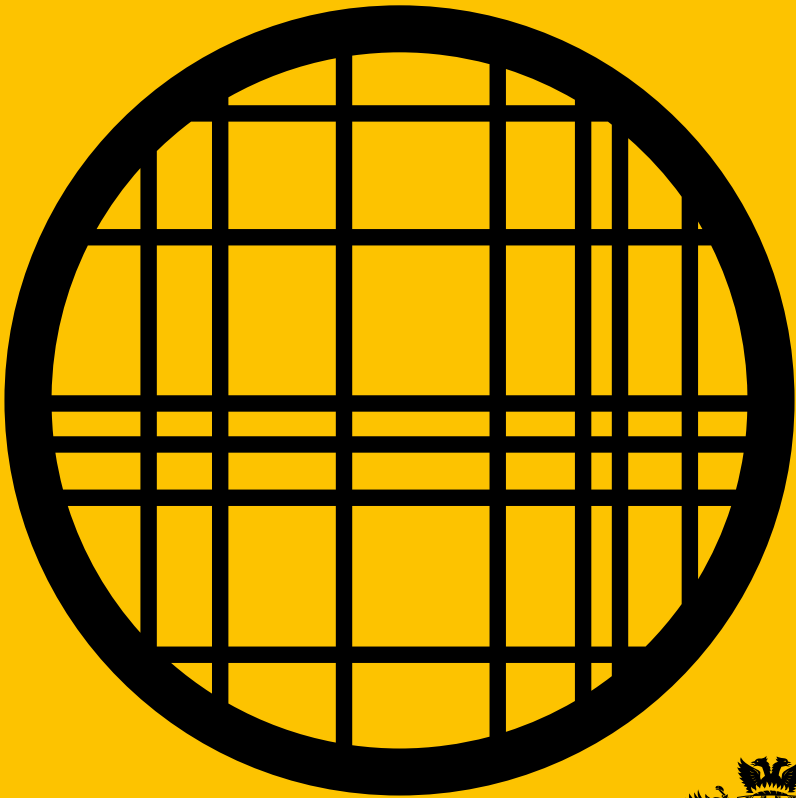


Understanding

Charles Bonnet syndrome

See differently

Visual hallucinations caused by sight loss



The ROYAL COLLEGE of
OPHTHALMOLOGISTS

The Sight Advice FAQ

The Sight Advice FAQ answers questions about living with sight loss, eye health or being newly diagnosed with a sight condition. It is produced by RNIB in partnership with many other sight loss organisations. sightadvicefaq.org.uk

Contact us

We're here to answer any questions you have about your eye condition or treatment. If you need further information about Should say 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 images that aren't there. Medically, these are known as hallucinations. CBS hallucinations are caused by sight loss and are not a sign that you have a mental health problem.

What people see with CBS fall into two main areas:

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

CBS hallucinations are silent and do not involve any of the other senses. You cannot hear, smell or touch the images. Although they can be disturbing or frightening, people are usually aware that what they are seeing isn't real.

The hallucinations usually get less frequent with time. It was thought that hallucinations would come to an end within 12 to 18 months. However, a recent study found that it is 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 may come back if your sight gets worse. Everyone is different in how they experience CBS and for some people the hallucinations remain with them intermittently throughout life.

"Initially, like many people, I didn't speak about it. I was seeing lots of patterns, like a grid and they would follow me, on the wall and the floor. It was really disorientating, especially when I was outdoors, and the lighting would change, and this pattern would emerge."

Kalsum

Who develops CBS?

CBS occurs in people who have lost a lot of their vision from any eye condition. As sight loss is more common in older people, many people who have CBS also tend to be older. However, anyone of any age may develop CBS following sight loss.

It's difficult to know how many people in the UK have CBS because quite often people are unaware that sight loss can cause hallucinations and think that they might be developing a mental health condition. Therefore, they 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. This means that at least 1 million people in the UK are living with 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

CBS is named after a Swiss philosopher and writer called Charles Bonnet, born in 1720. In 1760 Charles Bonnet wrote about the experiences of his grandfather, who lost his sight following cataract surgery. His grandfather, who was of sound mind, began having "visions"; seeing patterns, people, birds and buildings, which were not really there.

