the person may have increasing issues with memory, speech and problem-solving. They are likely to need support with daily living activities, such as dressing or preparing meals.

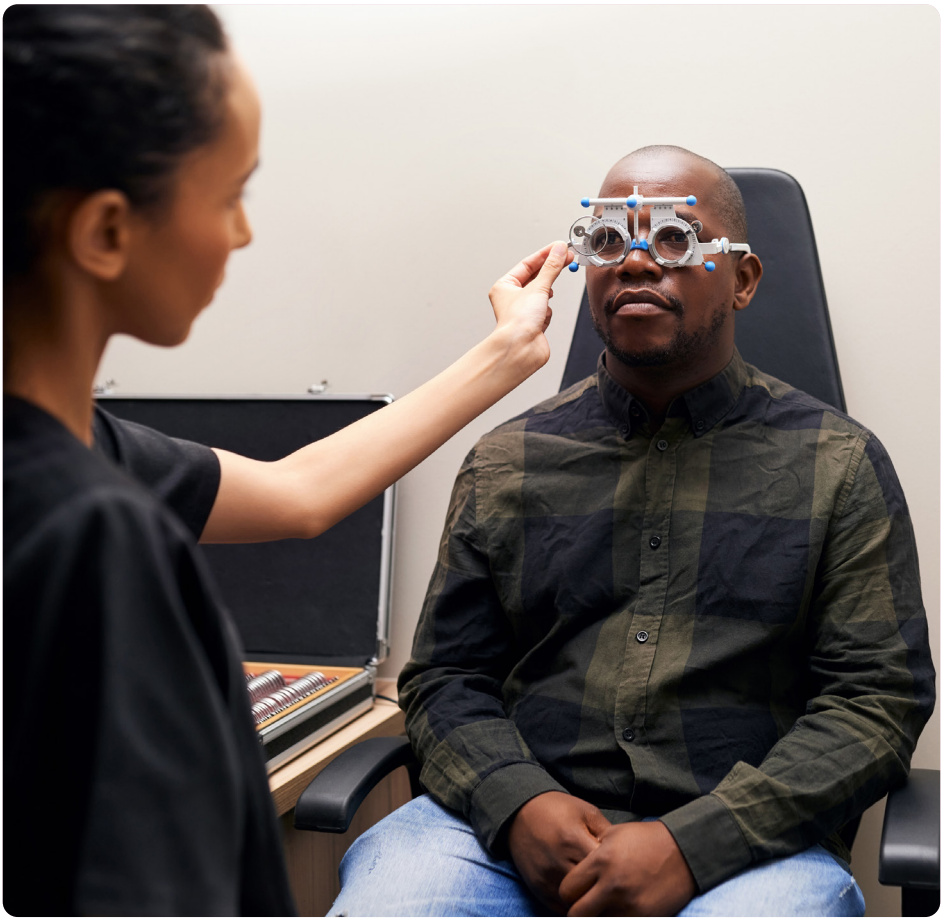
What causes PCA?

PCA is caused by damage to cells in the back of the brain (the occipital lobes) and the top of the brain (the parietal lobes). It is thought that this is caused by a build-up of abnormal proteins, which are also seen in Alzheimer's disease. This leads to changes in the areas of the brain that are responsible for visual and sensory processing.

As the disease progresses, other areas of the brain may also be affected – such as those responsible for emotional processing and behaviour regulation – leading to changes in memory, thinking, problem-solving, behaviour, personality and mood.

Diagnosing PCA

Diagnosing PCA can be challenging, as the symptoms can overlap with other forms of dementia and conditions affecting the brain. Many people also believe that there is a problem with their eyesight and book an eye test only to be told there is nothing wrong.



If someone has symptoms of PCA, it is important for them to visit an optician to look for any eye issues which could be causing visual problems. They should also make an appointment with their GP to rule out any other conditions that may be causing the symptoms.

If these tests are normal and the symptoms persist the person will be referred for further examination and tests. This is usually with a neurologist (a doctor who specialises in the brain and nervous system).

The assessment will include:

- taking a detailed medical and family history, including discussing symptoms
- tests to evaluate cognitive function, including memory, attention, language and visuospatial ability
- a lumbar puncture (taking a small sample of fluid from the spine)
- an electroencephalogram (EEG) to trace brain activity
- imaging tests such as MRI or PET scans to look for changes in the brain that may indicate PCA

The person may also be referred to an eye specialist for specialised visual tests.

