

WHAT IS POSTERIOR CORTICAL ATROPHY?



Created in
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**Rare
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Support**
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Patient Information Forum

INTRODUCTION

This booklet is for anyone who wants to know more about posterior cortical atrophy (PCA), an uncommon type of dementia. This includes people living with PCA, their family, friends and carers.

We provide an overview of the causes, symptoms, diagnosis and treatments for PCA.

The information here does not replace any advice that doctors, pharmacists or nurses may give you. If you are worried about your health, including issues with vision and memory, speak with your doctor as soon as possible.

This information was updated in April 2025 and is due to be reviewed in April 2027. It was written by Alzheimer's Research UK's Information Services team with input from Rare Dementia Support, and expert and lay reviewers. Please contact us if you would like a version with references or in a different format.

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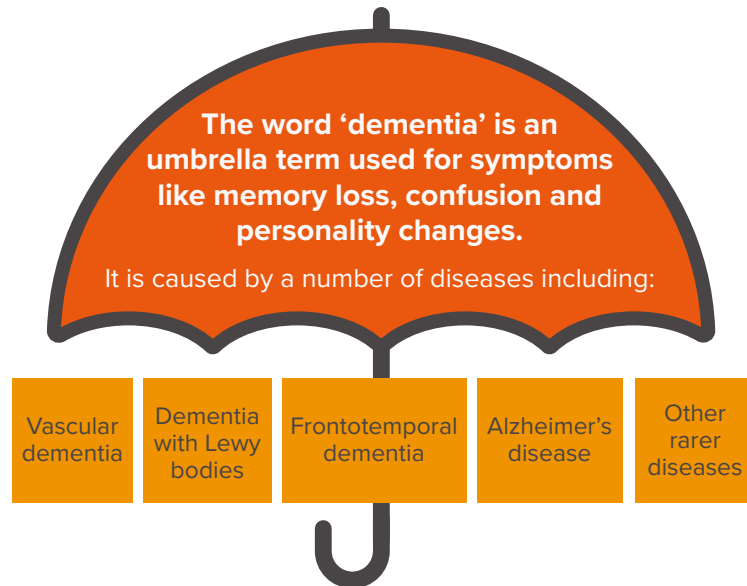
ANY QUESTIONS

If you have questions about dementia or dementia research, you can contact our Dementia Research Infoline on **0300 111 5111** or email infoline@alzheimersresearchuk.org or write to us using the address on the back page.

WHAT IS DEMENTIA?

The word dementia is used to describe a group of symptoms. These include memory loss, confusion, vision and communication difficulties, and mood changes.

Dementia is caused by different diseases that affect the brain, the most common of these is Alzheimer's disease. People living with dementia have a wide range of symptoms, and these gradually get worse over time and affect day-to-day life. Each person's experience of dementia is unique.



WHAT IS POSTERIOR CORTICAL ATROPHY?

Posterior cortical atrophy (PCA) is a rare type of dementia that usually affects a person's vision first. It is also known as Benson's syndrome, 'visual variant' or 'visual-spatial' Alzheimer's disease.

PCA is caused by damage that builds up in the brain cells at the back of the brain. This is the part of our brain that processes information from our eyes and allows us to make sense of what we are seeing and where things are.

Alzheimer's disease is most often the cause of PCA. But it can also be caused by vascular dementia or dementia with Lewy bodies too.

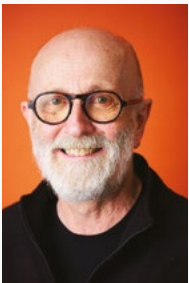
Posterior cortical atrophy often affects people in their 50's and 60's. It is sometimes referred to as a type of young onset dementia. But it can affect older people too. At the moment, we can't be sure how many people in the UK are affected by PCA. Around one in 10 people diagnosed with Alzheimer's disease at specialist dementia clinics might have symptoms of PCA.

SYMPTOMS

Most people will have problems with their vision first, but some people may have problems with dressing, moving around different spaces, coordination, and language too.

VISION

- Objects become less recognisable. People may struggle to recognise objects out of the corner of their eye or might see many different objects close together as one object.
- Surfaces and depth can look different. For example, a black object or puddle may appear to be a hole in the floor, or it may be difficult to find and reach for a door handle.
- People may not always be able to see what is right in front of them and may bump into things.
- Things may appear to have an unusual colour, appear distorted or look like they are moving around.
- People may still see an image of an object after looking away or not be able to see more than one object at a time.



“ I sometimes find it difficult to recognise people, even people that I know very well. It can be distressing even though I know it's not my fault. Luckily, the people that I have told about my symptoms have been very kind and understanding. ”

- Steve, who lives with PCA



PEOPLE WITH PCA ALSO HAVE PROBLEMS WITH:

- **Reading:** Losing their place on a page, missing out lines, letters jumbling up or finding it hard to read certain fonts and handwriting. This can also affect everyday tasks like entering a PIN on a cash machine.
- **Judging distances and depths:** Crossing roads, using escalators or stairs can become difficult. Moving around can also be challenging if there are lots of shadows, lights or patterns. A person may reach out to grasp an object but miss it.
- **Spatial awareness:** Some people may struggle with their sense of direction. Terms like 'left' and 'right' may be harder to follow.
- **Recognition:** Problems recognising objects or faces, especially when they are not in plain sight. People may experience problems reading clocks or signs, especially digital clocks or screens.
- **Light sensitivity:** Some people may have unusual colour experiences such as seeing patches of colour when it is dark or find bright light uncomfortable, including glare from shiny surfaces.
- **Coordination:** Problems with dressing, for example, having difficulty using buttons or zips, locating the sleeves of a jacket while dressing, or putting clothes on back to front. It might become difficult to use objects like kitchen utensils or a remote control.

