

# What is posterior cortical atrophy?



**Rare  
Dementia  
Support**

Advice Community Learning



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This booklet is for anyone who wants to know more about posterior cortical atrophy (PCA). This includes people living with PCA, their family, friends and carers. It provides an overview of the causes, symptoms, diagnosis and treatments for PCA.

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The information here does not replace any advice that doctors, pharmacists or nurses may give you. It provides background information that we hope you will find useful.

This information was updated in April 2021 and is due to be reviewed in April 2023, it was produced in partnership with Rare Dementia Support. Please contact us if you would like a version with references or in a different format.

## 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, such as Alzheimer's disease. People living with dementia can have a wide range of symptoms, and these gradually get worse over time and affect day-to-day life.



## What is posterior cortical atrophy?

Posterior cortical atrophy (PCA) is a rare form of dementia that usually begins by affecting a person's vision. It is also known as Benson's syndrome.

PCA is caused by damage to the brain cells at the back of the brain. This is the part of our brain that processes the 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 the brain cell damage in PCA, but it is sometimes caused by other types of dementia, such as dementia with Lewy bodies.

PCA is sometimes called 'visual variant' or 'visual-spatial' Alzheimer's disease. Alzheimer's usually affects a person's memory first, but in PCA the first symptoms are often problems with vision. For example, how we understand what we are seeing and where things are.

People often develop PCA between the ages of 50 and 65, but it can affect older people too. PCA is a rare form of dementia, and at the moment we can't be sure how many people around the world are affected by it.

Of people diagnosed with Alzheimer's disease at specialist dementia clinics, around

**8 to 13% may have PCA symptoms.**

## Symptoms

People living with PCA have symptoms that can vary from person to person and can change over time.

Most people will have problems with their vision first, but some people may have problems with dressing, handwriting, coordination, numbers, and language too.



### Vision

- Things may appear to have an unusual colour, appear distorted or look like they are moving around.
- 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 look like a hole in the floor, or it may be difficult to find and reach for a door handle.
- 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.
- People may not always be able to see what is right in front of them and may bump into things.

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 putting in a PIN on a cash machine.



### Judging distances and depths

Crossing roads and using escalators or stairs can become difficult. This can also be difficult 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 and 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

Finding bright light uncomfortable, including glare from shiny surfaces. People may have unusual colour experiences such as seeing patches of colour when it is dark.



### 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. Objects like kitchen utensils and remote controls may become difficult to use.



### Literacy

Finding spelling and writing hard. People can find it difficult to remember the shape or name of certain letters.



### Numeracy

Problems with simple calculations and dealing with money such as small change.



### Mood

Some people become low in mood, irritable or anxious, or may lose interest in things.

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. This can take several years, but each person's progression is different and unique.

## 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, therefore seeking help for symptoms as early as possible is recommended.

At first, people with PCA might think they have something wrong with their eyes and visit their optician. The optician may find that they have 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 doctor.



They will carry out tests to find out what is causing the symptoms. These tests include:

- 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 that involves electrodes being placed on the head to look at how your brain cells communicate. This does not hurt at all and takes about 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 a person may have.

## Treatments

While there are currently no specific treatments that can stop or slow down PCA, 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 four types of cholinesterase inhibitors;

**donepezil**

**rivastigmine**

**galantamine**

**memantine.**

Some people who have PCA and dementia with Lewy bodies (DLB) may benefit from treatments that can help with movement problems. Levodopa is a drug used to treat 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 DLB and PCA.

Drug and non-drug treatments may also be offered to help people 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.



## 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](mailto: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. There is some evidence that reading aids and home adaptations that support independent activities for people living with PCA can help.

Here are some more 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.**

**Try to use plain furnishings**, not patterned.

**Contrasting colours may help make objects clearer.** Black and yellow seem to work well for marking edges, e.g. kitchen worktops.

**At mealtimes**, try to use plain plates and bowls, and cutlery with 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 so try to let the person know that it is flat.

You can find out more about supporting someone with PCA by contacting **Rare Dementia Support** on **0203 325 0828** or email [contact@raredementiasupport.org](mailto:contact@raredementiasupport.org) for details.

## Support

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.

