

What is posterior cortical atrophy?



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This booklet is about posterior cortical atrophy (PCA). It is for people who have PCA, their family, friends and carers or anyone else with an interest in the condition.

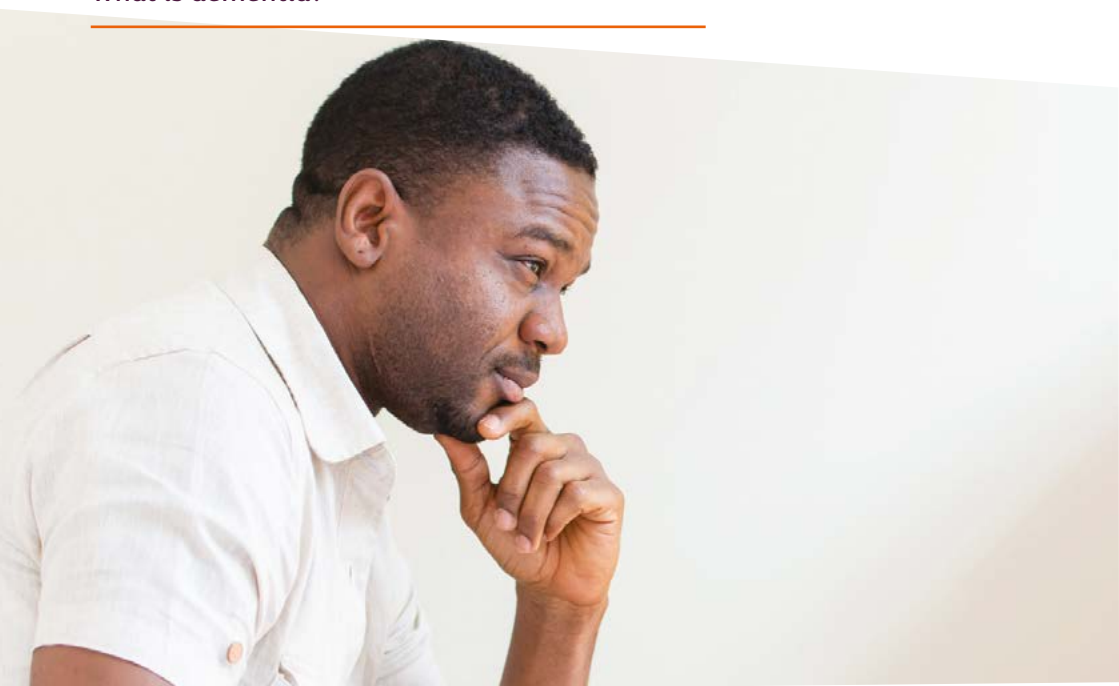
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The information here does not replace any advice that doctors, pharmacists or nurses may give you. It provides background information that we hope you will find helpful.

It was updated in April 2019 and is due to be reviewed in April 2021. Please contact us if you would like a version with references or in a different format.

This information booklet was produced in partnership with Rare Dementia Support.



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

Dementia symptoms gradually get worse over time and affect day-to-day life.

There are many causes of dementia, with Alzheimer's disease being the most common.

What is posterior cortical atrophy?

Posterior cortical atrophy (PCA) is a rare form of dementia that usually begins by affecting a person's vision.

PCA is caused by damage to the brain cells at the back of the brain that make sense of what our eyes are seeing. It is also known as Benson's syndrome.

Alzheimer's disease is most often the cause of the brain cell damage in PCA, but it is sometimes caused by other diseases, such as dementia with Lewy bodies.

PCA is sometimes called a visual form of Alzheimer's. However, the early signs of PCA and typical Alzheimer's can be very different.

Alzheimer's disease usually affects memory first, but in PCA the first signs are often problems with vision and perception.

People often develop PCA at an earlier age than typical Alzheimer's disease, usually between the ages of 50 and 65. PCA is a less common form of dementia, and at the moment we can't be sure how many people around the world are affected by it.

Symptoms

The problems caused by PCA can vary from person to person and can change over time.