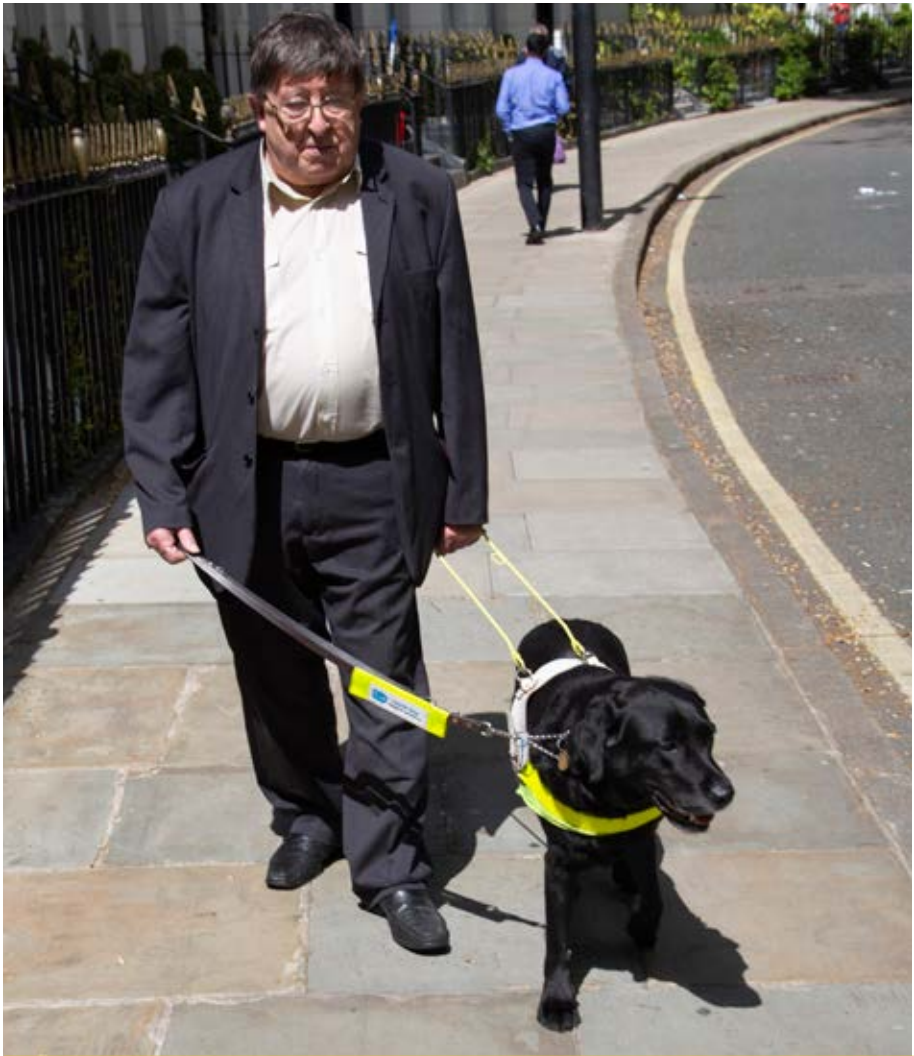


What causes CBS?

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 images are detected by the retina (the light sensitive layer at the back of the eye) and signals are sent via the optic nerve to the area of the brain that processes what you are seeing. This area is called the visual cortex. The visual pathway is the term used to describe the route the light takes from being detected by the eyes through to being processed in the brain. Any eye condition that causes damage to any part of the visual pathway can cause sight loss. If your visual pathway works well your eyes stop 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 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 but can develop at any time.



How will I know if I have CBS?

It's natural to be worried, confused or frightened when you see things that aren't 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 entirely by sight loss and the hallucinations aren't a sign of any other health problem. If you have lost a lot of sight to any eye condition and you start to see things that aren't there, then you may have CBS.