- **Literacy:** Finding spelling and writing hard. People can find it difficult to remember the shape or name of letters.
- **Numeracy:** Some people may find simple calculations and dealing with money such as small change difficult.
- **Mood:** Some people become low in mood, irritable or anxious, or may lose interest in things they used to enjoy.

In PCA, the damage to brain cells spreads through the brain over time. This means that eventually a person's memory, speech and problem solving skills will be affected too. As symptoms progress, people will need more support in their daily life and help to look after themselves. Worsening of symptoms can occur over several years, but each person's progression is different and unique.



“ We initially put it down to depression, but then we started to notice more worrying changes like hitting a lamppost while driving her car or putting odd objects in the fridge or washing machine. Within the first year of mum's diagnosis, she didn't know what day, week or year it was. She also lost the ability to read, write or draw which were her favourite things as an artist. ”

- Hat, whose mum was diagnosed with PCA

DIAGNOSIS

Getting the right diagnosis is important so that people can get help and support. The symptoms of PCA can be very mild to begin with and difficult to describe. Because the condition is rare it can take some time to get the correct diagnosis. Seeking help for symptoms as early as possible is recommended. If you have any concerns about your health, you are entitled to an accurate diagnosis.

At first, people with PCA might think they have something wrong with their eyes and visit their optician. The optician may find the person has perfectly healthy eyes, or people could wrongly be given glasses that do not help them. This is because PCA damages the brain and not the eyes directly.

If you are worried about yourself or someone else who is showing signs of PCA, it is best to talk to your GP. They will carry out tests to find out what is causing the symptoms.

These tests include:

- Asking questions about your symptoms and medical history.
- Speaking to your partner or someone close to you about the problems you are having.
- A physical check-up.
- A blood test to look for any underlying infections, vitamin deficiencies, thyroid disorders, or other conditions that could be causing the symptoms.

If your doctor suspects PCA or another form of dementia, they may send you to a specialist clinic for further tests.

These may include:

- Tests to work out how your brain processes the information it receives from your eyes.
- Memory and thinking skills tests.
- Brain scans to look for damage or loss of cells. This can be an MRI or CT scan and can also show if there are any signs of a stroke or brain tumour.
- A lumbar puncture. That involves taking a sample of fluid from the bottom of your spine. This test can help to identify abnormal levels of proteins linked to diseases like Alzheimer's in the brain.
- An EEG test, where sticky patches that measure electrical activity in the brain are placed on the head. This looks at how your brain cells communicate. An EEG is painless and takes around 20 minutes.

The results of all these tests will help a doctor to decide the likely cause of your symptoms and determine what type of dementia you may have.



“ We were relieved when we got a diagnosis. It meant that we could understand what was going on and were able to get support from different organisations. Having a diagnosis made it easier for us to start preparing for the future. ”

- Samantha, her husband lives with PCA

TREATMENTS

There are currently no specific treatments that can stop or slow down PCA available on the NHS but there may be medicines that can help with the symptoms. For example, if Alzheimer's disease is causing a person's PCA they might be offered drugs called cholinesterase inhibitors.

These drugs work by helping brain cells to communicate with each other. They may help to improve a person's symptoms for a time, but they do not stop the disease from getting worse. Some people find symptoms improve while taking these drugs, but others may not notice an effect.

There are different types of cholinesterase inhibitors

- donepezil
- rivastigmine
- and galantamine.

Memantine is another Alzheimer's medication that can help to manage symptoms and may be prescribed if cholinesterase inhibitors aren't well tolerated, or alongside cholinesterase inhibitors.

Some people who have PCA caused by dementia with Lewy bodies (DLB) may benefit from treatments that can help with movement problems. Levodopa is a drug used to treat both Parkinson's disease and DLB, and people may also benefit from physiotherapy. Your doctor will be able to discuss these treatments with you if you have PCA caused by DLB.

New Alzheimer's treatments lecanemab and donanemab are licensed for use in people with typical, early stage Alzheimer's. If you would like to find out if they are suitable for you, then you can speak with a private provider. Find out more at alzres.uk/treatment

Your doctor may also prescribe drug and non-drug treatments to help with symptoms like depression and anxiety. For more information, including some of the side-effects of these drugs, talk to your doctor or request our free **'Treatments for dementia'** booklet.



WHAT AFFECTS MY RISK OF DEVELOPING PCA?

It is thought that what makes up a person's risk of developing PCA is similar to other types of dementia. This is a complex mix of factors such as our age, the genes we inherit from our parents, and our environment and lifestyle.