It is important to note that there is currently no specific test for PCA, and diagnosis is usually based on a combination of clinical assessment, scans and ruling out other potential causes of symptoms.

Treatments and therapies for PCA

There is currently no cure for PCA, but treatments may help with managing symptoms and maintaining quality of life. It is important to discuss these with the person's healthcare provider, as treatment options may vary depending on the severity of their symptoms and their individual needs.

Medication: there are several medications that are typically used for Alzheimer's disease and can also help manage the symptoms of PCA. These include donepezil, galantamine, rivastigmine and memantine. They can help improve cognitive function and behavioural symptoms and may slow the progression of dementia. Please see Sources of support on p10 for information on medication for dementia.

Physiotherapy: this could help improve the person's balance, mobility and overall physical function. Exercises may focus on strength training, gait training and balance.

Occupational therapy: this may help the person with PCA maintain independence in their daily life. The occupational therapist may suggest strategies such as adaptations to the home, tips for meal preparation and recommendations for living aids and assistive technology. They may also suggest ways to improve memory, organisation and problem-solving skills.

Speech and language therapy: this could help improve the person's communication skills, such as speaking, writing and understanding language. A speech and language therapist may provide strategies to manage word-finding issues, or introduce alternative communication methods such as large text, speech apps and picture cards.

Cognitive training: these programmes may help improve the person's cognitive function, memory and problem-solving skills through exercises and activities to stimulate the brain.

S**upport groups:** joining a support group for people with PCA could provide the person and their carers with emotional support, education and resources; and connect them with others who are going through similar experiences.

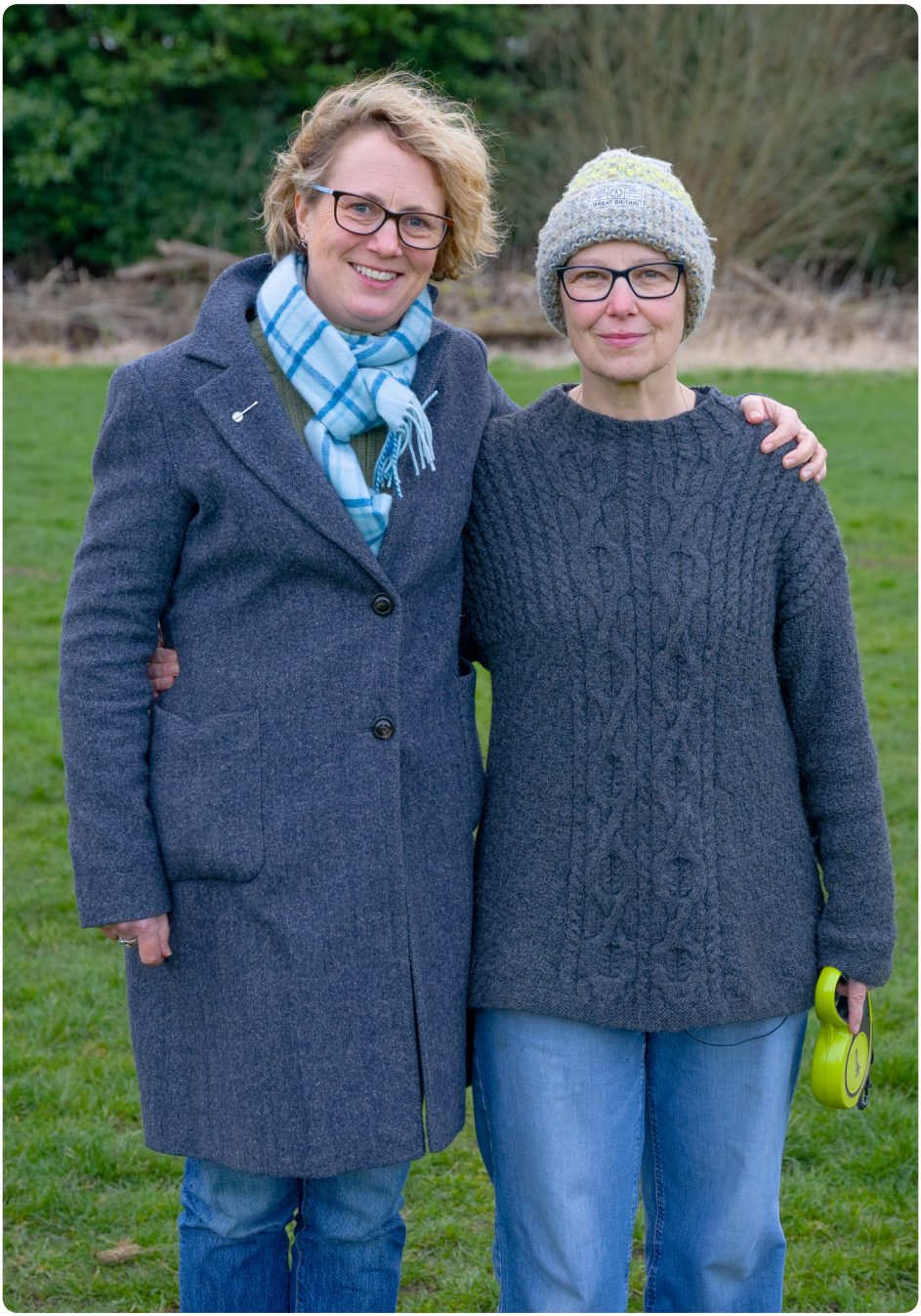
Lifestyle changes: following a healthy diet, engaging in regular physical activity and getting enough sleep can all help manage the symptoms of PCA and improve the person's overall wellbeing.

