

# Understanding Charles Bonnet syndrome



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partially sighted people



**RCOphth**

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Charles Bonnet syndrome is named after a Swiss philosopher and writer who lived about 250 years ago. Charles Bonnet wrote about his grandfather’s experiences after his grandfather lost his sight to cataracts and began having “visions”; he could see patterns, people, birds and buildings, which were not really there.

# About CBS

Charles Bonnet syndrome (CBS) is a common condition among people who have lost their sight. It causes people who have lost a lot of vision to see things that aren't really there, known as visual hallucinations.

CBS can be distressing, but the hallucinations are usually not permanent. Many people experience hallucinations for a year to eighteen months before they become a lot less frequent.

People who have CBS may have lost a lot of their vision from an eye condition, such as age-related macular degeneration (AMD), cataract, glaucoma or diabetic eye disease. Many of these conditions are more common in older people so many people who have CBS are older. However, anyone of any age, including children, may develop this condition as any eye condition that causes sight loss can trigger CBS.

There are thought to be more than 100,000 cases of CBS in the UK. Some research suggests that up to 60 per cent of individuals who are experiencing serious sight loss may develop it.

# Causes of CBS

The main cause of CBS is loss of vision and how your brain reacts to this loss. The exact way loss of sight leads to hallucinations isn't really known, but research is slowly revealing more about how the eye and the brain work together.

Current research seems to suggest that, when you are seeing real things around you, the information received from your eyes actually stops the brain from creating its own pictures. When you lose your sight, however, your brain is not receiving as much information from your eyes as it used to. Your brain can sometimes fill in these gaps by releasing new fantasy pictures, patterns or old pictures that it has stored. When this occurs, you experience these images stored in your brain as hallucinations. CBS tends to begin in the weeks and months following a deterioration in your sight.

# How you know if you have CBS

“I always thought that seeing things was a sign of mental health problems”.

If you have lost some sight to a condition like macular degeneration or glaucoma and you start to hallucinate or see things that aren't really there, then you may have CBS.

There isn't one test that your doctor can do to find out whether you have CBS or not. Usually, they try to rule out other causes of hallucinations by talking with you and in some cases doing tests. Your doctor will try and rule out the other causes of hallucinations, like mental health problems, Alzheimer's and other conditions. If there are no signs of these other conditions and you have lost sight then it is probable that CBS is the cause of your hallucinations.

It is normal to be worried, confused or frightened when you see things that are not really there. Until you know what's happening, you may be concerned that seeing things is a sign of a mental health problem, or you might think you have Alzheimer's disease. However, it is important to remember that CBS is caused by sight loss and not any other health problem.

If the hallucinations cause you to feel anxious, you may also be inclined to keep quiet about the things you are seeing. However, even though there is no cure for CBS, letting people know that you have this problem or talking about it may offer you some peace of mind. There is more information on “talking about CBS” later in the booklet.

There are other medical problems, such as Parkinson’s disease, Alzheimer’s disease, strokes, serious mental illness and other brain conditions, which affect the part of the brain concerned with seeing, and these conditions may cause some people to have hallucinations. It is important to remember that having CBS does not mean you’re more likely to develop any of these other conditions. Sometimes, if you have one of these conditions as well as CBS because of sight loss, it can make your hallucinations more frequent.

There are some things about CBS hallucinations which make them different to the hallucinations caused by other conditions. Usually, with CBS you’re aware – or can learn to recognise – that what you’re seeing might be vivid but it is not real. CBS hallucinations only affect your sight, which means that people with CBS don’t hear, smell or feel things that aren’t there. People with CBS do

not develop any obvious, complicated non-medical explanation about the cause of their hallucinations (sometimes called “delusions”). For example, someone with CBS wouldn’t have thoughts that the people they were seeing wanted to hurt them.

If one day you find you’re seeing a pattern, person, building or a landscape that you know is not really there, then don’t be afraid to mention this to your GP or optician, who should be familiar with CBS. You may find it useful to take a copy of this information along with you.



# What you see if you have CBS

The visual hallucinations caused by CBS can take many forms, ranging from simple shapes and dots of colours, simple patterns, straight lines or a network of branches, to detailed pictures of people, animals, insects, landscapes and buildings. Although when you have lost a large amount of your vision it may be difficult to see everyday things, you may find that your CBS hallucinations are very detailed, and much clearer than your normal vision. The images can appear “out of the blue”, lasting for just a few minutes or in some cases, several hours.

At times, the hallucinations will fit alongside the background you are looking at, giving them an understandable feeling of being real, like seeing cows in a field, when the field is actually empty or seeing a fence across the pavement. At other times, they will seem totally unreal, like seeing fantasy images such as dragons.