Researchers have found that the symptoms of PCA are caused by changes in the brain cells that process visual information from our eyes.

When PCA is caused by Alzheimer's disease, it is not clear why the disease affects this part of the brain more than the areas affected in typical Alzheimer's cases. In typical Alzheimer's the areas of the brain affected are involved in memory and learning.

Scientists are working hard to find out more, as well as exploring specific genetic or lifestyle risk factors for the PCA.

There are things that we can all do to keep our brains healthy and to reduce our risk of dementia. For more information, request our **'Reducing your risk of dementia'** booklet or visit alzres.uk/risk





LIVING WITH PCA

Some people with PCA may benefit from using visual aids and resources for people with sight problems. These may include audio books, devices with large and simple displays, voice recognition software and walking aids. People may choose to carry a symbol cane to let others know they have sight problems.

For more information about visual aids and for support, contact the **Royal National Institute of Blind People** at helpline@rnib.org.uk or call **0303 123 9999**.

People may also need to make changes to their home to help them stay independent and move around safely.

EVERY PERSON'S EXPERIENCE WITH PCA IS UNIQUE, AND WHAT WORKS FOR ONE PERSON MAY NOT WORK FOR ANOTHER.

HERE ARE SOME WAYS TO HELP SOMEONE LIVING WITH PCA:

- At home, keep pathways clear by removing rugs, clutter and low furniture.
- Adding coloured stickers to glass doors can help someone see them more easily.
- Rooms should be well-lit. In the evenings and at night, nightlights may be helpful.
- Grab-rails around the house, non-slip mats on hard flooring, and handrails on the stairs are helpful for maintaining safety and independence.
- Try to use plain furnishings and flooring, not patterned.
- Contrasting colours (for example, black and yellow) may help make objects clearer and mark edges, e.g. steps or kitchen worktops.
- At mealtimes, using plain plates and bowls, and cutlery with bright coloured handles may also help.
- Use a plain tablecloth and set out the plate, glass, etc. in the same way each time.
- Outdoors, different coloured paving may look like steps rather than a flat surface.

It's important to remember that every person's experience with PCA is unique, and what works for one person may not work for another.



SUPPORT FOR PCA

A diagnosis of PCA can leave a person with many questions. With the right information and support, people can live well and carry on doing the things they enjoy doing for some time. Talking to other people in the same situation can also help.

Rare Dementia Support PCA Group

The Rare Dementia Support PCA Group sends out newsletters and holds meetings across different parts of the country. These Support Group meetings provide opportunities for people affected by PCA to meet others and share their experiences. Visit raredementiasupport.org/posterior-cortical-atrophy for more information. You can contact them by email contact@raredementiasupport.org

Admiral Nurse Dementia Helpline

The Admiral Nurse Dementia Helpline offers practical and emotional support to anyone affected by dementia, including advice on managing the symptoms. Call **0800 888 6678**.

Alzheimer's Society

Alzheimer's Society provides support and care information for people with all forms of dementia and their loved ones and can tell you about local support groups in your area. Call **0333 150 3456**.

Young Dementia Network

The Young Dementia Network supports people with young onset dementia (which affects people before the age of 65), their families and professionals. You can contact them by email info@youngdementianetwork.org

You can also talk to your doctor or nurse for advice on caring for someone with PCA or ask for our booklet **'Support for people affected by dementia: organisations that can help'**.



RESEARCH

Alzheimer's Research UK has funded over £1 million of research into posterior cortical atrophy. We believe that medical research will deliver life changing preventions and treatments, and better ways to detect and diagnose the diseases that cause dementia.

We've invested over **£176 million** in the best research powering the most forward-thinking scientists and joining forces with world-class organisations. This includes over **£1 million** of research into posterior cortical atrophy (PCA) helping to improve our knowledge of how the disease spreads through the brain.

With continued support, we will fund many more studies into dementia. We promise we will not stop until dementia can no longer destroy lives.

We are Alzheimer's Research UK.
We exist for a cure.

**STAY UP TO DATE WITH
THE LATEST DEMENTIA
RESEARCH**

Call **0300 111 5555** or scan the QR code.



HOW TO GET INVOLVED

Research is the only way we'll find new ways to prevent, diagnose and treat dementia and scientists need your help. Without people volunteering to take part in research, finding a cure would be impossible.

People with dementia, their carers, and people without dementia are all needed to take part.

Anyone over the age of 18 can register to Join Dementia Research, which is run by the NHS. This will match you to research studies you are suitable for. Then you get to choose which ones to take part in.

People have many different reasons for wanting to volunteer for dementia research, and it's their support that will drive forward our progress and change the lives of everyone affected by dementia.

Join them today.

Find out more and register to take part by calling the Dementia Research Infoline on **0300 111 5111** or visiting joindementiaresearch.nihr.ac.uk



Alzheimer's Research UK is the UK's leading dementia research charity.

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CONTACT US

0300 111 5111

info@alzheimersresearchuk.org

Alzheimer's Research UK

3 Riverside, Granta Park, Cambridge CB21 6AD

VISIT

alzheimersresearchuk.org/dementia-information

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