

Devon in Sight Eye Condition Fact Sheet 7

Charles Bonnet Syndrome

Introduction

Charles Bonnet syndrome (CBS) is a common condition among people with poor vision. It is when you experience silent visual hallucinations. These can seem real and can be confusing or frightening. They are caused by the brain trying to 'fill in' detail in the blind areas. The hallucinations usually decrease or disappear over time.

Who is affected by Charles Bonnet syndrome?

Anyone, including children, who has an eye condition that results in sight loss can develop Charles Bonnet syndrome. However, it is more common in older people as they are more likely to have conditions, such as age-related macular degeneration, cataract, glaucoma or diabetic eye disease, which result in sight loss.

Visual hallucinations.

Hallucinations can occur as a result of sight loss. Up to half of all people with macular degeneration are thought to experience visual hallucinations at some time. They are more likely to occur if both eyes are affected by sight loss but can occur with problems in one eye only.

The hallucinations often start after a sudden worsening of vision. When hallucinations happen as a result of sight loss, they are known as **Charles Bonnet syndrome (CBS)**, after an 18th century Swiss scientist and philosopher who first described the condition. **Charles Bonnet hallucinations are not a sign of mental illness.**

What is a visual hallucination?

A visual hallucination is the same experience as really seeing something, but the 'something' is not actually there. Visual hallucinations appear to exist in the real world rather than in the mind's eye. They come and go unannounced and can last for just a few seconds or as long as a day or more. The syndrome itself can last from days to many years. For most people the hallucinations improve with time so that they only occur very occasionally.

What do these hallucinations look like?

Charles Bonnet hallucinations can be simple unformed flashes of light, colours or shapes. However, many people see more elaborate forms such as geometrical grids and lattices. Some people report seeing landscaped gardens or vistas, animals, people, or processions of miniature costumed figures wearing hats, or even disembodied faces with staring eyes.

The hallucinations are often seen in more vivid detail than real life. Some people enjoy their hallucinations. However, they are more often an unwanted distraction and can be frightening. They can get in the way of normal vision too.

Why do the hallucinations happen?

When visual signals leave the eye they go to the back of the brain (the occipital lobe) to the primary visual receiving area. From here the signals are relayed to a series of map-like areas, each specialised in a different aspect of seeing. There is an area specialised for movement, an area for colour, several for faces, one for landscapes and many others. With our eyes open, the visual brain expects to receive and process a flood of complex electrical signals. In people with eye disease, what was once a flood becomes a trickle. This leaves the visual areas of the brain with little to do. The idle visual brain cells, waiting for an appropriate trigger, begin to fire spontaneously. If this happens in the colour area, people experience hallucinations of colour; if in the object area, they see objects and so on. After a while, the visual brain gets used to the lower level of information from the eye and the

spontaneous firing lessens or stops. This explains why, for many people, the hallucinations gradually reduce over time.

If you find your hallucinations upsetting, talk to your doctor or ophthalmologist about the problem.

Coping Strategies

It can be extremely distressing to have your life disrupted constantly by vivid, silent, visual hallucinations. There are measures which can be tried to dispel the hallucination when it occurs. However, everyone is different and some strategies work better than others. If the hallucination does disappear at that moment, it may return later.

- Reach out towards the hallucination, try and touch it or sweep your hand to brush away the image.
- Shine a torch upwards from below your chin in front of your eyes (NOT INTO THE EYES).
- If sitting, try standing up and walking round the room. If standing, try sitting.
- Walk into another room or another part of the room.
- Turn your head slowly to one side and then the other. Dip your head to each shoulder in turn.
- Stare straight at the hallucination.
- Change whatever it is you are doing at that moment – turn off/turn on the television/radio/music.
- Change the light level in the room. It might be the dim light that is causing the hallucinations. If so, turn on a brighter light – or vice versa.
- Clap your hands or click your fingers
- Sing or whistle
- At night, try wearing a thick eye mask
- Blink your eyes slowly once or twice –

Eye-movement exercise created by Professor ffytche

When the hallucination starts, look from left to right about once every second for 15 seconds without moving your head. If the hallucination continues, have a rest for a few seconds and then repeat the eye movements. You may need four or five repeats of the eye movements

to have an effect, but there is no point in continuing beyond this if there is no benefit.

Charles Bonnet syndrome information, advice and support

The Macular Society runs a buddy service for people affected by Charles Bonnet syndrome. Telephone the helpline during office hours (Monday to Friday, 9am to 5pm) 0300 30 30 111.

Macular Society Website:

<https://www.macularsociety.org/macular-buddies>

Esme's Umbrella

Helpline: 0207 391 3299

Website: <http://www.charlesbonnetsyndrome.uk/>

NHS Choices Website:

<https://www.nhs.uk/conditions/charles-bonnet-syndrome/>

RNIB Website:

<https://www.rnib.org.uk/eye-health/eye-conditions/charles-bonnet-syndrome-cbs>

What to do next?

If you are experiencing any of the above symptoms or your sight loss deteriorates, please contact your GP/Optician/Accident & Emergency Department at your local Hospital.

If you need any further advice call our Helpline: 01392 876 666

Devon in Sight is a member of the **Helpline Partnership Community**.

Credit- We would like to thank the Macular Society, Esme's Umbrella and Dr Dominic Ffytche, King's College, London.

Further Support Available from Devon in Sight

- **Information, Advice and Guidance**
 - **Demonstrations of Low Vision Aids & Daily Living Equipment**
 - **Assistive Technology Solutions - Sight & Sound Technology Partnership**
 - **Our holistic needs assessment (Sight Loss MOT)**
 - **Training for people with central vision loss (Skills for Seeing)**
 - **Emotional Wellbeing Service**
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Information Disclaimer

Devon in Sight is committed to producing Information, Advice & Guidance Resources that are clear, accurate, evidence-based, up-to-date and easy to use. We have a robust information production process based on best practice to ensure that information we produce meets the needs of people who are blind or partially sighted and their family and friends.

Devon in Sight is not a medical organisation; therefore we can only provide general information that is not intended to be a substitute for a proper medical assessment. Our information is not intended to be used for individual cases. If you have a specific question about your eye condition, we recommend that you consult an eye care professional.

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Our Information, Advice & Guidance Resources were correct at the time of writing. However, due to research and medical advances, the content may not be completely up to date.



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