When you first develop CBS your visual hallucinations may happen quite often, you may see things every day and for long periods of time. Your CBS may stay like this for a number of months, but over time the hallucinations may become less frequent and they may eventually stop. However, some people’s hallucinations carry on for longer and you may find that you are prone to hallucinations every now and again.

# Types of hallucinations

The kinds of things people see with CBS hallucinations seem to fall into two broad types:

- simple repeated patterns
- complex hallucinations of people, objects and landscapes.

Both kinds of hallucination can vary. Sometimes they may be in black and white and at other times in colour, or they may move or stay still. You may experience one type of hallucination more than another or you may have both types of hallucination at the same time or one after another.

## Simple repeating pattern hallucinations

Many people with CBS experience hallucinations of repeating patterns. These may be grids or shapes or lines, which can be quite vivid in colour, like bright green dots surrounded by vibrant pink squares. You may also see complicated brickwork or mosaic patterns which grow in size to cover more and more of vision. Or you may have patterns more like a network of branches or roots from a tree, growing over everything you can see.

People usually describe this type of hallucination as being laid on top of everything they see, or growing across any surface they look at. Sometimes people also experience patterns of distorted faces which appear in their vision and can change shape or move towards them.

## **Complex hallucinations**

The second type of hallucination you may experience are more complicated and include hallucinations of people, places, insects and animals. Like the pattern type of hallucination, these hallucinations also come in different types.

You may experience hallucinations where whole scenes appear, such as landscapes, like waterfalls, mountains or a garden full of flowers. At other times you may see individuals or groups of people. You may see people dressed in costume, like Edwardian families, Roman soldiers or small children in bonnets. The figures of people in your hallucinations may be life size, larger than life sized or very commonly very small. All these types of figures may move or remain still.

At times, the hallucinations may fit with the room that you are in when you experience them, so that you may

see animals in your bed or people working in your garden. At other times the hallucinations can appear very odd, such as double-decker buses in your kitchen or hallway.

In most cases, CBS hallucinations do not include familiar people or past events that you may have experienced. The things that you see are usually not threatening or unpleasant, but of course most people are frightened when they first start to have their hallucinations. Over time, the more you experience the images, the more comfortable you may become with them. You might begin to recognize similar things appearing in your vision, such as the same tiny people, or the same field of flowers.

# Treatment

There is currently no medical cure for CBS. When you experience CBS, the most effective form of treatment can come from knowing that the condition is not a mental health problem or a symptom of another disease but is due to sight loss. Knowing that CBS usually improves with time (even if it doesn't go away completely) might also help you cope with the hallucinations. Having information on CBS and sharing your experiences with friends or family can also help.

Although there is no proven drug you can take to stop CBS hallucinations, some drugs for other problems have been successful in helping some people. The drugs that have been tried are usually very strong and are designed for people with epilepsy, Parkinson's disease, dementia or mental health problems. All these drugs can have serious side effects and should only be used under proper supervision and probably only for people who are very upset or confused by their CBS hallucinations.

Some common medications people take as they get older can interact when they're taken together. This can make your CBS hallucinations more frequent. If you're not sure if the medication you're taking is making your CBS worse, ask your GP to review your medication. This may help to lower the frequency of your hallucinations.

# Coping

Having a hallucination can be frightening, particularly when you're also dealing with losing your sight. Although the hallucinations may not be of anything frightening, just having the experience of a hallucination can make you anxious and confused. These are all natural reactions to hallucinations.

## Talking about CBS

There is no cure for CBS but you may find it helps to talk. Sometimes describing your hallucinations and how they make you feel can help you cope with them. Most people find that talking about their hallucinations with their GP, optician, ophthalmologist, family, friends or carers can help them deal with CBS.

Although CBS is not connected to mental health problems, the professionals in the mental health field are the experts at helping people deal with hallucinations. If your CBS hallucinations become upsetting, your GP could refer you to the local mental health team for further help. Talking over your feelings with a counsellor, psychologist or psychiatrist may provide you with ways of coping with the hallucinations you are experiencing.

## Dealing with the hallucinations

For most people there isn't one way to deal with their hallucinations, but there are a few general points that some people find can sometimes help.

One way of trying to cope with the hallucinations is to make some changes to the things around you and what you are doing, to see if this will cause your hallucinations to stop. Many people experience their hallucinations when they are sitting quietly without much occupying their mind. Having the TV or radio on or moving around a little can sometimes help. Sometimes just standing up or moving slightly can help to get rid of the hallucinations. Some people also find that looking directly at the image they are seeing causes them to fade. Sometimes moving your eyes or blinking rapidly can also help.