There isn't one specific test that your doctor can do to find out if you have CBS. 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 most likely that you have developed CBS.

There are some medical conditions, 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 hallucinate. It's important to remember that having CBS doesn't mean you're more likely to develop any of these conditions. Sometimes, if you have sight loss and one of these conditions as well, 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. Even though you may see images which are disturbing or frightening, you would not think that the people or animals you are seeing want to hurt you.

If you suddenly find that you're seeing a pattern, person, animal, building or a landscape that you know is not really there, then don't be afraid to tell your GP, Ophthalmologist (eye doctor) or optometrist (optician), who should be familiar with CBS. You may find it useful to take a copy of this information along with you.

You may not want to tell anyone about the hallucinations 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 “Managing your CBS” later in this publication.



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, the kinds of images 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 simple repeating patterns across 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 hallucinate entire scenes, 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, tiny. All these things may move or stay still.

At times, the hallucinations may fit with your surroundings such as seeing 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. Not all the images that you see are threatening or unpleasant, but of course, most people are frightened when they first start hallucinating.

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 images every day and for long periods of time. However, everyone has a different experience of CBS, for some people the hallucinations may get less frequent over a few months and they may eventually stop, but for others the condition may continue 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 unwell with an infection, such as a bladder infection (also known as a water or urinary tract 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.

You may also find that your hallucinations get worse when you are anxious, isolated or stressed. You can contact your GP if you are struggling with feelings of anxiety or stress or call our helpline so that we can offer emotional support, advice and information to help with your situation to reduce your stress, access befriending services and emotional support.

**"As the hallucinations increased,
I was so fascinated by what
happened during them, that I
stopped being so worried."
Bee**

Is there any treatment for CBS?

Currently there is no medical cure for CBS, but this does not mean there is nothing that can be done to help. Sometimes just knowing that the condition is not a mental health problem, nor 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 are also ways to manage CBS that are described below.

Everyone with CBS should have a general health check to look for other factors that may be making the hallucinations worse. This includes ruling out memory problems and infections as well as thinking about the medication you are taking. Some medications given for other conditions may have side effects which make CBS worse. It is always worth checking with your GP if your medications may be making your CBS worse. There may be alternatives that you could take instead. It is important you do not stop any prescribed medications without talking to your GP first.

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. If you are taking more than one type of anticholinergic it can sometimes make your hallucinations worse. Some eye drops can also increase CBS.

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 (optician) or ophthalmologist (hospital eye doctor) can refer you to your local low vision service for an assessment.

For those people with particularly troubling or distressing CBS there are medications that can be tried. 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 to help manage CBS hallucinations. 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 some people.



Managing your CBS

Hallucinations 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 may help you cope with them. Most people find that talking about their hallucinations with their GP, optometrist (optician), ophthalmologist (hospital eye doctor), family, friends or carers can help.

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 to reduce the anxiety the hallucinations may cause.

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.

Change what you are doing

Many people find that their hallucinations appear 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. Moving your head slowly from side to side, dipping your head at each shoulder may also help.

"I try and keep my mind off it, either by listening to an audiobook, music, or something on tv."

Lee

Change the lighting

If your hallucinations happen in dim light, then try opening the curtains, turning on a light or the television. 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.

Look directly at the image or reach out to it

Some people also find that looking directly at the image they are seeing or reaching out to touch it or brush it away causes it to fade.

Eye movements and blinking

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.

Relaxation or mindfulness

Some people find that their CBS hallucinations are worse when they're tired or stressed. It is important to make sure you have enough sleep at night and have time to relax.