How does PCA progress?

It is difficult to predict how a person's PCA will progress. It will depend on individual factors like the underlying cause of the condition and the age when symptoms developed. Some people experience a slow decline in cognitive function, while other people's symptoms progress more rapidly.

The impact of PCA on daily functioning can also vary, with some people able to maintain their independence for some time, while others need more support and assistance.

While there is currently no cure for PCA, it is important to focus on maximising the person's independence, keeping socially active and providing a safe and supportive living environment. With the right management and support from healthcare providers, family and other carers, the person can maintain a good quality of life and function to the best of their abilities for as long as possible.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Sources of support

If you are living with dementia or caring for someone with the condition, register for our free online sessions, 'Dementia: what next?' at **dementiauk.org/dementia-what-next**

To speak to a dementia specialist Admiral Nurse, call our free Helpline on **0800 888 6678** (Monday-Friday 9am-9pm, Saturday and Sunday 9am-5pm, every day except 25th December) or email **helpline@dementiauk.org**

If you prefer, you can book a phone or video call with an Admiral Nurse at a time to suit you: please visit **dementiauk.org/book**

Dementia UK resources

Alzheimer's disease
dementiauk.org/alzheimers-disease

Getting a diagnosis of dementia
dementiauk.org/how-to-get-a-diagnosis-of-dementia

Getting a diagnosis of young onset dementia
dementiauk.org/young-onset-dementia-getting-a-diagnosis

Lewy body dementia
dementiauk.org/dementia-with-lewy-bodies

Medication for dementia
dementiauk.org/medication

Types of dementia
dementiauk.org/types-of-dementia

Young onset dementia section
- dementiauk.org/young-onset-dementia

Living with young onset dementia
- dementiauk.org/living-with-young-onset-dementia

Young onset dementia support groups
- dementiauk.org/find-support

Other resources

Corticobasal degeneration
- nhs.uk/conditions/corticobasal-degeneration

Creutzfeldt-Jakob disease (CJD)
- nhs.uk/conditions/creutzfeldt-jakob-disease-cjd

Rare Dementia Support: information and support around rare dementias, including PCA
- raredementiasupport.org

Young Dementia Network: an online community of people living with young onset dementia, their family and friends, and professionals working in the field
- youngdementianetwork.org

To speak to a dementia specialist Admiral Nurse about any aspect of dementia:

Contact our Helpline:
0800 888 6678 or **helpline@dementiauk.org**

Book a virtual appointment:
dementiauk.org/book

Our charity relies entirely on donations to fund our life-changing work. If you would like to donate to help us support more families:

- Call **0300 365 5500**
- Visit **dementiauk.org/donate**
- Scan **the QR code**

Thank you.

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