

What is posterior cortical atrophy?



**The Power
to Defeat
Dementia**



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 written in May 2017 and is due to be reviewed in May 2019. 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, mood changes and difficulty with day-to-day tasks.

The symptoms of dementia get worse over time, so that a person will need more and more help with everyday 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. It is also known as Benson's syndrome. PCA is caused by damage to the brain cells at the back of the brain that make sense of what our eyes are seeing.



Alzheimer's disease is most often the cause of the brain cell damage in PCA. 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. 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 may 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, so things like memory, language and problem solving will also start to get worse. 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 be wrongly 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 will look at what's causing the changes and may find that something else is to blame.



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



Here, a doctor 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.

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 are:

donepezil (Aricept)

rivastigmine (Exelon)

galantamine (Reminyl)

memantine (Ebixa or Axura)

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 their condition improves on these drugs, but others may not notice an effect.

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 (RNIB) at **www.shop.rnib.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.rarementiasupport.org/pca for more information, email contact@rarementiasupport.org or call **07341 776 317** for details.

Admiral Nursing Direct can offer 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 '**Caring for someone with 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 seems 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's not clear why the disease affects these areas of the brain rather than the areas affected by typical Alzheimer's disease. Scientists are trying to find out more, as well as exploring possible genetic and lifestyle risk factors for the condition.

Recently, 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 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 **£3.7 million** of pioneering research into posterior cortical atrophy, and was one of the first charities to invest consistently in this important area of research.



Our studies are helping to increase understanding of the condition, improve diagnosis and work towards potential new treatments.

We believe that dementia can only be defeated through research. Thanks to the generosity of our supporters we hope to fund many more pioneering studies into PCA.



Find out more

If you have questions about dementia research or want to find out more about how to get involved in studies, 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.

Freepost Plus RTSJ-ZCSB-RGCK
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Send me more information

For free information, simply complete this slip. You can drop it straight in a post box or put it in an envelope labelled with the freepost address overleaf. 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 (SCIHITFD) ☐

Caring for someone with dementia: organisations that can help (SCIHICARE) ☐

The latest dementia research (SMTTHINK) ☐

Name

Address

We'd really like to keep you updated with the latest research developments, how your support is making a difference, and fundraising activities that you can get involved in. Your details are always held securely, but if you'd rather not hear from us please tick the relevant box:

No information by post ☐ No information by phone ☐

If you're happy for us to contact you by email, please enter your email address here:

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PCA

We are the UK's leading research charity aiming to defeat dementia.

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.



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