A recent study has shown that a specific eye movement exercise can help. When a hallucination starts, look from left to right about once every second for 15–30 seconds, without moving your head. As a guide to how far to move your eyes, imagine two points about a metre apart on a wall in front of you and look from one point to the other when standing about a metre and a half away. Your eyes should be held open during the movements. If the

hallucination continues, have a rest for a few seconds and try another 15–30 seconds of looking left and right. If the hallucinations have not diminished or stopped after four or five periods of looking left and right for 15–30 seconds, the treatment is unlikely to work and you can stop. It may be worth trying again on another occasion or for a different type of hallucination.

The level of lighting may influence your hallucinations. If your hallucinations happen in dim light, then try opening the curtains, or turning on a light or the television as the change in lighting may help to stop the hallucinations. Lighting conditions in certain rooms may also mean that you see the hallucinations more often in one room than another. For example, you may find that you rarely get your hallucinations in your garden or kitchen but that you often see them in your living room. This may be because the kitchen and garden are much brighter and this is helping to control the hallucinations. If your CBS happens when there's a lot of light then switching off a light may also help. Making sure that the lighting is the right level for your sight problem in all the rooms in your house helps make the most of your sight and might help your hallucinations.



Some people find that their CBS hallucinations are worse when they're tired or stressed. Making sure you have enough sleep at night will help with this.

Sometimes it can help to get to know your hallucinations so that you become familiar with them. Many people find that this means the hallucinations become less frightening and easier to cope with. This sort of adjustment may allow you to have some form of control over the way you feel about the things you are seeing. If you see something in more detail than you normally would, this may be a clue that it is a hallucination. When you see something that you are frightened or unsure of ask yourself, "is this too detailed to be real?". As well as these general points there are also some tips which may help you deal with particular types of hallucinations.

## **Dealing with hallucinations of space**

You may find you have hallucinations that change the shape of streets and rooms. For instance, your hallucinations might suddenly make it look like there is a wall or fence in front of you which may make walking difficult for you and it may take you longer to get around than normal. This can cause you to lose confidence when you're moving around.

If you experience hallucinations like this it's important that you are not afraid to check the area around you. It may be sensible to go slowly, to reach out and feel around for what is real and what is not. Having a good knowledge of your surroundings can also help with these kinds of hallucinations.

## **Dealing with hallucinations of people**

If your hallucinations are of people, then this can also be frightening, particularly if they're inside your home. If the hallucination is of very small people or people in costumes then it may be easier to realise that they are hallucinations than when the figure is in ordinary clothes. Having a good idea of when you're likely to have visitors may make you more confident if you have this type of hallucination. As will feeling secure in your home or your surroundings.

## **Dealing with hallucinations of animals**

Hallucinations of animals are also very common. Often people describe animals on their chairs or in their bed. Sometimes this can be very upsetting, especially if you aren't keen on a particular type of animal.

Using touch to make sure that the animals are hallucinations is not a bad thing and sometimes reaching out towards the hallucination may cause them to stop and disappear.

## Further help

If you have CBS, you're likely to have very poor vision but there is a lot you can do to make the most of the vision you have. This may mean making things bigger, using brighter lighting or using colour to make things easier to see. There is more about this in our publication, "See for yourself: make the most of your sight" which is available from our Helpline on 0303 123 9999.

If you have very poor sight you may be able to register as sight impaired or severely sight impaired, this can be a gateway to services from your local social services department. Our Helpline can also give you information about the low vision services available, and our website offers lots of practical information about adapting to changes in your vision and products that make everyday tasks easier.

# Useful contacts

Talking about the hallucinations and working out a way to deal and think about them can help a lot. Organisations like The Macular Disease Society and RNIB can all offer you information and support while you're experiencing CBS.

## **Royal National Institute of Blind People**

105 Judd Street, London WC1H 9NE

t: 0303 123 9999

helpline@rnib.org.uk

www.rnib.org.uk

## **Royal College of Ophthalmologists**

17 Cornwall Terrace, London NW1 4QW

t: 020 7935 0702

www.rcophth.ac.uk

## **Macular Disease Society**

PO Box 1870, Andover SP10 9AD

t: 0845 241 2041

www.maculardisease.org



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# Information sources

We do all we can to ensure that the information we supply is accurate, up to date and in line with the latest research and expertise.

The information used in RNIB's Understanding series of leaflets uses:

- Royal College of Ophthalmologists guidelines for treatment
- clinical research and studies obtained through literature reviews
- information published by specific support groups for individual conditions
- information from text books
- information from RNIB publications and research.

For a full list of references and information sources used in the compilation of this leaflet email [publishing@rnib.org.uk](mailto:publishing@rnib.org.uk) or call 020 7391 2006.

# RNIB Helpline

0303 123 9999

helpline@rnib.org.uk

If you, or someone you know, is living with sight loss, we're here to help.

This leaflet has been produced jointly by the Royal College of Ophthalmologists and Royal National Institute of Blind People.

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