People may have problems with:



Vision

Things may appear to have an unusual colour, or to move when they are still. A black object can look like a hole. 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. They may not always be able to see what is right in front of them and may bump into things.



Reading

Losing the place on a page or missing out lines. 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. A person may reach out to grasp an object but miss it.



Recognition

Problems recognising objects or faces, especially when they're not in plain sight.



Light sensitivity

Finding bright light uncomfortable, including glare from shiny surfaces.



Coordination

Problems with dressing and using objects like kitchen utensils and remote controls.



Thinking

Finding spelling or simple calculations hard.



Mood

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

In PCA, the damage spreads through the brain over time. Eventually a person's memory, speech and problem-solving skills will be affected. As time passes, people will need more support in their daily life and help to look after themselves. This often takes several years, but each person's experience is different.

Diagnosis

Getting the right diagnosis is important so that people can get help and support. 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.

If you are worried about yourself or someone else who is showing signs of PCA, talk to your doctor. They can carry out tests to find out what's causing the changes. The doctor may find that something else is the cause.



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



Here, a specialist will run through more detailed tests with you. These may 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.
- Activities to work out how your brain processes the information it receives from your eyes.
- Assessments of your memory and thinking skills.



You may be offered other tests including brain scans, blood tests or sometimes a lumbar puncture.

In a lumbar puncture, a needle is used to take a sample of fluid from the bottom of the spine. Abnormal levels of proteins in this fluid can indicate the presence of diseases like Alzheimer's in the brain.

Together all these things will help a doctor decide the likely cause of your problems.

Treatments

While there are no treatments specifically for PCA, medicines that are given to people with Alzheimer's disease may be offered to those with PCA.

These drugs work by helping nerve cells in the brain 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 on these drugs, but others may not notice an effect.

These drugs are called:

donepezil

rivastigmine

galantamine

memantine

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.

Physiotherapy or occupational therapy may help people with PCA to find ways to manage some of their symptoms.

Some people with PCA may also benefit from visual aids and resources for people with sight problems. These may include audio books, devices with simple displays, voice recognition software and walking aids. People may choose to carry a symbol cane to let others know that they have sight problems. For more information contact the Royal National Institute of Blind People at www.shop.mib.org.uk or call **0303 123 9999**.



Support

A diagnosis of dementia will affect people in different ways.

With the right information and support, people can carry on with day-to-day life and the things they enjoy doing for some time. Talking to other people in the same situation can also help.

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

Visit www.raredementiasupport.org/pca for more information, email contact@raredementiasupport.org or call **07388 220 324** for details.

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 information and help for people with all forms of dementia, and can tell you about local support groups and Dementia Cafés in your area. Call **0300 222 1122**.

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**'.

Here are some tips for helping someone with PCA:

- At home, keep pathways clear by removing rugs, clutter and low furniture.
- Adding coloured stickers to glass doors can make them more easily seen. Take care with revolving glass doors when out and about.
- 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.

More about the condition

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

These cells are at the back of the brain. In PCA, it is not clear why the disease affects these areas of the brain rather than the areas affected by typical Alzheimer’s disease, like memory. Scientists are trying to find out more, as well as exploring possible genetic or lifestyle risk factors for the condition.

Alzheimer’s Research UK helped to fund the largest genetic study of PCA to date. The researchers found several genes that may influence a person’s risk of PCA, some of which had previously been linked to Alzheimer’s. You can’t be tested for these risk genes on the NHS because many only have a small effect on risk. However, their discovery is helping researchers understand more about why some people develop PCA.

Research

Alzheimer’s Research UK has funded over

£10 million

of pioneering research to help advance our understanding of PCA, and was one of the first charities to invest consistently in this important area of research.



Our studies are helping to improve diagnosis and work towards potential new treatments.

Backed by our passionate scientists and supporters, we’re challenging the way people think about dementia, bringing together the people and organisations who can speed up progress, and investing in research to make breakthroughs possible.



Find out more

If you have questions about 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**

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.

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3 Eagle Avenue
Magnetic Park
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NN14 2WD



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):

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

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

PCA19

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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