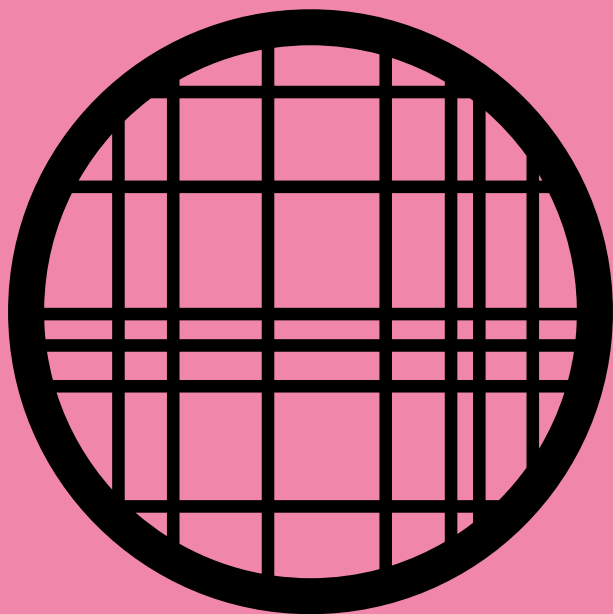


Understanding

Charles Bonnet syndrome



Supporting people
with sight loss



The ROYAL COLLEGE of
OPHTHALMOLOGISTS

Contact us

We're here to answer any questions you have about your eye condition or treatment. If you need further information about Charles Bonnet syndrome or on coping with changes in your vision, then our Helpline is there for you.

Just give us a call on **0303 123 9999** or email us at **helpline@rnib.org.uk** and we'll be happy to speak with you.

RNIB's Understanding series

The Understanding series is designed to help you, your friends and family understand a little bit more about your eye condition.

The series covers a range of eye conditions, and is available in audio, print and braille formats.

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What is Charles Bonnet syndrome?

Charles Bonnet syndrome (CBS) causes people who have lost a lot of sight to see things that aren't there. Medically, this is known as having hallucinations. CBS hallucinations are only caused by sight loss and aren't a sign that you have a mental health problem.

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

- simple repeated patterns or shapes, such as grids or brickwork patterns
- complex hallucinations of people, objects and landscapes.

CBS hallucinations do not involve hearing things or feeling things that aren't there, and people are usually aware that what they are seeing isn't real.

CBS can be frightening, but the hallucinations usually get less frequent with time. Initially, it was thought that hallucinations would come to an end within 12 to 18 months. However, a recent study found that it's not unusual if you still have occasional hallucinations even five years after they first started. There may come a time when the hallucinations stop, but they might come back if your sight gets worse.

Who develops CBS?

CBS occurs in people who have lost a lot of their vision from an eye condition, for example, age-related macular degeneration, cataracts, glaucoma or diabetic eye disease. As these conditions are more common in older people, many people who have CBS also tend to be older. However, anyone of any age, including children, may develop CBS following sight loss.

It's difficult to know how many people in the UK have CBS because quite often people don't always want to tell doctors that they are experiencing the condition.

Recent research suggests that about one in five people who experience sight loss develop CBS. It's not yet known why some people with sight loss get CBS and some people don't, but if you have an eye condition which might cause sight loss, it's helpful to know about CBS so that you are prepared if it does occur.

Origins of the name CBS

Charles Bonnet syndrome is named after a Swiss philosopher and writer who lived about 250 years ago. Charles Bonnet wrote about the experiences of his grandfather, who lost his sight following cataract surgery. His grandfather began having “visions”; seeing patterns, people, birds and buildings, which were not really there.



What causes CBS?

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

When your sight is good and 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 isn't receiving as much information from your eyes as it used to. Your brain can sometimes fill in these gaps by creating new fantasy pictures, patterns or pictures. When this happens, you experience these pictures as hallucinations. CBS tends to start in the weeks and months following a big deterioration in your sight.

How will I know if I have CBS?

It's natural 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 that you have dementia. However, CBS is caused by sight loss and the hallucinations aren't a sign of any other health problem.

If you have lost some sight to an eye condition like macular degeneration or glaucoma, and you start to 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. Your doctor will want to rule out other causes of hallucinations, usually by talking with you and in some cases, carrying out tests. If there are no signs of any other conditions that might be causing your hallucinations, and you have recently lost your sight, then it's likely that your hallucinations could be caused by CBS.

There are some medical problems, such as Parkinson's disease, Alzheimer's disease, strokes, serious mental illnesses and other brain conditions, that can affect the parts of the brain concerned with seeing. These conditions may cause some people to have hallucinations. It's important to remember that having CBS doesn't 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.

