

# Charles Bonnet Syndrome

Ophthalmology

## Who is this leaflet for?

This leaflet is for people who have loss of vision and are experiencing hallucinations (something that somebody imagines seeing, when it is not present or actually occurring at the time) in their vision.

## What is Charles Bonnet Syndrome (CBS)?

CBS is the presence of visual hallucinations, seen by some people who have significant sight loss. CBS tends to begin in the days and months following any deterioration in your sight. Not everyone experiences these symptoms.

## What causes Charles Bonnet Syndrome?

The reason for these hallucinations is not really known. It is thought that it may be caused by the brain reacting to the loss of information which it normally receives from the eyes and the stimulus that this provides.

## What are the hallucinations like?

The hallucinations can take any form but commonly involve detailed images of people, buildings walls or simple patterns or straight lines. CBS can be distressing but the hallucinations are rarely permanent. There are some things about CBS hallucinations which make them different to the hallucinations caused by other conditions. People who have CBS are aware that these images are not real. These hallucinations only affect the sense of sight, which means that people with CBS do not hear, smell or feel things that are not there.

## Who can suffer from this syndrome?

People who are mentally healthy people with significant vision impairment. It can affect people of all ages; however, it is more common in those who lose their sight later in life.

The condition often appears after a period of worsening sight (for example people with age-related macular degeneration).

If one day you find you are seeing a pattern, person, building or a landscape that you know is not really there, then do not be afraid to mention this to the staff at the eye clinic. Staff members should be familiar with CBS. You could also talk to your GP, Optician or Eye Clinic Liaison Officer (ECLO). You may find it useful to take a copy of this information along with you.

**The prevention of infection is a major priority in all healthcare and everyone has a part to play.**

- Please decontaminate your hands frequently for 20 seconds using soap and water or alcohol gel if available
- If you have symptoms of diarrhoea and/or vomiting, cough or other respiratory symptoms, a temperature or any loss of taste or smell please do not visit the hospital or any other care facility and seek advice from 111
- Keep the environment clean and tidy
- Let's work together to keep infections out of our hospitals and care homes.

## How long will I have CBS?

This varies from person to person. When you first develop CBS your visual hallucinations may happen quite often, you may see things every day and for long periods of time. The visual hallucinations usually stop within a year to 18 months but this can vary greatly. Over time the hallucinations will become less frequent and usually eventually stop. However, some people's hallucinations carry on for longer and you may find that you are prone to hallucinations intermittently.

## How do I know if I have Charles Bonnet Syndrome?

Understandably, you may be frightened, anxious or confused, when you see things that are not really there. However, it is important to remember that CBS is caused by loss of sight and not by any other health problem.

You should speak to your GP, Optician or Eye Clinic Liaison Officer (ECLO) as they can rule out other possible causes of hallucinations, like mental health problems, Alzheimer's disease, 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.

Take this leaflet along and show your GP; most health professionals are aware of this syndrome.

## Can CBS be treated?

There is no medical treatment, but just knowing the hallucinations are not as a result of mental illness can help people to cope. Most people with CBS manage their hallucinations well.

The Macular Disease Society has carried out research which suggests that the hallucinations are most likely to happen when a person is quiet and relaxed. Therefore, getting up and moving about can often help to drive away the images temporarily, or changing activity.

Changing the lighting conditions that you are in; making it brighter if it is dark, or dimmer if it is bright, may help.

If the hallucinations cause you to feel anxious, you may be inclined to keep quiet about the things you are seeing. However, even though there is no cure for CBS, you may find comfort in letting other people know that you have this problem. It will also help those who care and support you, to understand what you are going through.

Closing your eyes, blinking or eye movement can sometimes make the hallucinations disappear for a brief period.

Alternatively, imagine 2 points on a wall, approximately a meter away and look from point 1 to the other every second for about 20 seconds with your eyes open. The exercise can be tried several times and is quite effective at halting that specific hallucination.

These techniques work particularly well for grid, checkerboard lattice and colour hallucinations, but can also work for other types of hallucination.

## Can I get help with this condition?

If you have any questions or concerns, please talk to one of the staff at your next appointment or contact us on the telephone. We can listen and help you to manage this condition.

We are here to help, please contact us on these numbers if you need advice:

### **Eye Referral Unit**

01902 695805

Monday-Friday, 8:00am-5:00pm

Weekends, 8:00am-3:00pm

### **Mary Jones Ward**

01902 695801

Monday-Friday, 7:00am-7:30pm

### **Outpatients Department**

01902 695831

Monday-Friday, 8:30am-4:30pm

### **Eye Clinic Liaison Officer**

01902 307999 ext 86800

Monday-Friday, 9:00am-5:00pm - out of hours messaging service

**Outside of these hours, please attend the main Emergency Department or contact NHS Direct on telephone number 111**

## Other useful contacts:

### **Royal National Institute for the Blind**

105 Judd Street, London WC1H 9NE

Tel: 0303 123 9999

Email: [helpline@rnib.org.uk](mailto:helpline@rnib.org.uk)

### **Royal College of Ophthalmologists**

17 Cornwall Terrace, London NW1 4QW

Tel: 020 7935 0702

### **Macular Disease Society**

PO Box 1870, Andover SP10 9AD

Tel: 0845 241 2041

### **Low Vision Advice**

Beacon Centre

01902 880111

If you have any personal access needs or require wheelchair access and wish to talk to a member of staff, please get in touch using our contact details.

## English

If you need information in another way like easy read or a different language please let us know.

If you need an interpreter or assistance please let us know.

## Lithuanian

Jeigu norėtumėte, kad informacija jums būtų pateikta kitu būdu, pavyzdžiui, supaprastinta forma ar kita kalba, prašome mums apie tai pranešti.

Jeigu jums reikia vertėjo ar kitos pagalbos, prašome mums apie tai pranešti.

## Polish

Jeżeli chcieliby Państwo otrzymać te informacje w innej postaci, na przykład w wersji łatwej do czytania lub w innym języku, prosimy powiedzieć nam o tym.

Prosimy poinformować nas również, jeżeli potrzebowaliby Państwo usługi tłumaczenia ustnego lub innej pomocy.

## Punjabi

ਜੇ ਤੁਹਾਨੂੰ ਇਹ ਜਾਣਕਾਰੀ ਕਿਸੇ ਹੋਰ ਰੂਪ ਵਿਚ, ਜਿਵੇਂ ਪੜ੍ਹਨ ਵਿਚ ਆਸਾਨ ਰੂਪ ਜਾਂ ਕਿਸੇ ਦੂਜੀ ਭਾਸ਼ਾ ਵਿਚ, ਚਾਹੀਦੀ ਹੈ ਤਾਂ ਕਿਰਪਾ ਕਰਕੇ ਸਾਨੂੰ ਦੱਸੋ।

ਜੇ ਤੁਹਾਨੂੰ ਦੁਭਾਸ਼ੀਏ ਦੀ ਜਾਂ ਸਹਾਇਤਾ ਦੀ ਲੋੜ ਹੈ ਤਾਂ ਕਿਰਪਾ ਕਰਕੇ ਸਾਨੂੰ ਦੱਸੋ।

## Romanian

Dacă aveți nevoie de informații în alt format, ca de exemplu caractere ușor de citit sau altă limbă, vă rugăm să ne informați.

Dacă aveți nevoie de un interpret sau de asistență, vă rugăm să ne informați.

## Traditional Chinese

如果您需要以其他方式了解信息，如易读或其他语种，请告诉我们。

如果您需要口译人员或帮助，请告诉我们。