Familiarise yourself with the images

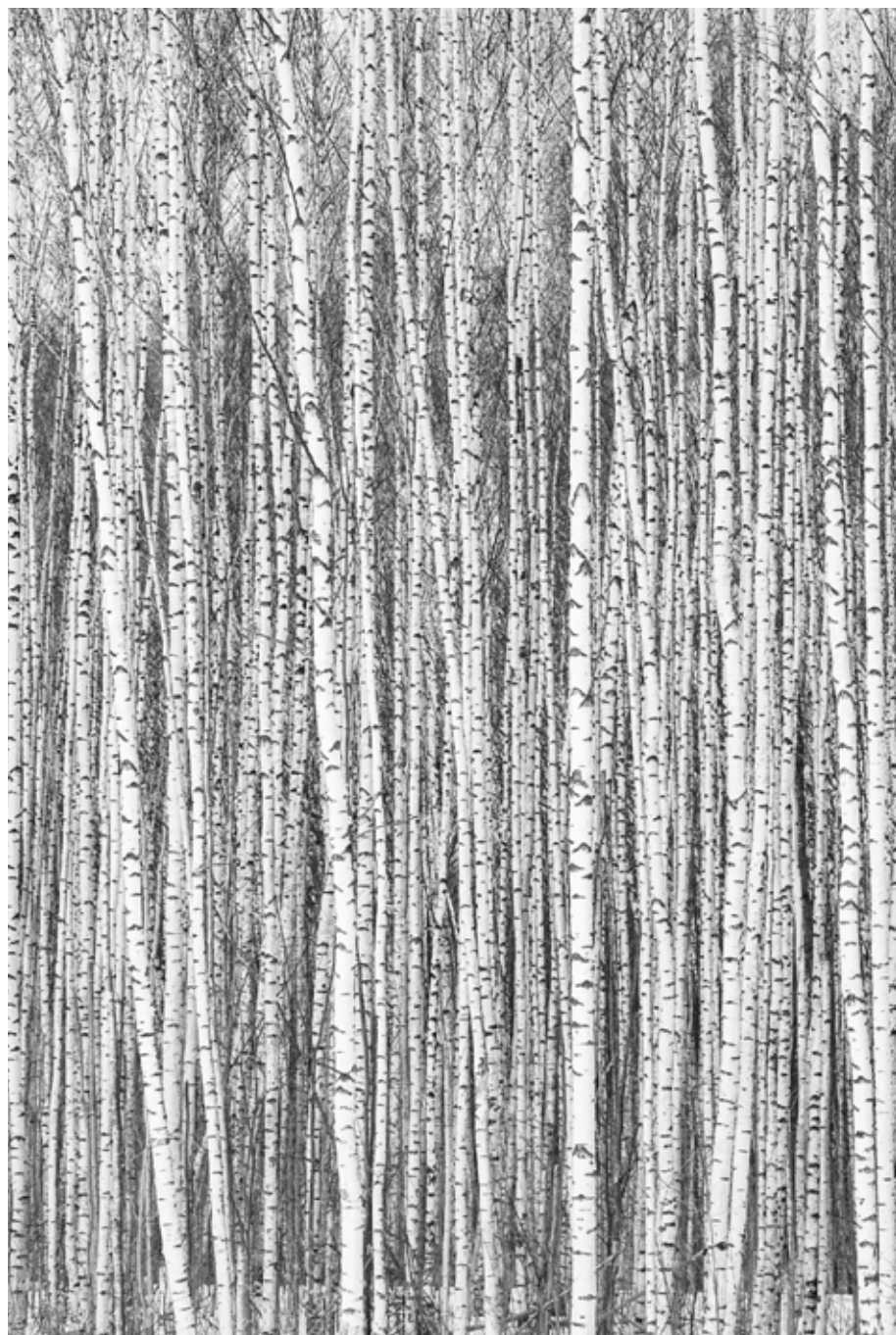
Sometimes it can help to get to know your hallucinations so that you become familiar with them. You may find that this means the hallucinations become less frightening and easier to cope with. This could mean you have some control over the way you feel about the images you are seeing.

Food supplements

The addition of real ginger or Omega 3 in your diet has been found to be helpful by some people but it is important that you check with your GP before trying this because this can interfere with some medications.

Is it too detailed to be real?