Certain things about CBS hallucinations 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 isn't real even though it's very vivid. CBS hallucinations only affect your sight, which means that you don't hear, smell or feel things that aren't there. People with CBS don't develop any delusions, that is, have obvious, complicated thoughts or ideas about why they are seeing things. For example, if you are having CBS you wouldn't think that the people you were seeing wanted to hurt you.

You may want to keep quiet about the things you are seeing because you are anxious about what you are seeing, or about what people may think. 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. You can read more about this in the section on “Coping with CBS” later on in this publication.

If you suddenly find that you’re seeing a pattern, person, building or a landscape that you know is not really there, then don’t be afraid to tell 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 kinds of things might I see?

Your hallucinations can be of almost anything you can think of – they can range from simple patterns, shapes or colours, to vivid detailed pictures of people, animals, objects or buildings. When you have lost a large amount of your vision it can be difficult to see everyday things, but your CBS hallucinations may be very detailed, and much clearer than your everyday vision. The images appear very suddenly, lasting for just a few minutes or in some cases, several hours.

As mentioned before in the introduction, the kinds of things you may see with CBS generally fall into two types: simple repeated patterns or shapes, or complex hallucinations of people, objects and landscapes.

Both types 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 have one type of hallucination more than another or have both types of hallucination at the same time or one after another.

Simple repeating pattern hallucinations

Your CBS hallucinations may be of patterns or shapes laid on top of everything you see, or growing across any surface you look at. You may see grids or shapes or lines, which can be quite vivid in colour, for example, bright green dots surrounded by vibrant pink squares. You may also see brickwork or mosaic patterns that can grow in size to cover more and more of your vision. People can also see patterns that look like a network of branches or roots from a tree.

Complex hallucinations

Your CBS hallucinations may be of more complicated things like faces, people, places, insects and animals. The faces may be distorted or grotesque and move up in front of you.

You may have hallucinations where whole scenes appear, such as landscapes with waterfalls, mountains or a garden full of flowers. At other times you may see a single person or animal, 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 things may move or stay still.

At times, the hallucinations may fit with your surroundings, 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. Sometimes the images can be totally unreal, like fantasy pictures of dragons or unicorns.

CBS hallucinations don't usually 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 hallucinations.

Over time, the more you see the images, the more comfortable you may become with them. You may begin to recognise the same things appearing in your hallucinations, such as the same tiny people, or the same field of flowers.

Does CBS get better with time?

When you first develop CBS your visual hallucinations may happen quite often; you may see things every day and for long periods of time. However, your hallucinations usually get less frequent over a number of months and they may eventually stop. For some people, they can carry on for longer, and it's not unusual if you still have occasional hallucinations for years.

If your hallucinations do stop, it's possible that they may come back if you lose more sight. Many people also find that their hallucinations can come back or get worse if they are poorly with an infection, such as a bladder infection (also known as a water or urinary infection) or a chest infection. If you find that your hallucinations do come back or get worse, speak to your GP who can check for reasons such as infections.

Is there any treatment for CBS?

Currently there is no medical cure for CBS. Sometimes just knowing that the condition is not a mental health problem or a symptom of another disease can help a lot. Knowing that CBS usually improves with time (even if it doesn't go away completely) and having information on CBS as well as sharing your experiences with friends or family can also help.

There's no proven drug you can take to stop CBS hallucinations. Some drugs designed for other conditions, such as epilepsy, Parkinson's disease, dementia and mental health problems have been tried. However, all these drugs are very strong and can have serious side effects. Most people with CBS wouldn't need them, but they may be useful if used carefully for people who are very upset or confused by their CBS hallucinations.

Anticholinergics are a group of medications which can sometimes make hallucinations worse, especially in older people. They can be prescribed for lots of different health conditions including motion sickness, bowel and bladder problems, and if you are taking more than one type of anticholinergic, it can sometimes make your hallucinations worse.

It's important that you don't stop taking any of your medications without speaking to your GP. If you're concerned that your medications are making your CBS hallucinations worse, let your GP know and ask them to review your medication.

If you have CBS, you're likely to have very poor vision, but trying to make the most of the sight you have can help to make the hallucinations less frequent. This may mean making things bigger by using a magnifier, using brighter lighting or using colour to make things easier to see. A low vision assessment can explore these things with you. Your GP, optometrist (also known as an optician) or ophthalmologist (also known as a hospital eye doctor) can refer you to your local low vision service for an assessment.



Coping with CBS

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, it's natural to feel anxious and confused just by having the experience of a hallucination.

Talking about CBS

If your hallucinations make you anxious, you may feel like keeping them to yourself. However, even though there's no cure for CBS, letting people know you have this problem or talking about it may help give you peace of mind.

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, optometrist, ophthalmologist, family, friends or carers can help them cope with CBS.