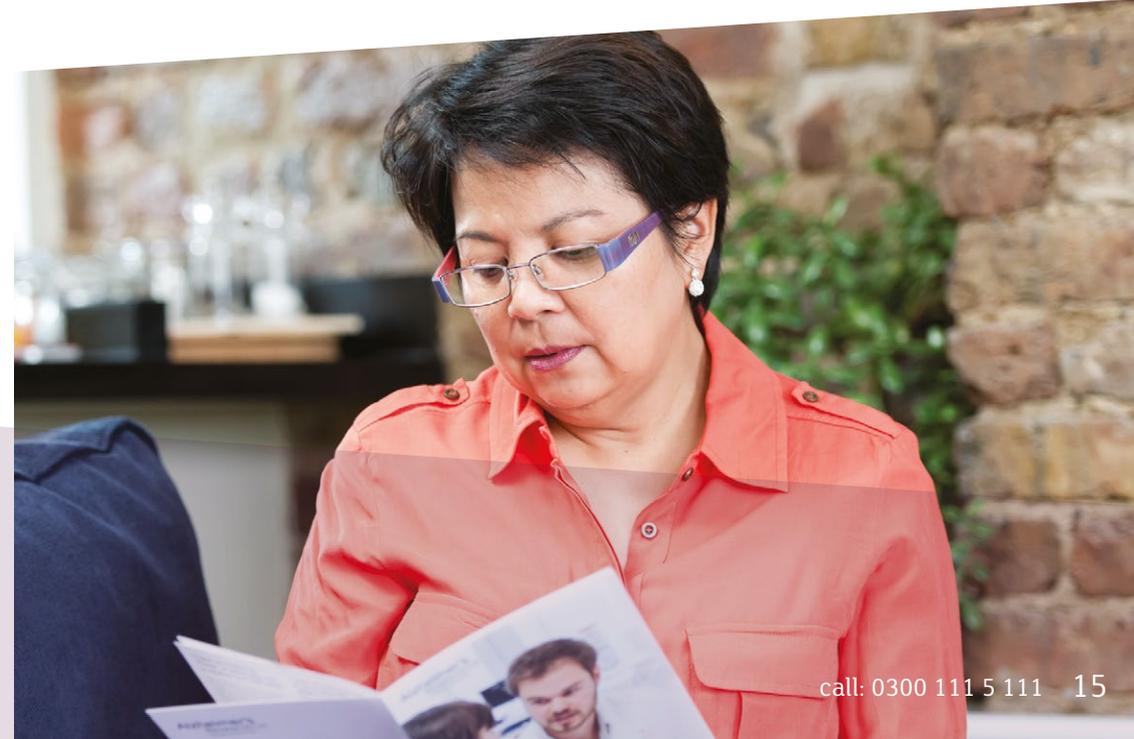
The **Rare Dementia PCA Support Group** sends out newsletters and holds meetings across different parts of the country. These Support Group meetings provide opportunities for people affected by PCA to meet others and share their experiences. There is also a supportive Facebook group (search 'Posterior cortical atrophy awareness').

Visit [www.raredementiasupport.org/posterior-cortical-atrophy/](http://www.raredementiasupport.org/posterior-cortical-atrophy/) for more information. You can contact them by phone on **0203 325 0828**, leave a message and one of the team will get back to you, or email [contact@raredementiasupport.org](mailto:contact@raredementiasupport.org).

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** 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**.

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**'.



What affects my risk of developing PCA?

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## What affects my risk of developing PCA?

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

In PCA, it is not clear why the disease affects the visual region at the back of our brain rather than the areas affected by typical Alzheimer's disease, like memory. 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, lifestyle, genetics and environment. Scientists are working hard to find out more, as well as exploring specific genetic or lifestyle risk factors for the condition.



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## Send me more information

For free information, simply complete this slip and drop it straight in a post box. Alternatively, phone us on **0300 111 5555**.

### I would like to know more about

Dementia: symptoms, diagnosis, causes, and risk reduction (SCIHIAAD)

Treatments for dementia (SCIHITMT)

Support for people affected by dementia: organisations that can help (SCIHICARE)

The latest dementia research (SMTTHINK)

Name

Address

Email

We'd like you to be the first to know about the latest research and how your support makes a difference, as well as ways you can get involved and help fund our life-changing work. We'll keep your information safe and never sell or swap it with anyone.

Let us know how we can contact you (tick below):

Post  Email  Telephone  Text message

You can change how we talk to you at any time, by calling **0300 111 5555** or emailing [enquiries@alzheimersresearchuk.org](mailto:enquiries@alzheimersresearchuk.org)

Our Privacy Notice can be found at [www.alzheimersresearchuk.org/privacy-policy](http://www.alzheimersresearchuk.org/privacy-policy) and explains how we will use and store your information.

## Research

Alzheimer's Research UK has funded

# £437,000

of research into PCA and were one of the first charities to invest consistently in this important area of research.



We have now funded over £64 million of pioneering research to help advance the understanding of all types of dementia, discovering new ways to diagnose, prevent and treat the diseases that cause dementia.

Backed by our passionate scientists and supporters, we are challenging the way people think about dementia, and investing in research to make breakthroughs possible.



### Find out more

If you have questions about dementia, dementia research or want to find out more about how to get involved in research, contact our **Dementia Research Infoline** on **0300 111 5 111** or email [infoline@alzheimersresearchuk.org](mailto:infoline@alzheimersresearchuk.org)

The Infoline operates 9.00-5.00pm Monday to Friday. Calls cost no more than national rate calls to 01 or 02 numbers and should be included in any free call packages.

We are the UK's leading dementia research charity dedicated to making life-changing breakthroughs in diagnosis, prevention, treatment and cure.

We welcome your comments to help us produce the best information for you. You can let us know what you think about this booklet by contacting us using the details below.



### Contact us

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### Dementia Research Infoline

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