When you see something that is frightening or makes you unsure, ask yourself "Is this too detailed to be real?" The fact that the image is detailed and vivid compared with the way you usually see, is a clue that this is an hallucination. 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

Your hallucinations may 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, reach out and check the area around you before you move. Using a cane or walking stick to do this is useful. Moving slowly, 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

Hallucinations of people can be frightening, particularly if they're inside your home. Often the images are of very small people or people in costumes, these can be easier to recognise as 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.

"There's no cure for Charles Bonnet, but I've learned techniques that help me to cope with it – for example moving my eyes from right to left or blinking swiftly may help to alleviate some hallucinations for a short period. Distractions like listening to audiobooks can also be helpful."

Bee

Further help and support

If you have CBS, you will 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 or by visiting our website.

As mentioned 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 if 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.

Stress and anxiety can make CBS worse and therefore contacting our sight loss advice team on **0303 123 9999** may help you. They can talk with you about practical ways to reduce stress, such as benefits advice, support for daily tasks and assistive technology, and they can refer you to other specialist teams such as emotional support. Improving your day to day activities with support and advice, can reduce your overall stress and anxiety, which may also reduce your CBS hallucinations.

RNIB Helpline

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

RNIB Helpline

Call: **0303 123 9999**

email: **helpline@rnib.org.uk**

or say, **"Alexa, call RNIB Helpline"** to an Alexa enabled device.

We're ready to answer your call Monday to Friday 8am to 8pm and Saturday 9.30am to 1pm.

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

RNIB

105 Judd Street

London WC1H 9NE

rnib.org.uk

Other useful contacts

Macular Society

PO Box 1870

Andover SP10 9AD

0300 3030 111

macularsociety.org

Esme's Umbrella

A campaign organisation working to raise awareness of CBS

Email: **esmesumbrella@gmail.com**

Visit: **charlesbonnetsyndrome.uk**

Call: Helpline (managed by RNIB Eye Health team) **0207 391 3299**

RNIB booklet series

About the Starting Out series

The Starting Out series aims to give people who are losing or have recently lost their sight essential information about living with sight loss. Titles include:

- Benefits, Concessions and Registration
- Emotional Support
- Help from Social Services
- Making the Most of Your Sight

About the Confident Living Series

The Confident Living series is for people who are losing or have recently lost their sight and are trying to build their confidence to continue to lead full and independent lives. Titles include:

- Reading
- Shopping
- Technology
- Travel

About the Understanding Series

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

- Age Related Macular Degeneration
- Cataracts
- Charles Bonnet Syndrome
- Dry Eye
- Eye Conditions Related to Diabetes
- Glaucoma
- Nystagmus
- Retinal Detachment
- Inherited Retinal Dystrophies including Retinitis Pigmentosa
- Posterior Vitreous Detachment

All these leaflets are available in audio, print and braille formats. To order please contact our Helpline on **0303 123 9999** (all calls charged at local rate), email **helpline@rnib.org.uk** or visit **shop.rnib.org.uk**

For a full list of the information sources used in any of these titles or to provide feedback on the Starting Out and Confident Living Series, please email **ckit@rnib.org.uk**

We value your feedback

You can help us improve our information by letting us know what you think. Is this booklet useful, easy to read and understand? Is it detailed enough or is there anything missing? How could we improve it?

Send your comments to us by emailing us at **eyehealth@rnib.org.uk** or by writing to the Eye Health Information Service, RNIB, 105 Judd Street, London, WC1H 9NE.

Connect with others

Meet or connect with others who are blind or partially sighted online, by phone or in your community to share interests, experiences and support for each other. From book clubs and social groups to sport and volunteering, our friendly, helpful and knowledgeable team can link you up with opportunities to suit you. Visit **rnib.org.uk/connect** or call **0303 123 9999**

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

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.

rcophth.ac.uk

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 textbooks
- 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**.



RNIB Helpline



Call: **0303 123 9999**



Email: **helpline@rnib.org.uk**



Or say, **"Alexa, call RNIB Helpline"**
to an Alexa enabled device.

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