Although CBS isn't connected to mental health problems, professionals who work in the mental health field have a lot of experience in helping people deal with hallucinations. If your 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 your hallucinations.

Dealing with the hallucinations

For most people there isn't just one way to deal with their hallucinations, but there are a few things that you can try to do that may help.

When you have a hallucination, you can try making some changes to the things around you and to what you are doing, to see if this will make your hallucination stop. Many people get their hallucinations when they are sitting quietly without much occupying their mind. Putting the TV or radio on, or standing up and moving around, or going into a different room can sometimes make the hallucination disappear.

Some people also find that looking directly at the image they are seeing or reaching out to touch it causes it to fade. Sometimes moving your eyes or blinking rapidly can also help.

A study has shown that a specific eye movement exercise may 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 (three feet) 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 (five feet). 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 you've tried four or five times and the hallucination is still there, then it's unlikely to work, but you may want to try again another time or when you have a different type of hallucination.

If your hallucinations happen in dim light, then opening the curtains, turning on a light or the television may help. 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 hallucinations happen 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 condition in all the rooms in your home will help you make the most of your sight and might help with 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 and having time to relax can help with this.

Sometimes it can help to get to know your hallucinations so that you become familiar with them. You may find that this means the hallucinations become less frightening and easier to cope with. This may mean you have some 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's a hallucination. When you see something that you are frightened of or unsure about, ask yourself, "Is this too detailed to be real?" As well as these general points, here are a few more tips which may help you deal with certain 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 and you may have to check if this is real. This can make you lose confidence when walking around and it may take you longer to get out and about.

If you experience hallucinations like this, don't be 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 isn't. Having a good knowledge of your surroundings can also help with these kinds of hallucinations.

Dealing with hallucinations of people

Hallucinations of people can be frightening, particularly if they're inside your home. If the images are of very small people or people in costumes then it may be easier to realise that they are hallucinations than if the figure is in ordinary clothes. Having a good idea of when you're likely to have real people visiting you will help in making you feel 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.

You can try using touch to make sure that the animals are hallucinations, and sometimes reaching out towards the hallucination may cause them to disappear.



Further help and support

If you have CBS, you're likely to have very poor vision, but there are a lot of things you can do to make the most of your remaining vision. This may mean making things bigger, using brighter lighting or using colour to make things easier to see. We have a series of leaflets with helpful information on living with sight loss, including how to make the most of your sight. You can find out more about our range of titles by calling our Helpline.

As mentioned earlier in the section on "Is there any treatment for CBS?", you should ask your ophthalmologist, optometrist or GP about low vision aids and having a low vision assessment.

You should also ask your ophthalmologist whether you're eligible to register as sight impaired (partially sighted) or severely sight impaired (blind). Registration can act as your passport to expert help and sometimes financial concessions. Even if you aren't registered, a lot of this support is still available to you.

Local social services should be able to give you information on staying safe in your home and getting out and about safely. They should also be able to offer you some practical mobility training to give you more confidence when you are out.

If you have questions about anything you've read in this publication, please get in touch with us.

Our Helpline is your direct line to the support, advice and services you need. Whether you want to know more about your eye condition, buy a product from our shop, join our library, find out about possible benefit entitlements, or be put in touch with a trained counsellor, we're only a call away.

It's also a way for you to join RNIB Connect, our community for anyone affected by sight loss. RNIB Connect is free to join and you'll have the chance to meet other people with similar experiences in our helpful, welcoming and supportive community.

Give us a call today to find out how we can help you.

RNIB Helpline

0303 123 9999

helpline@rnib.org.uk

We're ready to answer your call Monday to Friday 8am to 8pm and Saturday 9am to 1pm.

You can also get in touch by post or by visiting our website:

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macularsociety.org

Esme's Umbrella

A campaign organisation working
to raise awareness of CBS

0345 051 3925

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Information sources

RNIB and The Royal College of Ophthalmologists 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.

This publication uses information from:

- The Royal College of Ophthalmologists' guidelines for treatment**
- clinical research and studies obtained through literature reviews**
- specific support groups for individual conditions**
- medical text books**
- RNIB publications and research.**

For a full list of references and information sources used in the compilation of this publication, email eyehealth@rnib.org.uk.

About The Royal College of Ophthalmologists

The Royal College of Ophthalmologists champions excellence in the practice of ophthalmology and is the only professional membership body for medically qualified ophthalmologists.

The College is unable to offer direct advice to patients. If you're concerned about the health of your eyes, you should seek medical advice from your GP or ophthalmologist.

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

RNIB Helpline

0303 123 9999

helpline@rnib.org.uk

Ask RNIB is the simple and easy way to find the answers to your questions online – try it today at **rnib.org.uk/ask**

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